

“Space, Place and ‘Home’: lived experiences in  
Hospice Day Care”

By

Andrew Moore

A thesis submitted for the degree of DPhil at the University  
of Central Lancashire

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Care”

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A thesis submitted in partial fulfilment for the requirements of  
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## **TABLE OF CONTENTS**

<b>LIST OF FIGURES</b>	<b>vii</b>
<b>ACKNOWLEDGEMENTS</b>	<b>ix</b>
<b>A READER’S GUIDE TO THE TEXT</b>	<b>xi</b>
<b>ABSTRACT</b>	<b>xiii</b>
<b>AN INTRODUCTION TO THE STUDY</b>	<b>xv</b>
Why this study?	xv
Volunteering as an introduction to place	xvii
A guide to the chapters	xxi
<b>CHAPTER 1: BACKGROUND AND LITERATURE REVIEW</b>	<b>1</b>
The relationship between palliative care and traditional medical care	2
Palliative care and hospice	4
The current situation and influences on hospice care	6
Palliative day care	8
Cancer	9
Space, place and home	9
Space, place and home in hospice care	14
Health, Homelikeness and Inhabitation	18
Hospice, place and the use of CAM	20
Therapeutic Landscapes	24
Conclusions	26
<b>CHAPTER 2: METHODOLOGICAL APPROACH</b>	<b>27</b>
The Aims of the Study	28
Ontology, Epistemology and Theoretical Perspective	29
Essences	32

<b>Embedded Knowledge and Fields of Care</b>	<b>32</b>
<b>Hermeneutic phenomenology</b>	<b>33</b>
<b>The Hermeneutic Circle</b>	<b>35</b>
<b>Sampling</b>	<b>36</b>
<i>Sample size and inclusion/exclusion criteria</i>	<b>37</b>
<b>Methods of Data Collection</b>	<b>38</b>
<i>Semi-structured Interviews</i>	<b>39</b>
<i>Photo-elicitation Interviews</i>	<b>41</b>
<i>Observation</i>	<b>43</b>
<i>Postcard Diaries</i>	<b>44</b>
<b>Trustworthiness and Validity</b>	<b>46</b>
<b>Generalisability</b>	<b>48</b>
<b>Conclusion</b>	<b>48</b>
 <b>CHAPTER 3: CONDUCTING THE STUDY</b>	 <b>50</b>
<b>Access and Ethical Considerations</b>	<b>50</b>
<b>Recruitment and consent</b>	<b>55</b>
<b>Data Collection: How the methods were used</b>	<b>60</b>
Day care Patients	
<i>Interviews</i>	<b>60</b>
<i>Taking photographs</i>	<b>61</b>
<i>Photo-elicitation Interviews</i>	<b>61</b>
<i>Postcard Diaries</i>	<b>61</b>
<i>Observations</i>	<b>62</b>
Staff and Therapists	
<i>Photo-elicitation interviews</i>	<b>64</b>
<i>Postcard diaries</i>	<b>65</b>
<b>Data Organisation and Analysis</b>	<b>65</b>
<i>Transcribing the Interviews</i>	<b>66</b>
<i>Analysing the interviews</i>	<b>69</b>
<i>Grappling with technique</i>	<b>70</b>



<i>Returning to a hermeneutic approach</i>	71
<i>Ensuring validity in the analysis</i>	75
<i>Deviant cases</i>	76
<i>Observation: format and analysis</i>	76
<i>Postcard Diaries: format and analysis</i>	77
<i>The Reflective Diary</i>	77
<i>Data used</i>	78
<b>Conclusion</b>	<b>78</b>
 <b>CHAPTER 4: AN INTRODUCTION TO THE FINDINGS</b>	 <b>80</b>
<b>The Hospice Location</b>	<b>80</b>
<i>The Complementary Therapy Rooms and the Building Development</i>	83
<b>An introduction to the participants</b>	<b>84</b>
<b>Three Existential Modes of Being</b>	<b>89</b>
 <b>CHAPTER 5: DRIFTING</b>	 <b>91</b>
<b>Losing the map</b>	<b>91</b>
<b>A sense of isolation – present but distant</b>	<b>97</b>
<b>Fear of entering the hospice</b>	<b>100</b>
<b>CT as a way in</b>	<b>111</b>
<b>CT – “trying to put things back together” – Re-creating self</b>	<b>115</b>
<b>Conclusion</b>	<b>118</b>
 <b>CHAPTER 6: SHELTERING</b>	 <b>121</b>
<b>The Certainty of Being Cared For</b>	<b>122</b>
<b>“Nothing was trivialised” - The certainty of time and place</b>	<b>122</b>
<b>Beyond expectations of care – developing confidence</b>	<b>125</b>
<b>Feeling cared for – “A sense of care without a sense of duty”</b>	<b>129</b>
<b>Called into belonging – “everybody knows your name here” – Being known</b>	<b>131</b>
<b>Finding a space - being smothered</b>	<b>132</b>

<b>A Sense of Relatedness</b>	<b>133</b>
“We’re a rather odd group of people” – Normality in the abnormal community	133
Permanence and sustaining the community	138
Creating a space to cope	140
Walking with the patient	141
Sheltering within relationships – intimate spaces	143
<b>A Sense of Homeliness</b>	<b>146</b>
“A home from home”	147
Caring for day care and maintaining the home	152
Placing day care – “An extension of their own home”	153
<b>Complementary Therapies: Sheltering/protecting/relieving</b>	<b>160</b>
CT as an invitation to shelter	161
CT room as a homely environment	163
CT as a shelter	167
CT as part and parcel of sheltering	171
<b>Conclusion</b>	<b>176</b>
 <b>CHAPTER 7: VENTURING</b>	 <b>178</b>
<b>The opportunity to live</b>	<b>179</b>
<b>Making achievements</b>	<b>182</b>
<b>“A vastly more interesting way forward”</b>	<b>183</b>
<b>“The opportunity to make a new start”</b>	<b>184</b>
<b>Venturing on common ground</b>	<b>186</b>
<b>The Garden: A part of place and a place apart</b>	<b>187</b>
<b>Expanding spaces</b>	<b>192</b>
<b>“They don’t have to be here to get all this...” - moving out of the safe haven</b>	<b>194</b>
<b>CT as expanding the patients’ world</b>	<b>195</b>
<b>Autonomy and the freedom to venture</b>	<b>197</b>
<b>Illness and venturing: the journey into new places</b>	<b>199</b>
<b>Crossing Thresholds And The Limits To Venturing</b>	<b>203</b>
The boundaries to venturing	203
Upstairs Downstairs – the Living and Dying places	206
<b>Conclusion</b>	<b>209</b>

<b>CHAPTER 8: DISCUSSION AND CONCLUSIONS</b>	<b>211</b>
The discovery of three existential modes of being	212
A view through the lens of my experience	213
Returning to the beginning	214
Notions of Home	216
Drifting and the loss of home	217
Crossing the hospice threshold	221
Complementary therapies as a way of finding home	225
Blurring the boundaries of therapies	228
Coming to Shelter	229
A home from home	233
Venturing – points of departure	235
Sheltering and venturing: dialectic experiences in hospice	238
Conclusion – Finding a sense of home	240
Limitations of the study	241
Contributions to knowledge	243
Implications for practice and recommendations	246
 <b>REFERENCES</b>	 <b>248</b>
 Appendix 1: Electronic mail correspondence with Gavin Andrews	 262
Appendix 2: Memo to hospice departments from Head of Care	264
Appendix 3: Letter to Head of Care and Day Care Sister suggesting a gardening activity	266
Appendix 4: Table of participation in data collection methods	270
Appendix 5: Core Services available across the whole hospice	272
Appendix 6: Electronic mail correspondence with David Seamon	273
Appendix 7: Invitation Letter to Patient	278
Appendix 8: Invitation Letter to Staff	279
Appendix 9: Invitation Letter to Complementary Therapist	280
Appendix 10: Patient Information Sheet	281
Appendix 11: Healthcare Staff Information Sheet	286

<b>Appendix 12: Complementary Therapist Information Sheet</b>	<b>291</b>
<b>Appendix 13: Patient Consent Form</b>	<b>296</b>
<b>Appendix 14: Staff Consent Form</b>	<b>297</b>
<b>Appendix 15: Complementary Therapist Consent Form</b>	<b>298</b>
<b>Appendix 16: Patient Interview Schedule 1</b>	<b>299</b>
<b>Appendix 17: Patient Interview Schedule 2</b>	<b>301</b>
<b>Appendix 18: Healthcare Staff Interview Schedule</b>	<b>304</b>
<b>Appendix 19: Complementary Therapist Interview Schedule</b>	<b>307</b>

## LIST OF FIGURES

Figure 3.1 Thematic analysis and the cut and paste method.....	p.74
Figure 6.1 The dining room.....	p.135
Figure 6.2 ‘The butterfly monument’ .....	p.139
Figure 6.3 A symbol of simplicity.....	p.143
Figure 6.4 The kitchen in day care.....	p.148
Figure 6.5 The balcony in day care overlooking the gardens.....	p.150
Figure 6.6 The gardens as viewed from the balcony in day care.....	p.150
Figure 6.7 Flowers on the balcony in day care.....	p.155
Figure 6.8 The day care living room.....	p.158
Figure 6.9 The physiotherapy room.....	p.164
Figure 6.10 The reflexology chart, the picture of flowers and fruit, and the light box.....	p.164
Figure 6.11 The complementary therapy room.....	p.165
Figure 7.1 The river at the bottom of the garden.....	p.187
Figure 7.2 Cathy’s reading place.....	p.188
Figure 7.3 A view of the garden from the dining room in day care.....	p.188

<b>Figure 7.4 The expansive top lawn of the hospice gardens.....</b>	<b>p.192</b>
<b>Figure 7.5 The front entrance and reception.....</b>	<b>p.200</b>
<b>Figure 7.6 The reception and corridor looking towards the inpatients' wards.....</b>	<b>p.200</b>
<b>Figure 7.7 The corridor from reception.....</b>	<b>p.202</b>
<b>Figure 7.8 The corridor through day care.....</b>	<b>p.202</b>
<b>Figure 7.9 The staircase from day care.....</b>	<b>p.207</b>

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## A READER'S GUIDE TO THE TEXT AND TERMINOLOGY

I provide here a guide to the grammatical presentation of the text to enable clarity and consistency.

Where I have used single quotation marks around a word such as 'home', I am emphasising a word or concept that its essential meaning is important to the idea being discussed, or indicating a quotation within a quotation.

Where I have used *Italics* I am introducing a new concept for the first time or emphasising a particular word within a quote.

The use of double quotation marks, as "here" - indicates a word, or words quoted by either a participant or an author.

The use of square brackets enclosing an ellipsis [...] means that there is some text missing. It may be omitting something I have said within an interview that is extraneous to the meaning of the quotation, such as "yeah", or "I understand", or it may be a part of a referenced quotation that is extraneous to the point being made. An ellipsis without brackets indicates a pause in the interview conversation.

Square brackets indicate an observation, action or event that occurred at the time during an interview, such as [smiling] or [getting up to close the door].

I also provide a list of abbreviations and meanings:

CT – Complementary therapy

CAM – Complementary and Alternative Medicine

PEI – Photo-Elicitation Interview

TL – Therapeutic Landscape

Terminal illness – Within the context of this thesis I am using the generally accepted lay understanding of the term in that a ‘terminal illness’ is an illness that cannot be cured and is reasonably expected to end the life of the sufferer.

## ABSTRACT

Up to a third of cancer patients have been shown to use some form of complementary or alternative medicine (CAM), with hospices being the largest provider of this care in the UK. The high demand for CAM among UK cancer patients and increasing political pressure to develop CAM services has led to a more integrative approach to cancer care, though progress is hindered by a narrow focus on medical determinants of efficacy. Subsequently, calls for a wider research perspective have been made in order to encourage a more complex and multi-dimensional analysis of this provision.

The importance of setting and in particular, 'place', is recognised by the field of health geography, and it is suggested there is a need for a focus on how 'place' affects CAM and vice versa. There is little mention of hospice as a place for such research, yet as the largest provider of complementary therapies (CT) to cancer patients in the UK, hospices represent an important area for research.

Though some studies have engaged with geographical perspectives and metaphors, there has been no consideration of hospices as places in themselves, which have utilised a humanistic geographical framework. This study explores patient, staff and therapist interpretations of their experiences of a hospice day care unit as a place. It seeks an understanding of how space and place affects, and is affected by the use and provision of complementary therapies within a hospice day care unit. The concept of therapeutic landscapes (TL) was initially proposed as an analytical framework. However, through the analysis of the data it was evident that concepts from humanistic geography combined with a phenomenology of medicine provided a more fitting conceptual framework for a critical examination of the data.

A hermeneutic phenomenological approach has been adopted. The sample incorporates day care patients, complementary therapists and healthcare professionals. Photo-elicitation interviews, semi-structured interviews, participant observation and postcard diaries have been used. Twenty-three participants (6 therapists – 6 health care staff and 11 patients) were interviewed using a combination of these data collection methods.

I propose three existential modes of being that characterised the patients' lived experiences of hospice day care as a place. *Drifting* - characterised by states of uncertainty and anxiety; *Sheltering* characterised by homeliness, familiarity, and security; and *Venturing*, characterised by seeking and exploring new experiences, places and spaces. Through an examination of these modes, it was discovered that patients found 'home', both within the self and within the world. This was possible through various facets of the hospice including complementary therapies, which were seen as an integral part of the holistic landscape of care.

This study makes a significant contribution to the fields of health geography, palliative care and complementary therapies. The three existential modes of being can be utilised as a conceptual framework for future research within a variety of settings where the lived experiences of individuals and the meanings they give to place are sought.

## **AN INTRODUCTION TO THE STUDY**

This study originally set out to explore the experiences, perceptions and meanings held by hospice day care patients, staff and therapists, within a day care hospice setting, about the use and provision of complementary therapies in creating a therapeutic environment. It is fair to say that the focus of the study changed substantially. It soon became clear that complementary therapies constituted only a small part of the patients' experience. The wider therapeutic environment and the patients' experiences of space and place became key to the thesis, and central to its focus. This was both as a result of the emergent nature of interpretive inquiry, and as a result of the author's increasing awareness of these key elements.

The study is set within a free-standing hospice location, which I originally chose because I felt that it was fairly unique, in the sense that the day care unit was adjacent to the in-patient hospice and the provision of complementary therapies was well established and provided by both contract and voluntary therapists. The location of the hospice itself is discussed in greater detail in Chapter 4.

### **Why this study?**

I have had an abiding interest in complementary and alternative therapies and always found the science and nature of these modalities made more sense to me on a human level. The promise of a holism that works with the natural flow of the world and all its processes, from microcosm to macrocosm was attractive to me. I was drawn to its art, its complexity and its simplicity. The human experience of health and illness, more than the dehumanising Newtonian bio-mechanistic paradigm of orthodox medicine intrigued me. This interest led me from my early career as a technical officer in the Staffordshire pottery industry, to university to study Health Sciences for Complementary and Alternative Medicine where I graduated in 2003. I worked and travelled for a number of years to gain some life experience, before securing a doctoral studentship at the University of Central Lancashire where I had completed my undergraduate degree.

The origins of this work were based around a tentative proposal for a doctoral studentship project that focused on the use of CAM by UK cancer patients. Subsequently I developed this proposal based on my interests in complementary therapies and an urge to find out about people's experiences and perceptions of complementary therapies as used and provided in this context.

The current context of CAM use by cancer patients shows that CAMs are slowly being integrated into cancer care (Roberts, McNulty and Caress 2005). This has become apparent in its use within hospice care, as hospices are the largest provider of CTs to cancer patients in the UK (Macmillan Cancer Relief UK 2002). When developing the proposal, I decided to look at a number of possible sites where I could interview people who used or provided CTs. I had a number of questions that I was curious about:

- Why did cancer patients use CTs?
- What meanings did patients attribute to them?
- What did patients and staff know about CTs?
- What benefits did patients get from using them?
- How did the staff perceive CTs?
- How did the therapists perceive CTs?

I took these questions to the various sites and talked to the therapists and staff involved in their provision.

I decided to look at the provision and use of complementary therapies as a whole, rather than to deconstruct one or more of the individual types of complementary therapies offered. The most common forms of complementary therapies offered by hospices are touch and relaxation therapies, such as massage, aromatherapy and reflexology (Macmillan Cancer Relief UK 2002)

While talking to a therapist at one of the hospices, she made a comment that changed my thinking about the nature of complementary therapies and subsequently the nature of the proposal. She suggested that the room in which the therapies were provided was used in a particular way by the patients – as a place to talk about things they could not

talk about elsewhere. This led to a consideration of the nature of the environment and setting or the 'space and place' of not only complementary therapies, but of the hospice itself. This raised questions as to how the patients experienced and perceived the hospice as a place, and how they experienced complementary therapies in this place. I began to examine Gesler's (1992) work on therapeutic landscapes, and the links between health and place. This led to an exploration of health geography, humanistic geography and existential and phenomenological geography, as developed through the works of Andrews, Kearns, Relph, Seamon, Tuan and Buttimer. This further informed the development of the proposal, which subsequently spanned three different fields: complementary and alternative medicine, palliative care and humanistic geography.

This was potentially a large and ambitious project and I decided on a single site study. I visited three hospices and a palliative care ward to gain a sense of what constituted palliative care and hospice care. I settled on one particular hospice where the staff and the director of care were very supportive of the project. In order to get to know the hospice better and to gain a deeper understanding of the patients' world I decided to take on a voluntary role at the hospice.

### **Volunteering as an introduction to place**

I knew almost nothing of hospices when I started this research. There is no history of cancer in my family, and I have never known anyone close to me who has suffered from cancer. I accept that I must be one of the very few. I knew of the Douglas Macmillan home, near to where I grew up in the Midlands. It was where 'people who were dying, went to die'. To me, the name seemed to be synonymous with charity work in the area. My uncle had a friend who went there. He went to visit, and from the little I remember the impression was of his friend going into a nice place and not coming out again. I thought that must be what happened - a designated place to die. As I grew older, I realised there was link between Macmillan homes and cancer. I assumed that people who had no one to care for them, went there to die. Beyond that understanding, I had no cause to investigate further. It was not until I engaged with this study and began to read the literature that I began to find out what hospices were all about.

I wanted to know the hospice as someone who worked there might know it. The obvious way to do this was by working there. Volunteering seemed like the perfect way to familiarise myself and to gain a greater sensitivity to the setting. I wanted to know how the patients were treated, what they did when they were there, what they talked about. I wanted to know what 'patients' were like as people. I was going into the study thinking "these are people with cancer", as though they were fundamentally different from people without cancer. I was guilty to some degree of seeing these men and women as 'patients' and not as human beings. The staff at the hospice told me they tried to treat everyone as human beings rather than patients, though the term is still often used in a generic sense to distinguish the sick from the healthy or from others who work at the hospice. Most often people were addressed as they wished, usually by their Christian or given name, or by title and surname...Mr. Smith, Mrs. Smith.

Another reason for volunteering was that I felt I could give something back. I felt I would be taking a lot from the hospice and I needed to replace this in some way. I would be asking people to give up their time and effort for me. Ultimately I hoped that whatever the study revealed would be of use to the hospice in return, but in the initial stages, I was simply conscious of taking. Taking up the patient's time and effort was of most concern to me. Time was something perhaps more precious to the patients in light of their illnesses. I wanted to show gratitude and respect.

I attended the induction day for volunteers, where various people from the palliative care team came to explain their roles. I spoke to other volunteers, all of whom seemed to have already had some experience of the hospice. Many had loved ones who had been patients, and it seemed to me that they also wanted to give something back. Some of the volunteers had developed strong bonds with the hospice, attracted by the prospect of working in a caring environment, and some had forged connections and relationships with the staff who had cared for their own loved ones. They spoke of the exemplary care they had received and how much it had meant to them. What stuck in my mind was the element of humanity that people spoke of. This manifested itself in the behaviour of staff towards visitors. I would often see staff, carers and patients hugging and showing genuine affection and concern for each other. This was something that was commented on in the interviews that would follow. The impression I got of the staff was one of complete devotion to their work and the people they cared for. Many



staff and volunteers spoke of the special atmosphere that pervaded the hospice, a warmth, a feeling of being welcome, an 'intangible something' that everyone seemed to notice yet could not adequately describe. This was the same *something* that I felt when first visiting the hospice. I would come to think of it eventually as a sense of intimacy.

My duties as a volunteer involved welcoming the patients and serving them with cups of tea and biscuits; setting the dinner tables in the dining room ready for lunch; giving drinks to those who could not use their arms and helping them around in their wheelchairs. I took it upon myself to take patients out into the gardens as I felt that perhaps this facility was not used enough. We would follow the paths and look at the flowers, discuss gardening and anything that came to mind. This became something of a ritual in the summer with a small group of patients.

I would take patients in wheelchairs to the complementary therapy room, or down to the hairdressers, and bring them back again, acting as a ferryman of sorts. I sat and talked with them about everyday things. They were often interested to know how I was getting on with the study as I did not keep this a secret. I felt that I wanted to be as open and honest as possible with the patients and staff. The notion of being covert about my reason for being there struck me as deceitful in such circumstances. I had made the decision to keep my role as volunteer separate from that of researcher. I volunteered one day a week on a Tuesday. I would only invite participants from other days of the week. I felt that if I invited someone from the Tuesday group it would be unethical.

Over the course of volunteering, I noted changes in my own mode of being. Relph (1976) suggested the essence of a place - what sets it apart in space and defined its physical characteristics, activities and meanings - lay in the experience of an *insideness* that was different from an *outsideness*:

"To be inside a place is to belong to it and to identify with it, and the more profoundly inside you are the stronger is this identity with the place." (Relph 1976 p.49)

Relph describes various modes of insideness and outsideness, which I will explore in later chapters, but it is worth mentioning here that I experienced these modes myself, as both researcher and volunteer. When first entering the hospice as a volunteer, I thought

of myself as a researcher acting out the role of volunteer. I was alert to all possibilities and had a conscious intellectual gaze with which I tried to take-in and analyse everything I saw. I observed the routines and activities that were played out, and became familiar with the physical environment and how people used it. I got to know the patients and staff. As I became more comfortable, I moved further into the realm of insideness. I began to develop a more emotional and empathetic involvement with the place.

As I became more involved as a volunteer, I became more comfortable with the role. I started to forget that I was also a researcher. I would suggest that I was on the verge of becoming such a part of the place that I was almost reaching a state of what Relph refers to as “existential insideness”, a fundamental form of insideness that requires no conscious reflection and yet is full of significances (Ibid p.55). I had become so familiar with the place that on occasion I ceased to become conscious of my reason for being there, only that I was a part of the place. This form of insideness is most commonly associated with how people experience their own home or hometown. I had started to identify myself as volunteer rather than ‘researcher who is volunteer’. I would be shaken out of this comfortable haze when people asked me how my research was progressing. I realised that I had become too comfortable with my role as volunteer and I had to pull myself back and remind myself why I was there in the first place.

The role of volunteer provided me with a greater insight into what it was like for the staff and therapists who worked there and for the patients who made up the day care community. It informed much of the study in terms of helping me to understand how patients experienced their illness, how they experienced the hospice as a place and their perceptions of CT. The role of volunteer also provided me with a moral comfort, in the sense that I was giving something back, that I had helped perhaps to brighten someone’s day a little. It also provided me with a sense of gratitude and privilege, that I had become part of the patients’ lives in a small way and they had shared their time with me. It also gave me a bearing from which to conduct the study, as I had effectively placed myself within the hospice.

## **A guide to the chapters**

The chapters of this thesis tell the story of the research project, from the literature and context that informed the study; its philosophical underpinnings; to the methods of data collection and analysis; and finally to the findings and their implications.

In the first chapter, I discuss the range of literature that informs the study and show that there has been little consideration of space and place experiences in hospice care from a geographical perspective, and that there is some confusion over whether hospice is a philosophy or a place. Further gaps exist as the settings in which complementary therapies are delivered although addressed by some authors, have not been explicitly addressed in the context of hospice day care. I also introduce literature that informs the humanistic and existential geographical perspectives adopted in this study.

In the second chapter, I set out the aims of the study and discuss the ontological and epistemological underpinnings and the philosophical perspectives of the study that are aligned with my phenomenological and geographical approach, aiming to provide a firm basis on which to consider the findings of the study. A hermeneutic phenomenological approach to the data analysis has ensured that the themes discussed have arisen from the data. I discuss the methods of data collection that I use and the reasons that I use these particular methods. Issues of trustworthiness and validity are also considered.

In the third chapter, I further explain how access was negotiated and how I recruited participants to the study and gained their consent. I also discuss the ethical issues related to the project, with particular reference to issues surrounding palliative care research and the vulnerable population represented by the patients. Following on from the explanation in chapter two as to the reasons I chose particular data collection methods, in chapter three I explain how these were used and how the data was organised and analysed.

In chapter four, I introduce the reader to the hospice location to bring context to the study in preparation for the reading of the findings chapters. As Cohen et al (2000) state, a place cannot be understood separately from the events that occur within it, or

from the words of the people who frequent it. I introduce the reader briefly to the findings of the study, explaining how these were organised, before introducing vignettes on the participants, so that the reader can develop a more human frame of reference with which to consider the words of those participants.

In chapters five, six and seven I discuss the three existential modes of being that characterised the patients' experiences of the hospice as a place and their experiences of complementary therapies. I show how in these different modes the patients' experiences were characterised, using quotes from the patients and staff as exemplars of these experiences.

In chapter eight, I discuss the findings in more depth and use phenomenological and humanistic geographical theories to show that the patients were essentially finding a home both within themselves in the event of their illness, and within the hospice as a place. The limitations of the study are addressed and the contributions to knowledge and implications of this study are then considered.

This study represents an in-depth exploration of how day care patients experienced the hospice as a place in the context of their illness, and how they experienced complementary therapies. It contributes to a broader perspective and understanding of palliative and hospice day care, and of the lived experiences of the terminally ill people who attended day care. It also contributes to a wider knowledge base and a complex multi-disciplinary understanding of complementary therapies and adds to an existential geographic consideration of place.

# **CHAPTER 1**

## **BACKGROUND AND LITERATURE REVIEW**

In this chapter, I will provide some background literature and a review of the current literature that informed this study. Charmaz (2006 p.166) asserts that a certain amount of reading of the literature is unavoidable, especially to the novice researcher who is required to have a “sophisticated knowledge of leading studies and theories” but, that once achieved, this material should be left until the data analysis is over. I engaged with the literature initially to inform the development of the proposal. Van Manen (1997) suggests that engaging with phenomenological literature too soon in the study may inhibit the ability to suspend one’s interpretive understanding of the phenomenon. He suggests that “it is sound practice to attempt to address the phenomenological meaning of a phenomenon on one’s own first” but eventually one’s interpretations must be tested against those of others who belong to the area and tradition of one’s study (ibid 1997 p.76). In this way, the work of others reveals “as yet unformulated or unsuspected specifications and dimensions of meaning” revealing a “conversational partnership that reveals the limits and possibilities of one’s own interpretive achievements” (ibid 1997 p.76). My engagement with the literature follows both intentionally and unintentionally Van Manen’s suggestions. The literature review is at once a review of the literature that informed the development of the proposal, and a review of the literature pertaining to the emergent concepts and ideas that arose from both the data collected and a re-engagement with the literature of others. At the beginning of the study, theories of space and place and therapeutic landscapes specifically contributed to the formation of the original proposal. Later, as I followed the data, notions of ‘home’ began to emerge. Following these allowed me to better grasp what was happening within the data.

Specifically I have concentrated on literature on palliative day care, rather than hospice care as a whole, as palliative day care remains one of the most under researched areas of palliative care. I have also concentrated on literature around works that have influenced my understanding of humanistic geography and concepts of space and place,

such as Relph (1976) and Seamon (1979). The literature around complementary and alternative medicine (CAM) is ever-growing and wide-ranging, and in light of the use of complementary therapies specific to hospice day care, I have concentrated on the literature around this provision, particularly in context of its recognition of environmental influences. The concept of therapeutic landscapes provided a useful introduction to understandings of the relationships between health and place experience, and during the study and particularly the data analysis, led me to the core texts of humanistic geography, upon which I base much of my discussion. I did however retain some use of the therapeutic landscape concept in an interpretation of how complementary therapies contributed to the overall landscape of care.

The literature represents, broadly three main areas. Palliative care, Humanistic Geography and Complementary and Alternative Medicine. In searching through the literature I employed various search strategies to maintain a focus on relevant literature. I used search engines and databases such as Science Direct, Ingenta, Web of Science, and Ebsco Host, JSTOR, Pub Med, and ISI Web of Knowledge as well as Google and Google Scholar in combination with keywords, such as 'hospice', 'day care', 'palliative care', 'space', 'place', 'existential', 'phenomenology', 'geography', 'home', 'homelikeness', 'complementary therapy', 'massage', 'aromatherapy', and 'CAM'. I used these key words in various combinations. I also searched author's names to locate their works and home pages, and followed the trail of references from journal articles. Additionally, I searched internet book depositories such as amazon.co.uk for keywords and authors. A convergence of these methods allowed me to identify key texts and articles that informed the development of the research from the beginning and the resultant interpretations arising from the data analysis.

### **The relationship between palliative care and traditional medical care**

Historically, traditional medical care has focussed on the cure of disease at all costs. Palliative care developed out of a dissatisfaction with the way in which medical care failed to deal effectively with the dying. Central to the introduction and development of hospice and palliative care services, nurses and nursing philosophy have been

influential in the development of these services, as nursing work has always included the palliation of symptoms and the care and comfort of the dying and bereaved (Payne 2008). With the development of palliative care services and a greater understanding of care of the dying, there has also been a significant shift in the last 10 years from a focus on “dying well” to “living well until one dies” (National Gold Standards Framework Centre 2009).

Yet despite these changes and developments, there have been tensions and challenges to the integration and delivery of these services as specialist palliative care services often struggle to be recognised as a speciality with specialist knowledge, especially amongst other health care professionals (Payne 2008).

Cancer has also been a significant driving force in the development of these services. Palliative care, including specialist contexts such as hospices, hospice day care centres, palliative care hospital wards and home care services are now considered integral to cancer services. The National Institute for Clinical Excellence guidelines for cancer services (NICE 2004) make recommendations that commissioners and providers across Cancer Networks should ensure there is adequate specialist palliative care in-patient facilities available in hospices, homes, hospitals and care homes at any time of the day or night. These guidelines also recognise the increasing role of patient choice and preservation of autonomy as individuals have more control over where they receive palliative care.

Whilst the majority of cancer patients in the UK die in hospital, the overriding preference for place of death is reported to be the home, with hospice a close second (Higginson and Sen-Gupta 2000). Yet there are arguments against this, which suggest that preference may change as the time of death draws nearer, and the home may become an untenable option as a lack of resources and increased need for specialist palliative care necessitates a move to hospice (Thomas, Morris and Clark 2004). There are also concerns about poor quality of care and a prevalent use of invasive treatments up until the end of life within hospitals, (Mills, Davies and Macrae 1994; Edmonds and Rogers 2003) and in comparison to hospital based palliative care services, there is some limited evidence to suggest that people are generally more satisfied with hospice care (Wilkinson 1999a). Hospice in-patient services have been reported to be more

satisfactory, and are seen to provide better pain control, better communication with patients and families, better medical, nursing and personal care and provided the patient with more dignity (Addington-Hall and O'Calahan 2009). The importance of place of death therefore becomes more starkly apparent and is highlighted by current policy emphasis on patient choice at the end of life and preferred places of care (National Gold Standards Framework Centre 2009).

It can also be argued that one of the features that defines the relationship between palliative care and traditional medical care is the acceptance of complementary therapies within palliative care, evidenced by the fact that hospices are the largest provider of complementary therapies to cancer patients in the UK (Macmillan Cancer Relief UK 2002). A viewing of any hospice website will almost certainly show some evidence of the provision of complementary therapies. But while CTs have found some level of acceptance in palliative care settings they remain marginal in acute care settings, due to a reported lack of a sufficient evidence base (House of Lords Select Committee on Science and Technology 2000; NICE 2004; Roberts et al 2005). The use of complementary therapies will be addressed more in subsequent sections of the literature review.

### **Palliative care and hospice**

There are links between the 'modern hospice movement' (a term used to describe hospices that have developed over the last 4 decades) and the early shelters provided for travellers and sick people, variously provided by religious orders throughout Europe. The word 'hospice' derived from the Latin word *hospes*, meaning *guest*, which came to denote hospitality, particularly to strangers (Clarke & Seymour 1999; Winn 1987). While the shared name suggests a connection between these early institutions and the modern hospice, Clarke and Seymour (1999) warn against making too many comparisons between the two, as these early institutions routinely provided care to travellers, pilgrims, the elderly and infirm without being devoted to the sick or dying. Modern hospices have however sought to "re-kindle the tradition of devotion, calling and the ethic of service" found in their early religious predecessors, and in describing their history have developed a discourse concerned with journeying, pilgrimage and the



meaning of suffering (Clarke & Seymour 1999 pg.66). The term “guest” is still used in preference to “patient” in some institutions, while an atmosphere of “hospitality” is a fundamental influence on how the atmosphere of the hospice is experienced (Rasmussen & Edvardsson 2007; Rasmussen, Jansson, & Norberg 2000).

The modern hospice movement developed soon after the Second World War, in response to powerful critiques of the dehumanising hospital death and the poor quality of care for those who were dying. The hospice movement dedicated itself to the care of the dying, and in this respect was able to provide better quality care than larger institutions such as the hospitals (Howarth 2007).

It is generally accepted that the first modern hospice was St Christopher’s Hospice, which was opened in Sydenham, London in 1967 by Cicely Saunders. Saunders was considered as being the pioneer of the modern hospice movement. Since the opening of St Christopher’s Hospice the number of hospices in the UK has risen to 217 palliative care and hospice in-patient units, and 279 day care units in the UK (Help the Hospices 2009)

The World Health Organisation defines palliative care as:

“...an approach that improves the quality of life of patients and their families facing the problem associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” (World Health Organization 2002, p.84)

It is further suggested that:

“Care of the dying extends beyond pain and symptom relief. It also supports the social, psychological and spiritual needs of the patients and their families. Therefore it is important to assess these needs and be able to respond with a holistic approach.” (World Health Organization 2002, p.87)

Hospices developed as a critique of modern hospitals, which put an emphasis on intrusive procedures, increasing technological interventions and prolongation of life. In contrast, the hospice model of care was developed on principles that aimed to give a good death for dying people (Howarth 2007).

Prior to her work at St Christopher's Hospice, it was at St Joseph's Hospice in the 1950's that Dame Cicely Saunders began to develop pain control techniques using analgesic drugs administered before the patient appeared to need them. This had the effect of alleviating pain but also easing the anxiety that was associated with pain. Pain management, the control of symptoms and the personalized care of the dying became the trademark of the modern hospice (Lewis 1989 pg.19). Saunders recognised that the pain suffered by cancer patients had more than one component and composed of physical, emotional, spiritual and social elements. In 1967 Saunders coined the phrase 'Total Pain' (cited by Baines 1990 pg.26) to describe this. The alleviation of total pain became the foundation for the multi-disciplinary approach for the care of the dying patient and his or her family (Baines 1990). By attempting to relieve total pain the hospice movement produced a model of care that assumes that with the easing of physical pain, emotional and spiritual pain will also be reduced, thereby improving the quality of life of the dying person (Howarth 2007).

### **The current situation and influences on hospice care**

In the last 10 years there have been significant developments in UK government and health policy particularly in relation to patient choice at the end of life and preferred place of care. These have had substantial influence on hospice care and palliative care services in the UK. There are three core documents, (Department of Health 2000; National Institute for Clinical Excellence 2004; National Gold Standards Framework Centre 2010) discussed here, which have influenced the provision of palliative care services:

The NHS Cancer Plan (Department of Health 2000) recognised that the majority of cancer patients would prefer to die at home and pledged £50 million to enable hospice and palliative care services to support end of life care in the community. Such

contemporary assumptions about home being the preferred place of death for most people, have informed the emphasis on the development of community based palliative care services. However, Thomas et al (2004 p.2436) found that “preference [concerning place of death] was rarely stated categorically, but took the form of a stronger or weaker leaning in one direction, qualified by speculation about how things might change with events.” This more nuanced reflection of people’s preferences is not always reflected in discussions where place of death is always already assumed to be the home and thus focuses on elements that would or would not enable this. These assumptions do not account for changes in the dying person’s situation, which may lead to changes in preference for the site of death. Townsend, Frank and Fermont (1990) noted that the preference for home as the site of death decreased while that of hospice and hospital increased as individuals neared their time of death (Townsend et al 1990). In light of their findings and those of others, Thomas et al (2004) suggest further questioning of the “home is best” mantra. They also note that because of the high number of hospice beds available in the particular location of their own study (Morecambe Bay) many more patients opted to die in hospice. The authors also felt that many opted to die in a hospice because they felt it would provide what has become known as ‘the good death’, characterised by choice, control and self determination or agency, enabling a sense of dignity and identity, particularly in the face of loss of bodily control and what Lawton (2000) called the ‘unbounded body’.

The National Institute for Clinical Excellence (2004) guidance on cancer care recognised that although the hospice has been seen to provide a model of excellence in the care of the dying, the provision and type of services available varies widely throughout the UK which may act to confound the choices available to patients in regards to preferred care and place of death. As part of the NHS End of Life Care programme, NICE (2004) recommended the use of the Gold Standards Framework (GSF), developed by Dr. Keri Thomas in collaboration with the NHS Cancer Services Collaborative and Macmillan Cancer Relief, which sought to facilitate a more consistent, high quality care for those approaching the end of life. This was initially piloted in 2001 (National Gold Standards Framework Centre 2010) and aimed to meet the holistic needs of the patient via best practice initiatives such as the Liverpool Integrated Care Pathway (King et al 2005). The GSF proved to be successful by

improving communication, consistency and co-ordination of services (King et al 2005) particularly in the community setting.

While initiatives such as the GSF have improved the development and provision of palliative care services in the community, it would seem that the free standing hospice and day care centres still retain a lack of uniformity and therefore remain confusing entities to many patients and health care professionals who are unsure as to what hospice provide and to whom (Myers and Hearn 2001; Littlewood and Johnson 2006).

### **Palliative day care**

Palliative day care services are diverse, broad and complex in their scope and philosophy. The first day care centre opened in 1975 at St Luke's hospice in Sheffield (Thompson 1990). From its inception, day care recognises that patients' physical, emotional, social and spiritual needs are inextricably intertwined. To meet the wide range of needs of patients, day care centres have evolved with different emphasis because of differences in access to resources and different populations in different localities. As such, there is a wide diversity of provision with some services being more medical whilst others are more social in emphasis (Myers & Hearn 2001). Day care also provides a transition environment for patients moving from curative to hospice care, offering opportunities to access resources and services earlier than they may have done otherwise (Corr & Corr 1992). The creation of a facilitative environment that offers services such as complementary therapies, hairdressing, arts and crafts, gardening, and music, enables patients "to access their own innate resources and transcend the circumstances of their illness to find self-esteem, meaning and purpose in life." (Kennet 2001). Medical provisions for patients in day care vary in input depending on the resources available, though it is recognised that patients often have increasingly complex needs and the role of the doctor is one of assessment and management of such patients (Tookman & Scharpen-von Heussen 2001). In the UK, there are currently 234 day care services (National Council For Palliative Care 2009). Palliative day care is the fastest growing but least researched of the palliative care services (Myers & Hearn 2001; Spencer & Daniels 1998) and as such the lack of research needs to be addressed, which may inform further development of this service.

## **Cancer**

In the UK, palliative care services are predominantly provided to people with cancer, although attempts are being made to provide services to those with non-malignant diseases (Eve & Higginson 2000). In coming to recognise the failure of modern medicine to deal sufficiently with this disease, people have come to fear it, and to attach to it a nightmare scenario of insidious decay. It is often thought of as a “death sentence” and to know that one has cancer, or that someone we love has cancer is potentially, to be consumed by such thoughts. Ford (1998 p.51) describes terminal cancer as “a cluster of potential and real tragedies that could be seen as a whole, demanding to be dealt with as a multi-faceted human disaster”. As patients spoke to Cicely Saunders they told of other things besides physical pain: loneliness, spiritual pain, feelings of abandonment, fear of treatment and of oblivion. Saunders saw that cancer led also to the disruption of families, to financial and psychological ruin, and that dependents and carers needed help with the devastating consequences of the disease. In response to the nature of cancer, the hospice movement developed its central theme of whole person care, finding a niche in public appreciation and support both in the UK and abroad (Ford 1998).

To give some idea of the predominance of cancer in the United Kingdom, the statistics from Cancer Research UK show that this disease accounts for over a quarter (27%) of all deaths (Cancer Research UK 2007). In 2006 the number of people diagnosed with cancer amounted to 293,601, with the four major types of cancer - breast, lung, colorectal and prostate cancers, account for over half of all new cases of cancer (Cancer Research UK 2009a). The mortality rate from cancer in 2007 was 155,484 (Cancer Research UK 2009b).

## **Space, place and home**

The development of a more humanistic geography of the lifeworld of human beings resulted from the inability of the physical sciences to find meaning in the world and to apprehend what the human experience of “being-in-the-world” is really like. Seamon (1979 p.160) suggests that the essential flaw of conventional approaches to the study of

human relationship with world, such as behavioural geography and environmental psychology is:

“...their implicit separation of person from his world. By speaking of a person-environment relationship - even as mediated by inner process - these approaches define the geographical world as an entity apart from man.”

This has been remedied in part by the development of humanistic geography, which takes its lineage from phenomenology, existentialism and humanism (Blunt & Dowling 2006). Humanistic geographers such as Tuan (1974;1977), Relph (1976) and Seamon (1979) sought to find a deeper understanding of the human experience of place and our immersion in the world.

Relph suggested that the essence of a place lies “in the experience of an inside that is distinct from an outside” (Relph 1976 p.49). His major contribution to the understanding of a sense of place was his development of the notion of *insideness* and *outsideness*. Relph suggests that the more inside a place we are the stronger our sense of belonging, and the more we identify with that place. The strongest sense of this experience he termed *existential insideness* – a deep and complete, yet unselfconscious identity with place. It is the insideness that people experience within their own home, community or region, where they feel they belong and are known and accepted there (Relph 1976).

The polar opposite of existential insideness is *existential outsideness* – the experience of “selfconscious and reflective uninvolvedness, an alienation from people and places, homelessness, a sense of the unreality of the world, and of not belonging.” (Relph 1976 p.51) These two modes represent the polar extremes of a continuum of different levels or experiences of insideness and outsideness.

Intrinsic to the notions of insideness and outsideness are the notions of *rootedness*. Relph (1976) suggests that rootedness is felt in both communal and personal experiences of place, where a close attachment and familiarity is part of knowing and being known in that particular place; the familiarity of which involves a deep sense of care or concern for that place. Relph suggests that to have roots in a place is to have a

secure place on which to look out on the world; and with rootedness comes a care, concern and a deep responsibility and respect for the places in which we find ourselves rooted. Relph equated this sense of 'care-taking' with what Heidegger called 'sparing' which Relph (1976 p.39) describes as "a willingness to leave places alone and not to change them casually or arbitrarily, and not to exploit them." Relph suggests that it is only through this care-taking that 'home' can be realised. Home, for humanistic geographers is not necessarily a house or a shelter. Relph suggests that 'home' is a point from which we orient ourselves with the world, central to the concept of our being in the world and as such it is "an irreplaceable centre of significance" (Relph 1976 p.39).

Inspired by Relph's work, David Seamon (1979) further developed concepts such as "at-homeness", the components of which are *rootedness*, *appropriation*, *regeneration*, *at-easeness* and *warmth*. Seamon suggests that the body is the foundation of rootedness, as through the body we become familiar with the placing of objects and the temporal regularities for activities. In becoming at-home within a place we develop what Seamon (1980 p.158) calls "time-space routines" – "a set of habitual bodily behaviours which extend through a considerable portion of time." These routines such as waking at a certain time, breakfasting, leaving the house and buying a newspaper, happen unselfconsciously as taken-for-granted segments of daily living, forming an essential element of rootedness. *Appropriation* is the sense of possession and control over home-space. The loss of such control leads to feelings of anxiety, infringement and discomfort. *Regeneration* refers to the restorative powers of the home. Besides the obvious rest found in "sheltering sleep" (ibid p.82), the home also fosters psychological regeneration, providing a secure place in which a person may orient his or herself recouping both physical and psychic energies. *At-easeness* refers to the freedom to be oneself in the home. Seamon suggests that at-easeness is most important in times of sickness, when individuals may not have the energy to be something they are not. At easeness, he suggests, supports the renewal of self. Finally, *warmth* refers to an atmosphere of friendliness, concern and support, found in the successful home. It is found in places that are used often, supported by a presence of people and interpersonal harmony (Seamon 1979).

Tuan (1977) explains that unique to humans among primates is the sense of home as a place where the sick can be cared for. Tuan uses the analogy of a patient:

“At one place the patient is cradled back to health. Before full recovery he remains weak and passive like a child; he is able to respond to the immediacy of the world and see it with the fresh intensity of childlike eyes. The lasting affection for home is at least partly a result of such intimate and nurturing experiences.” (Tuan 1977 p.138)

I would suggest that at least some of the fresh intensity of a new (or authentic) way of seeing is due in part to the breaking open of the taken for granted veneer that covers the life world in times of health (Svenaeus 2001). This notion will be attended to in a later section, but it is important here that the notion of home is vastly important in times of illness, as suggested by Tuan.

Although the focus of this study is a more existential account of place experience, there is a wider complementary and supportive geographical and sociological literature that constitutes this emerging field of scholarly enquiry defining the phenomenon of home as central to the human experience. The meaning of home is vast and complex and there is a growing body of literature that addresses the multiple meanings of home and our attachment to it.

Studies have taken the perspective of local and global meanings of home such as Rowles' (1983) exploration of the phenomenon of place attachment in elderly residents of an Appalachian community. Rowles hypothesised that an increasingly mobile population, where the younger-old are more likely to be vicariously involved with a greater number of places than the old-old, may result in a less intense place attachment, or that it may assume a new form of place attachment involving a process of adaptation to maintain a “grand fiction of place attachment” (Rowles 1983: 303). This suggests that meanings of home and definitions of ‘attachment’ may keep changing, as mobility in the modern world increases. Whilst Rowles focused on place attachment, Sixsmith (1986) concentrated on elucidating a theoretical framework for a local and global theory of place experience. Sixsmith developed a superordinate structure forming a tentative model of home, which consisted of three modes of experience: the personal



home, the social home and the physical home, demonstrating that home consisted of multiple co-existent meanings.

From a more health-oriented perspective, Dyck's (1995) study of women with multiple sclerosis, describes how experiences of place change over time, and how the meaning of home is remade in the context of chronic illness. She describes how women 'remapped' and restructured their home and neighbourhood space in the context of illness and showed how the disruption to their life -course was both "profoundly social and inherently spatial." (Dyck 1995, p.318) The notion of health and illness (and caring) affecting the meaning of the home as a private residence has become an important focus in health and social geography. Home has been explored as the site of health care, a major observation of which is that as geographies of health care change, meanings of home also change. Milligan (2000) explores the demographic, social and environmental factors that influence a changing geography of care, where care-giving is seen to shift from institutional spaces towards the home space, blurring the boundaries between public and private spaces. Following in this vein, Williams (2002) in her study of informal care-giving in the home, further notes the increasing importance of exploring such places in order to assess the impact and meanings that such places have for those who experience them as health care settings.

It has long been recognised that 'home' is not simply a residence. Home is also to be seen as a way of being-in-the-world (Heidegger 1971), and a spatial metaphor for our relationship to a multitude of places (Manzo 2003). The notion of 'homely' places has been the focus of studies that explore the geographies of care settings including hospital isolation rooms (McKeever 2002) and residential care homes, where the replication of a 'homely environment' was depicted against a tensile relationship between institutional and domestic attributes which led residents to feel that they were in "a home" rather than "at home" (Peace and Holland 2001 p.408).

The home has also been explored as an embodied space where geographies of the body and home are intimately linked yet undergo transformations and restructuring during chronic illness (Dyck, Kontos, Angus and McKeever 2005). Dyck et al (2005) found that the private body is transformed into a 'public' space as the intimate care of the body becomes dependent on others; both the home and the body are seen as vulnerable

spaces, the boundaries of which become blurred, resulting in ambiguous meanings which are “worked through, as bodyspace/‘social flesh’ and home space are re-embodied.” (ibid p.181)

It is evident that home encompasses multiple meanings and is conceptually complex as research has focused on home as residence; as a way of being in the world; as an environmental quality; and as an embodied phenomena. As a concept, home also spans the global, local and personal levels of human experience. It may also stand to reason that as the geography of care changes, so too does the geography of research, as home becomes a focus for research due to changes in health care demands and needs.

One of the major critiques of notions of ‘home’ is that many authors, mostly male; seem to have an idealised notion of home that rarely considers women’s experiences, which research shows may just as likely show home to be a place of oppression, violence and domestic abuse (Rose 1993 cited by Blunt and Dowling 2006). In answer to this, Seamon and Sowers (2008) suggest that researchers often lose sight of the need to move out of lifeworld descriptions resulting in confusion as to the exact phenomena they are seeking to understand. They suggest that Relph’s modes of insideness and outsideness provide a language that offers an alternative understanding of such situations, and that rather than a lack of at-homeness, the victim’s experience is to be seen as a mode of existential outsideness, “which in regard to one’s most intimate place – the home – is potentially life-shattering” (ibid 2008). Seamon suggests that through Relph’s language of place, domestic violence is a situation where a place that ideally fosters existential insideness, paradoxically has become a place of extreme existential outsideness, and as such is profoundly destructive.

### **Space, place and home in hospice care**

Since the modern hospice movement began, a number of services have developed based on palliative care principles, in a number of different settings, such as hospitals, hospices, day care units and individuals’ homes. Thus, the terms ‘hospice’ and ‘hospice care’ are seen as a philosophy of care rather than a physical place (Howarth 2007; Salisbury 1999; Spencer & Daniels 1998). Raudonis and Acton suggest that:

“Hospice is a concept of care, not a place. Hospice is based on a holistic philosophy of living and dying.” (ibid 1997, p.140)

The lack of research on hospices as places cannot be helped by such assertions, as I feel they encourage a disengagement with place and environment. While I would agree that hospice is based on a holistic philosophy of care, I would suggest that in this instance Raudonis and Acton are wrong. I suggest hospice can be both a concept of care *and* a place in itself. Indeed if it is holistic, it *must* incorporate the environment/place in which it is set. Cooper Marcus (1999 p.505) also states that hospice embraces both a philosophy of care and a place. She makes this claim I feel because her focus is hospice gardens, and thus she is engaged with the interaction between people and the physical, psychological, spiritual, natural and symbolic landscapes of the hospice garden and thus the hospice, as a place. Brown (2003) describes the hospice as having a three-fold ontology in that it is a philosophy, a welfare policy and a place.

While Raudonis and Acton’s use of the term place seems to be implying that hospice is a concept that does not strictly rely on the place in which it is acted out, I contend that any action has meaning in the context of its physical surroundings. Thus, hospice care as a *holistic* philosophy of care must also incorporate the environment in which it occurs, as this gives it meaning and value, and as such must affect the experiences of those who utilise and provide care within its setting. Hospice should be seen as both a model of care and a place in itself, a place of meaning, value and significance to those who work there and to those who utilise its services.

There is a notable lack of research that engages with any geographical notion of the hospice as a place of care. I should point out that I am referring to the free-standing hospice. Some geographical considerations have been concerned with hospice care in the individual’s home (Brown 2003) and the location of an AIDS hospice in Toronto (Chiotti & Joseph 1995), but do not consider the individual’s engagement with the free-standing hospice as a place. The field of health geography is so small that attention has not yet addressed all healthcare settings, and there are many gaps to be filled, which has so far left hospice largely ignored (Andrews 2008 - see Appendix 1). This lack of research on the hospice environment from a geographical perspective, leaves an

important gap that needs addressing if the holistic intentions of palliative care are to be fully realised. Also it may be seen that hospice, as a philosophy of care and as a place is similar to that of practices such as counselling (Andrews 2004; Bondi 2003) as it is an intrinsically geographical form of care, being institutionally and spatially diverse in its provision. It also involves members of the multidisciplinary team travelling “with” patients on their metaphorical life journey, and being “there” for someone, providing a safe and secure place in which they can sustain their selfhood.

Though research is scarce, there has been some consideration. Interestingly, the notions of rootedness and uprootedness were used in the creation of a palliative care unit (Godkin 1980). An assumption was made that feelings of fear and anxiety in the dying patient are exacerbated by traditional care facilities, which effectively remove the person from his familiar surroundings. This reinforces the notion of death as totally separate from one’s life and living; a stressful and isolating experience. By creating a sense of continuity in the life of the patient via a homelike environment, it is possible to encourage the patient to envision death as an inescapable but natural part of one’s life. As such, there should be a reduction of fear and isolation and an enhancement of well-being. This sense of continuity is symbolised in the construction of a physical environment similar to that of a home, incorporating rooms such as a ‘dining room’, ‘kitchen’ and ‘family room’ (Godkin 1980). Godkin suggests that “the homelike environment provides a tangible and immediate sensory image which suggests that patients and families are in a safe place of rootedness where they feel cared for and secure” (1980 p.83).

Rasmussen, Jansson, and Norberg (2000 p.31) found that “the effects of, and reactions to, nursing care were inseparable from the hospice milieu and the patients’ situation” revealed the indivisible connection between people and place. As Rasmussen and Edvardsson (2007) point out, environments have not been the focus of palliative care, though often the findings of such studies reveal ‘environment’ as an important factor. Limited research has described hospice day care as a “safe retreat” or “safe haven” (Lawton 2000), whilst hospice in-patient wards have been described as a “no-place” (Lawton 2000); as a “home” setting (Gates 1991); and as a “space to live” (Cannaerts, de Casterle, & Grypdonck 2004). Others have noted the importance of creating a homely setting not only to create a sense of relaxed familiarity, but also to allay the

anxiety of new arrivals (Thompson 1990). In a study of Swedish in-patient hospices, Rasmussen and Edvardsson (2007) developed a conceptual framework that describes how atmosphere is created in the convergence of the person's needs/expectations and the environment, leading to either feelings of what they have termed "at-homeness" or "homelessness". The authors assert, "the challenge and call for palliative care is to offer an atmosphere in which the care and the physical and psychosocial environment harmonize and create possibilities for at-homeness" (ibid p129). The authors also claimed that their study was novel as it had begun to conceptualise the environmental field in palliative care, taking into account both physical and psychosocial elements of the palliative care environment. Their study is important in light of the lack of research into this area, particularly so in day care, and my own study is aimed in some ways at taking these ideas further.

In a case study survey of objects that in-patients and their families brought into a hospice in-patient setting, Kellehear, Pugh and Atter (2009) discovered that patients brought objects that reflected their desire to recreate their home settings or functions. Secondly, they found that almost every patient brought at least one personally unique object. The authors assert that the findings suggest an important reconsideration of both hospice settings and new ways of engaging patients about meaning, illness and loss. I would suggest there are parallels with Seamon's (1979) notion of at-homeness in the appropriation of space through the placing of objects, and at-easiness in creating individuality and familiarity through recreating a more personal homelike setting.

Kearns (1993) observed that there has been no adequate analysis of healthcare, illness and care giving and how it contributes to our experiences of place, and neither has there been sufficient research in the health services that has utilised a place-centred theoretical perspective (Kearns 1993;Williams 2002). However there has been little acknowledgement of healthcare settings becoming sites for home. Brown (2003) considered hospice at home, but not home at hospice. Roush and Cox (2000) consider the meaning of home and its importance to reshaping how hospice nurses care for individuals at home. So far, only the work of Rasmussen and Edvardsson (2007) and Godkin (1980) seem to have engaged with the hospice environment from a place-centred perspective, and these have focused on a Swedish in-patient hospice and an American hospital affiliated palliative care unit.

I feel that research into the meanings of hospice environments become ever more important in light of concerns about the encroaching medicalisation of hospice care and the routinisation of the 'good death' (McNamara et al 1994). McNamara et al (1994) assert that the ideal of the good death is not a single event but a series of social events that affect not only the individual, but their wider familial and social circle. I suggest that hospice day care is one of the initial settings in which the string of social 'death events' are first mediated, and as such it deserves more consideration from a multi-disciplinary approach to research.

### **Health, Homelikeness and Inhabitation**

Notions of home have also been used in a phenomenology of health and illness. Svenaeus (2001) describes *homelessness* as the pervasive feeling of not being at home in the world, which is experienced during illness. In Heidegger's terms (cited by Svenaeus 2001 p94), the familiarity of our lifeworld is always pervaded by a homelessness: "This is my world but it is also at the same time not entirely mine, I do not fully know it or control it." We share the world with other people, and though the world is *my* world and I am at home in *my* world, this 'mineness' also incorporates *otherness* in the sense that the world has meaning for other people as well. So there is a basic underlying not-at-homeness, which is kept at bay during health.

Svenaeus (2001 p.94) asserts that health is to be understood as *homelikeness*: "a being at home that keeps the not being at home in the world from becoming apparent". It is a taken-for-granted state that we fail to notice as our basic attunement to the world is one in which we find ourselves engaged, in activities that matter to us and therefore have meaning for us.

In illness, Svenaeus (2001) asserts that our engagement with our normal taken-for-granted world is broken and we suffer *unhomelikeness*. Thus, we experience anxiety, what Heidegger refers to as 'the uncanny', for which the German word is *unheimlich* meaning 'unhomelike'. As a result, the world is suddenly revealed to us in a more authentic manner. In illness, we become consciously aware of our being-in-the-world.

This experience is different to the rhythm of our usual unselfconscious state of health. It is an unhomelike feeling in which we become conscious of feelings alien to us. The unhomelikeness of illness is experienced as a form of senselessness, disorientedness, helplessness, resistance and despair (ibid 2001). These feelings are often directly related to the disease, as individuals struggle to comprehend them. As Svenaeus explains, the “alienating meaninglessness is experienced as a breakdown of understanding, which manifests itself concretely as pain, fatigue, nausea, anxiety, and so on” (2009 p.417). Svenaeus distinguishes between the general homelessness of being in the world, which is due to a loss of attunement with the “external tool-pattern” of the world, and the unhomelikeness of illness which is accompanied by a fatal change in the meaning structure of the self and a loss of control over the body (Svenaeus 2001 p.103). The “external tool-pattern” is synonymous with Jager’s “access to the flesh of nature” (1985 p.219) or the objects in the world we use to experience the world. The body thus becomes alien to our sense of self, yet at the same time it is still *of* the self as these experiences are lived by the self.

Jager (1985) asserts that alienation is a failure to inhabit the world. Drawing on the duality of the body as a “visible source of vision” (ibid p.218) through which we come to inhabit and experience the world, Jager suggests the objects of the world become extensions of ourselves as we learn to explore the world through them (the external tool-pattern) using the example of a blind man using a stick.

“To approach inhabitation in this way means to be able no longer to make such a radical distinction between flesh and matter, between bodies and mere things. Bodily existence floods over into things, appropriates them [...] draws them into the sphere of daily projects and concerns. A fully inhabited world is also at the same time a fully embodied world. Alienation – a painful discordant embodiment – is itself a loss of access to the flesh of nature [...] Alienation is ultimately the failure of inhabitation and embodiment.” (ibid p.219).

This suggests that the body (as a visible source of vision) once terminally diseased becomes alienated from our sense of self in Svenaeus’s terms. Thus, ill persons may become alienated from the world as their ability to inhabit it becomes lost with the failure of embodiment. Physically they can no longer engage with the world as they did

before the disease broke in upon them. Jager was not talking of alienation in terms of ill health, yet his explanation of inhabitation, coupled with Svenaeus notion of unhomelikeness, serves to potentially further an understanding of how our experiences of illness may affect our experience of place.

### **Hospice, place and the use of CAM**

The importance of setting, and in particular, 'place' is recognised by those in the field of health geography. The use and provision of CAM is growing considerably and it is noted that the characteristics of CAM consumption lend themselves well to geographic inquiry and calls have been made for such. While it is true that such calls came from the geographic discipline itself, there have also been calls for a wider research perspective from those in the CAM community (Andrews 2006; Andrews, Wiles, & Miller 2004; Roberts, McNulty, & Caress 2005) as well as the House of Lords Select Committee Report on Science and Technology.

Whilst CT's are noted within the NICE guidance on improving supportive and palliative care for adults with cancer (National Institute for Clinical Excellence 2004) as having a potential place in palliative care, NICE did not recommend CTs for core service provision because of the lack of quality evidence based research (Roberts, McNulty, & Caress 2005). However CT's have become a core service regardless, as the benefits of touch therapies are well recognised by patients and palliative care providers.

Despite the limited contributions from a geographical perspective, there still remains a need for a focus on 'place' in CAM research, how 'place' effects CAM and how CAM effects 'place' (Andrews, Wiles, & Miller 2004). There have been suggestions as to what these places and healthcare settings might be. These include psychological and imagined therapeutic places, physical places such as GP's surgeries, hospitals, palliative care wards, private CAM clinics, therapists own homes, consumers homes and workplaces, yet there is little mention of the hospice as a setting in which complementary therapy is provided. This is surprising as hospice is the largest provider of complementary therapies to cancer patients in the UK (Macmillan Cancer Relief UK 2002) and so it should represent an important area for CAM research, yet this seems to



have gone unnoticed. As Andrews (2008 - see Appendix 1) suggested, this may simply be because the field of health geography is so small and has not yet paid attention to it.

I feel that it is important to redress the lack of research in this area and to concentrate on the hospice as a place that has meaning for those who are associated with it – to consider the perspectives of patients, nurses and therapist's in regards to the use and provision of CT in the hospice. It is important to elucidate the meanings, values and perceptions surrounding the use and provision of CT in the hospice setting in order to understand the nature of such provision and what effects this has on individuals' place experience, and conversely, what effects the place has on the individuals' experiences of CT.

Nelson's (2006) study of the experiences of hospice residents receiving complementary therapies, found through an analysis of cultural practices and beliefs at the hospice, that non-physical responses to CT were perhaps more important to the patients sense of well-being. The study showed that CT was essentially embedded and integrated within the culture of the place itself, embedded by virtue of the shared similarities between its provision and the holistic philosophy of care practiced by the staff. CTs helped patients who initially suffered feelings of fear and a loss of control when initially entering the hospice to feel "safe" and "in control" again. Feelings of well-being associated with CT use allowed patients to move beyond their illness, to "escape" their present health experience. Patients felt that they were being cared for and supported in a very personal way that sustained their sense of individuality. CTs were seen to make "life feel easier", to "refresh" patients, and to facilitate a re-attunement with life (Nelson 2006). These findings have much in common with Seamon's notion of at-homeness, incorporating elements of at-easeness, regeneration, warmth and even appropriation as patients were encouraged to make their rooms "home-like" by tailoring them to their own tastes (Nelson 2006). Though the wider environment of the hospice was not the focus of this study it is evident that CT contributed to place experiences, and possibly feelings of at-homeness, which led one patient to liken the hospice to a kind of "Shangri-La" (Nelson 2006 p.157).

In an evaluation of a hospice based reflexology service Gambles, Crooke and Wilkinson (2002) found that the patients chose to evaluate the service holistically in

terms of the wider environment – the centre, the staff and the therapist as well as the therapy itself. Physical benefits of reflexology were identified as reductions in pain, nausea and swelling. Relaxation was identified as the main benefit helping patients to cope with psychological challenges posed by their illness. Patients positively evaluated their whole experience of the therapy, which included the ambience of the environment, the staff and the therapist. A trusting relationship in a safe environment enabled patients to share thoughts and concerns with the therapist; and allowed patients time-out from their illness. Feelings of at-easeness, friendliness, warmth and comfort were also evident. I would suggest there are elements of at-homeness within this study, and that the therapist/patient interaction created space within the relationship, which enabled patients to transcend and move beyond their situation for a short while. As the authors point out, the comments of the patients illustrate the importance of the wider therapeutic environment in their perceptions of the benefits of the therapy.

In light of the study, the authors concluded that a more positivist approach to evaluating the service would have constrained and possibly excluded supposedly ‘extraneous’ variables, reducing the therapy to the purely mechanistic, which is at odds with its holistic philosophy. The authors further conclude that future studies should employ a more holistic exploration, which neither imposes an artificial structure on the therapy itself, nor excludes extraneous variables that patients may identify as sources of benefit (Gambles *et al* 2002). It is intended that this current study in some ways has done exactly that.

Garnett’s (2003) exploratory study into the use of complementary therapies by palliative care nurses utilised the conceptual language of Giddens (1990;1991) to show that complementary therapies provide what may be termed a *protective cocoon*. I suggest that this study shows how CT potentially affects how patients experience the wider environment of the hospice. In the formation of trusting relationships with therapists, complementary therapies are shown to increase feelings of *ontological security* which refers to “the confidence that most human beings have in the continuity of their self-identity and in the constancy of the surrounding social and material environments of action” (Giddens 1990 p.92). Giddens (1990) asserts that ontological security is strongly related to trust. If trust is failing then feelings of existential anxiety will ensue as ontological security and existential anxiety exist in a dialectical

relationship. Questions that reveal existential anxieties are those such as “why am I here?”, “what will happen to me?”. Giddens suggests that in childhood we receive an *emotional inoculation*, a “basic ‘dosage’ of trust” through our primary caretakers, which blunts our existential susceptibilities allowing us to function ‘normally’ (ibid p.94).

Garnett (2003) suggests that terminally ill patients experience existential anxieties and therefore feel ontologically insecure, at which point experts are consulted and trust in experts is needed. He uses these concepts to show that complementary therapies foster ontological security and trust in the therapist/expert thus sustaining a type of protective cocoon at a time of particular vulnerability. However there is no suggestion that the sense of trust and security also extends to the material environment, whereas Giddens (1990) suggests that trust and ontological security by virtue of a more primitive faith in human beings extends to social and material environments of action. Thus there is opportunity to explore further the effects of complementary therapies on palliative care environments as places that foster ontological security and trust.

A level of trust and ontological security in this kind of palliative care environment is illustrated in Dunwoody, Smith and Davidson’s (Dunwoody, Smith, & Davidson 2002) focus group interviews with cancer patients who had experienced aromatherapy in a variety of different settings.

“It was apparent from the data that participants valued the chance to talk to the aromatherapist in what they all agreed was a ‘therapeutic’ setting, where they could discuss their everyday concerns rather than just focusing on their illness.” (Dunwoody, Smith, & Davidson 2002, p.499)

Dunwoody *et al* do not however say *why* the setting was ‘therapeutic’ and in what way. However they identify a ‘context of security’ that patients experienced when treated by an aromatherapist in the specialist cancer treatment centre. While some patients were reluctant to see a private aromatherapist, others expressed more ‘faith’ in a service that was provided by the specialist cancer unit, where therapists had access to the patients’ notes, and patients had access to an oncology team. Others felt that they preferred to have aromatherapy in a hospital environment, as they felt self-conscious about having

had surgery. There was a consensus that patients felt more at-ease being treated in a specialist cancer treatment environment, where they knew the therapist had knowledge of cancer (Dunwoody *et al* 2002). The study suggests that the environment is important to feelings of ontological security and trust, as 'faith' is directly related to feelings of trust (Giddens 1990). It is evident from this study that cancer patients have preferences for 'where' they receive complementary therapies, which partly results from the condition of health in which they find themselves. Thus, illness has a bearing on the preferred location of treatment. It is therefore important to study these locations in more depth. A humanistic geographic perspective may reveal more about the place experiences of patients, and what meanings places have for them, and possibly how these places are constructed with the patient experience in mind.

### **Therapeutic Landscapes**

The notion of therapeutic health environments has been the focus of health geographers in recent years and much of this work has built on the framework of Wilbert Gesler (1992), who argued that the metaphor of a 'therapeutic landscape' could be used as way of exploring the relationships between health and place (2005). Gesler (1992) proposed that healing and place are inseparable, and that certain places can have a positive effect on our health and well-being. These places or landscapes could be physical, such as healthcare settings, and places of treatment like doctor's offices, therapy rooms or 'healing' spas; or psychological landscapes such as those imagined places produced during visualisation and meditation practices associated with complementary therapies (Williams 1998). Williams describes therapeutic landscapes as "places, settings, situations, locales, and milieus that encompass both the physical and psychological environments associated with treatment or healing, and the maintenance of health and well-being" (1998, p.1193). Attention has been paid to the design and architecture of therapeutic spaces or 'physical landscapes'; social interaction within these settings or 'social landscapes' and the objects, artefacts and language that make up the 'symbolic landscapes' within these spaces (Smyth 2005).

The therapeutic landscape concept has been used to study a variety of healthcare settings and places associated with health, though Smyth (2005) suggests these have

been in the less extraordinary locations of health care such as the hospital, birthing room and family planning clinic (Fannin 2003; Gesler et al. 2004; Gillespie 2002; Kearns & Barnett 2000; Kearns, Ross Barnett, & Newman 2003). The concept has also been used to examine places associated with the maintenance of health and well-being in marginalised groups, such as Milligan et al (Milligan, Gatrell, & Bingley 2004) study of gardening activity and mental well-being in older people. Williams' (2002) uses the concept of therapeutic landscapes as a framework to explore care-giving in the home environment, and suggests that the use of therapeutic landscapes as a metaphor may have more to do with reclaiming health as a quality and rejecting the biomedical model in favour of a socio-ecological/holistic model of health (Williams 1998). Therapeutic landscapes are also explored in Williams' (1999) edited volume of work, that considers multiple perspectives on the positive, healing or therapeutic characteristics of place, affirming place as a central, dynamic element in health and well-being.

The emphasis on natural environments, well-being and psychological attachments within the therapeutic landscape concept, resonates strongly with the holistic philosophy and ideals of many complementary therapy practices, and it has been used to frame explorations of holistic medicine, extending the concept of therapeutic landscapes to include landscapes of the mind, experienced through meditation imagery and psychotherapeutic practices (Williams 1998). Similarly, Gesler (2000) utilised the concept to explore health and place in imaginative literature, indicating that health geographers could include imaginative forms in their reading of landscapes. Extending the meaning of landscape, based on these previous studies and others (Callard 2003; Philo & Parr 2003), Andrews (2004) proposed that therapeutic effects may be experienced in non-physical places, outside of 'real' (linear) time and physical space, in spaces and places created by, and within the mind. I would suggest that in consideration of this it is possible to use the concept of therapeutic landscapes to investigate complementary therapy provision within a hospice day care setting, and to consider the imagined or non-physical spaces and places associated with illness.

As yet, there has been no use of the therapeutic landscape concept within a hospice setting, nor has it been used to investigate the provision of complementary therapies within this setting, which as noted previously is surprising as hospices as the major provider of complementary therapies to cancer patients.

## **Conclusions**

What is clear from the literature review is that few studies have explored the perceptions and experiences of hospice day care patients, healthcare staff and complementary therapists in relation to the hospice, as a place. The use and provision of complementary therapies in hospice care has received no attention from a geographical perspective, and thus represents a gap in the current literature. By developing an understanding of how complementary therapies 'fit' into the hospice landscape of care, and how patients and staff experience and perceive the use and provision of these therapies, it may be possible to improve understandings of how and why complementary therapies are used within palliative care and what meanings are attributed to their use and provision. The aims of this project were formulated in response to the perceived deficiencies or gaps in knowledge identified in this literature review. The aims will be covered in the next chapter, where I will introduce the methodology and data collection methods.

## **CHAPTER 2**

### **METHODOLOGICAL APPROACH**

“Afraid to move from the shadows that give me comfort and safety. Afraid to step back onto the merry-go-round. We are given ‘choice’ and the harder we choose to look, the more choices we have. For those that feel pleasures so easily, those choices are ten-fold. For those that want peace, they must choose less.” (Author unknown)

In this chapter, I will first set out the aims of the study. I will then discuss the ontological and epistemological underpinnings and the philosophical perspectives of the study. In discussing the journey that led me to the philosophical perspectives that underpin my methodology, I aim to provide a firm basis on which to consider the findings of the study.

In conducting this study, I have used a variety of qualitative data collection methods - some well established, and others that lie more on the fringes of social and health research. I will discuss these methods and why I have chosen them.

It is important to consider what kind of research one is drawn to from the very start, as this will certainly influence the aims of the study. I feel that I am more attuned to a qualitative approach. My interests lie in exploring the experiences and perspectives of those who inhabit the world I wish to study. I enjoy listening to and talking with people and hearing their stories. I have a natural curiosity for how other people experience their lives. I enjoy ‘people-watching’, sitting in café’s and pubs and watching the world ‘happen’. Naturally then I am drawn to investigating how people interpret social phenomena within certain contexts, by talking and listening to them, observing them and placing myself within their world.

To pursue the aims of what is essentially an exploratory study, I felt it necessary to choose methods that would fully describe how the phenomena is locally constituted (Silverman 2006 p.44) and in what context it is explored. Thus seeking to explore the provision and utilisation of *complementary therapy - in a hospice* emphasises the activity and the place in which it occurs.

Qualitative research is difficult to define as the meanings attributed to it have changed time and again throughout its history. The main features of qualitative research include exploration in an inductive, interactive, and holistic manner via flexible and reflexive methods of data collection and analysis (Parahoo 2006). Denzin and Lincoln (2005 p.3) offer a generic definition of qualitative research as:

“...a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings and memos to the self.”

Denzin and Lincoln (ibid) assert that qualitative researchers study things in their natural settings, consistent with what is essentially a naturalistic and interpretive approach. The natural setting in this study is of primary focus as it is an exploration of the spaces and places in which the use and provision of CT is experienced.

### **The Aims of the Study**

This study sets out to explore the experiences, perceptions and meanings attributed to the use and provision of complementary therapies at the hospice. In light of the initial literature review, the aims most likely to achieve this were:

- To provide a qualitative account of complementary therapy use within a hospice setting and to seek to understand how complementary therapy is perceived and utilised by patients and staff within a hospice.



- To begin an exploration of the geography of care within the hospice and the nature of patient experiences of CT within this environment.
- To critically examine the dimensions, places and spaces within the patient/therapist interaction, and using the conceptual framework of therapeutic landscapes, identify the contribution of complementary therapy towards the care provided within a hospice setting.

Rather than searching to understand the perceived benefits of the individual therapies themselves, I have considered complementary therapy as a whole experience, as it is the provision and perceptions of that provision that is the focus of this study. Massage, aromatherapy massage, and reflexology are the three core therapies used at the hospice.

### **Ontology, Epistemology and Theoretical Perspective**

The quote at the beginning of this chapter reflects some of the turmoil that I felt, that I am sure many others have felt, during the cycle of personal discovery that occurs within the research process. At various points on this journey I have aspired to be an ethnographer, a phenomenologist, a grounded theorist and then a phenomenologist yet again. My epistemological stance has been more of an epistemological dance. Just when I felt I was certain about what it was I was actually doing, I realised I was doing something else entirely. The process of research has been a process of personal learning and discovery, enabling me to develop my own understanding of how I know what I know, and still leaves me grappling with these concepts, albeit in a more informed and less frantic manner than when I started.

I found an immediate affinity with the idea of Constructionism. It made sense to me, and excited me, as if, what *I* felt to be true, was given a voice. A constructionist epistemology, is defined by Crotty (1998 p.42) as:

“...the view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices being constructed in and out of interaction

between human beings and their world, and developed and transmitted within an essentially social context.”

Human beings thus construct meanings as they engage with the world they are interpreting. Meaning did not therefore exist before there were human beings in the world. The world had form, but there were no minds to interpret those forms - Heidegger and Merleau-Ponty repeatedly state that the world is “always already there” - and so before there were consciousnesses upon it, it had no meaning as such (Crotty 1998).

In a constructionist epistemology, meaning cannot therefore be described as simply objective (as if all objects already had meaning) or simply subjective (as if all human beings created meaning without objects). A ‘hospice’ is devoid of meaning if there is no-one to experience it as a ‘hospice’, and without the hospice in the first instance, no-one would even comprehend the concept of hospice to start with. You cannot have one without the other. So for meaning to exist there must be a relationship of intentionality between object and subject and for us to construct meaning there must be objects from which it is constructed. Moran (2000) affirms that the whole point of phenomenology is that the subjective domain cannot be separated from the domain of the natural world (the objective), as it is with naturalistic science. A constructionist epistemology holds objectivity and subjectivity together indissolubly (Crotty 1998). The doctrine of intentionality or the intentional relationship, attributed to Brentano (Moran 2000), demonstrates this connection.

It is generally accepted that the Scholastic notion of intentionality as reformulated by Franz Brentano heavily influenced the acknowledged founder of phenomenology Edmund Husserl. Essentially it is “the doctrine that every mental act is related to some object” (Moran 2000 p.47) or as Crotty (1998 p.44) explains “consciousness is always consciousness *of something*.” So, to be pleased one must be pleased about something, to hate, something must be hated, to desire, something is desired. As Crotty (1998 p.45) succinctly summarises: “Not only is consciousness intentional, but human beings in their totality are intentionally related to their world. Human being means being-in-the-world.” The concept of intentionality enables us to think about places as centres of meaning, rather than just collections of objects in quantifiable dimensions. The hospice

as a centre of meaning to me means something very different to me now than when I first started this study. My intentional relationship towards it has been strengthened by my experiences of it. It is a centre of meaning, a place, more so now than when I first saw the word on paper and had no experience of it. And yet I know that whatever meanings it has for me, it would have different meanings for a terminally ill patient, or a complementary therapist. I knew that my experience of the hospice, my interpretation of the data, my perspectives on complementary therapy, would all be different to those of someone else. As I became more aware of what constituted qualitative research, I became more aware that I would interpret my life-world in a unique way, and that whatever findings I gathered from the research, if someone else did the same research they would produce different findings and interpret them differently. This holds with the constructionist epistemology.

This variation in interpretation also shows how in ontological terms, reality is subjective and multiple, which means that as individuals we experience reality differently (Creswell 2007) - as a participant in research, as a researcher, as a therapist and as a reader. In a phenomenological study such as this one, these different realities are presented by including different quotes from the various actors that took part in the study. These quotes aim to show how individual's experiences of the same phenomena differ (Creswell 2007), and yet these quotes have been interpreted by me. Their meanings have been re-constructed by me and they are my representation of a truth.

Throughout this study, I hope to draw links between the experiences of those providing and using complementary therapy and the place in which it is provided and utilised. It is necessary then to use a theoretical perspective that is harmonious with both humanistic geography and health care. Historically, phenomenology has formed the basis for much of the thinking in humanistic geography, and remains part of a strong research tradition amongst healthcare researchers. Phenomenology asks, what is the essence of something? What is the essence of the experience of receiving complementary therapy? What is the essence of 'hospice' for a patient? What is the essence of the experience of visiting hospice for the first time?

## Essences

The essence of an object *for me* is what makes it distinct from other objects and that without which, it would no longer be distinguishable as that object *to me*. As Van Manen (1997 p.xv) explains, essence “asks what something “is” for the one who asked the question”, while pointing out that there is an awareness of context, (inter)subjectivity, language and other elements, which ensures that such interpretations can always be questioned by others. I recognise that the hospice in which the research took place is individual, and different from all other hospices by one degree or another. It is therefore impossible to draw any absolute moral convictions about all hospices from this one particular study. To do so would amount to a ‘categorical essentialism’, reducing social phenomena to fixed categories and fixed social groups from which absolutes would be drawn in a positivistic fashion (Van Manen 1997 p.xvi). Whatever my findings are from this study, I do not necessarily expect to find the same at any other hospice, nor would I judge other hospices on these findings, though they could prepare me for what I might find.

Relph (1976 p.43) asserts that “all consciousness is not merely consciousness of something, but of something in its place [...] the essence of place lies in the largely unselfconscious intentionality that defines places as profound centres of human existence.” This suggests that any meanings I derive from my interpretations of the data will be contextualised against whatever meaning this hospice has for me. This is reflected in Heidegger’s notion of *Dasein* or ‘being-in-the-world’ and demonstrates knowledge as embedded.

## Embedded Knowledge and Fields of Care

Heidegger’s notion of *Dasein* refers to our being-in-the-world. Human beings are always *in* and *of* the world in which they find themselves. They are fundamentally a part of it and as such, all meaning and knowledge is therefore inescapably embedded or (em)placed within it. Malpas (2006) believes that Heidegger’s concepts of being and place are inextricably bound together and that the question of essence is not what properly belongs to a thing, but what that thing properly belongs to. As such, the

question of essence becomes topographical as asking what a thing properly belongs to is also asking what determines its proper place. Hence, Malpas (ibid) notes that Heidegger's discussion of the essence of human being is always in terms of the "home", "abode" or "residence". Hence, it is always emplaced or embedded within place.

This suggests that human beings always think and act through objects in the world, and so places become meaningful because of how we interact with them (Crang 1998). I have different intentions towards different places and so I will act differently at the hospice than I would in the local supermarket, or visiting my hometown, or the Swiss Alps. Crang (ibid) points out that Heidegger does not talk about intentions so much as 'care':

"Thus our knowledge of the world is always em-placed, it is always starting from and based around places as centres of our 'care' about the world" (Crang 1998 p.110).

We are always engaged with the world but our attention is focused on different aspects of the world at different times and our level and type of care about different things will vary. Events that occur beyond our horizons mean little to us, whereas things that happen closer to home affect us greatly. Thus the world can be seen as comprising of different 'fields of care' (Relph 1976 p.38). A terminal patient's field of care may be greatly reduced as their health fails. They may be more concerned about what happens to them and their family than anything else in the rest of the world. A traveller may be more concerned about the political status of the Middle-Eastern country that marks his next destination.

### **Hermeneutic phenomenology**

If knowledge is always embedded within the world, Relph (1976) suggests that all consciousness is consciousness of something in its place, or in-the-world as Heidegger would say, and that those places are defined by their objects and their meanings. What I intend to explore is a consciousness of complementary therapy *in* the hospice. Places as

objects in their own right are Relph (ibid p.43) suggests “focuses of intention”, usually in a fixed locality and possessing persistent identifiable features. In a phenomenological sense then it is important not only to explore an account of complementary therapy but an account of the place in which complementary therapy occurs in order to explicate any ‘essential’ meanings.

Like the phenomenology of Husserl, Heidegger’s hermeneutic phenomenology is concerned with the lived-world of human beings and their experience of being-in-the-world (Lavery 2003; Van Manen 1997).

“The point of phenomenological research is to “borrow” other people’s experiences and their reflections on their experiences in order to better be able to come to an understanding of the deeper meaning or significance of an aspect of human experience, in the context of the whole of human experience.” (Van Manen 1997 p.62)

Although Husserlian and Heideggarian hermeneutic phenomenology share this goal, hermeneutics concentrates on the interpretation of text, whereas Husserlian phenomenology produces a description. Texts can be verbal and non-verbal and in this case they include interviews, photographs, diaries and observational notes. Hermeneutics treats these ‘texts’ as a way of transmitting meaning, experience, beliefs and values, from one person or group to another (Crotty 1998).

One of the characteristics of hermeneutic research is the prospect of understanding the text more deeply than the authors themselves, derived from the notion that the authors own meanings and intentions are implicit and go unrecognised by them. Almost as if they are unconscious of the meaning they ascribe to their experiences. In a hermeneutic inquiry, the interpreter of the text has the potential to uncover these *implicit* meanings that are woven into the text and to therefore gain an *explicit* understanding of the meanings and intentions that the author would not otherwise have been able to articulate (Crotty 1998).

In order to explicate implicit meanings the researcher must be aware of his or her own biases and previous experiences in relation to the phenomena being studied and the

process of interpretation that ensues. In Husserlian phenomenology, these biases, assumptions, presuppositions and beliefs are “bracketed” or put aside in an attempt to rediscover the phenomena anew. Heidegger’s belief that human beings are always ‘beings-in-the-world’, and therefore always conscious of the process of being in the world, means that it is impossible to completely bracket previous experiences. It would seem as if this would pose a problem, however Lavery (2003 p.17) suggests that biases and assumptions “are embedded and essential to the interpretive process.” Heidegger’s examination of the process and structure of questioning, reveals that in order to ask any question in the first instance, there must be at least an ‘average understanding’ of the question – a foreconception (*Vorgriff*) of what is involved (Moran 2000). This average understanding is necessary in order to enable the asking of the question in the first place and yet it may also render the question unanswerable in any meaningful way as the preconceptions distort and conceal the answer (Moran 2000). Before formulating the question on which the research is based, I already had an understanding of complementary therapy and what it meant to me. I trained as a therapist and received as a customer. But my conception of what CT is to me could already predispose me to imagine what the answer to the question may be, and this answer may affect how I interpret the subsequent answers of the participants. In light of this problem, we cannot completely bracket our prior knowledge and assumptions. As LeVasseur (2003 p.415) states, “we are necessarily embedded in a historical context.” Van Manen (1997 p.47) suggests that we try to make our assumptions, beliefs and presuppositions explicit in order to consciously hold them aside and “to turn this knowledge against itself...thereby exposing its shallow or concealing character.” By being reflective and “keeping tabs” on my own assumptions and attending to these, I would hope to have a purer interpretation of the data.

### **The Hermeneutic Circle**

Heidegger’s way out of the problem of bracketing is what came to be known as the Hermeneutic Circle. In answering questions we answer them in the light of what we already know – our presuppositions and assumptions. As Moran points out, how is it possible then to learn anything new if we can only understand in terms of what we already know? In the hermeneutic circle understanding becomes a development of what

we already knew in terms of our presuppositions. This developed understanding then returns to shed light on the starting point (Crotty 1998). Bernd Jager talks of 'dwelling' within the world, whether it is within one's body, within a house or within a city. Dwelling he suggests transforms that which we confront through vision, those objects we inspect and judge, into objects that can be used to shed light on other things:

“Dwelling sheds light on unknown things and then slowly transforms these things into a light that radiates out to other things.” (Jager 1985 p.219)

This brings to my mind the hermeneutic circle, and suggests that we may be able to dwell within a text. The understanding that comes from reading and re-reading the text produced by transcriptions of data and dwelling within it (“immersing oneself within the data”), transforms the text which then sheds light on our previous understandings and so on.

## **Sampling**

Coyne (1997 p.630) in considering the approach to sampling, noted that researchers should be “adaptive and creative in designing sampling strategies that are aimed at being responsive to real-world conditions and that meet the information needs of the study”. Within this study, I chose to create a purposive sampling frame to target a particular sample population with characteristics likely to provide data relevant to the research area, so I chose patients, therapists and staff who either received, provided or had knowledge of complementary therapies at the hospice. As the research area widened, I included others in the study that I had not previously expected to recruit as they were identified in the data as significant stakeholders. I felt the story would not be complete without including them, and felt that I had to be responsive and adaptive as Coyne (ibid) suggests. When a person's role at the hospice fell between that of staff and that of a therapist I felt it prudent to interview that person to find out what they perceived their role to be.



### *Sample size and inclusion/exclusion criteria*

My proposed sample aimed to consist of twelve to eighteen day-care patients. This number reflected both time constraints and the number of patients I expected to be able to recruit within the time frame. The day care facility had provision for up to 20 patients a day, yet there was very rarely more than 12 per day. On some days there were as few as four or five patients attending. At the time of writing the proposal there were only five therapists working at the hospice, consisting of three contract therapists and two volunteers. I decided to try and recruit all of them. By the time I came to collecting data this number had increased as 3 more volunteer therapists had been employed by the hospice. I chose five healthcare professionals to reflect the number of therapists I had recruited to gain some semblance of balance between the voices of each group. As the study progressed it became clear there were other stakeholders who should be included in the study. This led to the recruitment of one more member of staff and one more therapist.

It was decided that all participants should be above eighteen years of age though there was no upper age limit. Day care patients were considered to be those in the early stages of terminal illness and presented a less vulnerable group than in-patients. The research was aimed at those who intended to take a course of complementary therapy, generally the new or recently admitted patients. There were no restrictions on race or gender, though in light of research that shows women are far more likely to use CT than men (Downer et al. 1994; Thomas, Nicholl, & Coleman 2001) it was planned that equal numbers of male and female patients would be included in the study. The aim of doing this was to create an equal representation of views from men and women. Surprisingly it turned out that more men were interested in the study than women. Due to the difficulties experienced in recruiting patients to the study, it was decided to abandon this plan and to approach patients who fitted the inclusion criteria regardless of gender and to embrace this unusual trend in the hope of illuminating a reason for this. One of the tenets of hermeneutical phenomenological research as Cohen *et al* (2000 p.50) states is that participants are not seen "...in terms of groups of individual characteristics that can be seen as variables, but as people who offer a picture of what it is like to be themselves as they make sense of an important experience." Therefore, a researcher does not as the authors state, set out to equalise the number of male and female

participants as this may “oversimplify the complex human world that affects the way people interpret their experiences.” The fact that more men than women wanted to take part in the research represented an unexpected example of that complex human world, and this will be discussed in later chapters.

Participants who could not adequately understand verbal explanations or written information given in English would not be included in the study to reduce the risk of interpreter translation errors. As the study was to be a phenomenological study exploring feelings, experiences and perceptions it was envisioned that the use of translators and interpreters would add a higher risk of misinterpretation and complexity. However, in my time at the hospice I did not encounter anyone who would fall into this category. Those who were unable to consent or those who were too ill would also not be included in the study.

## **Methods of Data Collection**

It is often suggested that in phenomenological research there are no set methods, but there are “ways” of doing phenomenology, some more structured than others (Creswell 2007; Van Manen 1997). I planned to use a multi-method approach to data collection in the hope that a wide net would produce a larger yield of data, but also to try an approach that was more ‘place sensitive’ to data collection in the form of photo-elicitation. The methods I planned to use were:

*Semi-structured interviews with patients:* These would be used in the first instance with patients as close to their first admittance to the hospice as possible in order to find out how patients felt about the hospice and complementary therapy in general. Once the patients had completed a six to eight week course of complementary therapy the use of the photo-elicitation interview would hopefully show how the patients’ sense of place and perspectives on complementary therapy had changed if at all.

*Photo-elicitation interviews with all participants:* All participants would be asked to take photos of the spaces and places they found most therapeutic or conversely non-therapeutic. These photographs would then be discussed within the second half of this

interview to focus on the actual places and spaces within the hospice. The first half would be used to establish - in the patients case – if and how their experiences of CT and hospice had changed since their first admittance. In the case of the staff and therapists this would be their only interview, used to gain an understanding of how they perceive complementary therapy and hospice care.

*Postcard diaries with all participants:* These would be used with all participants to try and capture the day-to-day thoughts and experiences of the hospice, and to provide an outlet for any reflection. All participants would be asked to fill in one card per week for a period of six weeks. Patients would fill in one postcard per week between the first interview and the second interview.

*Observation of patient and therapist during a complementary therapy treatment:* Observation would be used to observe how the complementary therapy room is used as a space, and to see what happens during a therapy session with a patient. It was hoped that this would provide context and sensitivity to the rest of the data.

The decision to use these methods was based on two main reasons: (1) they fitted with my theoretical approach and research questions; and (2) their suitability to my own personal communication skills and style. I prefer to talk to individuals on a one to one basis and, based on previous experience of this, I expected that as a novice researcher I would feel comfortable with such methods. I also felt that these methods would not take up too much of the patients' time, and that they may even enjoy the photography and interviews. The postcard diaries were chosen in the hope that they would represent a less burdensome task than a more traditional diary. A more detailed explanation of these methods follows.

### Semi-structured Interviews

“...Talking directly to people and seeing them behave and act within their context is a major characteristic of qualitative research.” (Creswell 2007 p.37)

Interviews as methodological tools of qualitative research developed out of the interpretive tradition. They are first and foremost a way of communicating and extracting various forms of information from groups and individuals (Byrne 2004).

The qualitative interview is often held to be a useful tool for exploring the attitudes and values of individuals. The flexibility of structure and open ended questions are more likely to provide better access to the participants' interpretations of events, their perceptions of phenomena and the meanings they attach to these phenomena (Byrne 2004), than more rigidly structured techniques such as surveys and questionnaires.

Another advantage of this approach is that it allows for issues of a sensitive nature or a complex phenomenon - such as the provision or use of complementary therapy in a hospice - to be explored in a sensitive manner, enabling the interviewer to potentially open up a dialogue that will produce a fuller account (Broom 2005; Byrne 2004 ).

A loose schedule of open-ended questions allowed me to maintain a flexible approach and to adapt to each participant. Within this flexibility I maintained rigour by keeping a focus on the original questions. This ensured that there was a specific focus on the research topic, which guarded against letting the method rule the question (Van Manen 1997). This approach also aimed to allow me to adapt to emergent themes outside the realms of my own preconceptions, allowing a more complete story to emerge. I hoped that the loose schedule would allow me to follow participants through their stories and to bring them back if need be, to the focus of the study. I thought that if the schedule was too tight I might miss important things I had not yet considered. I did not want to stifle any 'flow' that might occur and yet I wanted to maintain a focus on the themes, in case the participant sailed straight past them without giving them any attention. I wanted to reduce as much as possible my influence on the participants' answers, and yet I thought that if I did not ask at least something vaguely connected to space and place then I would never be any the wiser. These fears were allayed as my experience of interviewing increased and the inductive approach allowed for the further development of a structure from the schedule and themes that were used initially. I formulated new ways of approaching questions. For instance during the second interview with one patient, I wanted to know how his experiences of complementary therapy had changed, if at all. The question relating to this on the schedule was:

“How do you feel about complementary therapies now...have your views changed?”

Because he had partly answered this question without me asking it, I asked him instead:

“How do you feel when you know you’re going for complementary therapies?”

For another patient, I asked a new question to try and uncover how he felt about complementary therapies:

“If someone said you couldn’t have complementary therapies today how would it make you feel?”

Although I maintained my focus on the original questions, as each interview progressed I would necessarily find different ways of approaching the same questions. As Rose (1994) suggested the process of interaction between interviewer and interviewee helps the structure to develop, courtesy of both participants.

### *Photo-elicitation Interviews*

“Photo elicitation is a straightforward way of using images in conjunction with other methods.” (Ali 2004 p.276)

Photo-elicitation represents a relatively ‘untapped’ methodological resource. In the past its use in social and health care research has been rare (Harper 2002). However, it has an increasing evidence base in the field of health care with the development of a coherent base of research studying space and place (Epstein et al. 2006; Oneha 2001; Radley & Taylor 2003; Rapport, Doel, & Elwyn 2007).

The use of the photo-elicitation method in this project was born out of my longing to understand the world of the participant as defined by that person, and to see what aspects of place and spaces around the hospice made most impressions on the participants. Using photographs of the spaces and places that constituted the hospice would hopefully stimulate a deeper discussion of what those places and spaces meant to

that person, more than a simple word based interview could. This notion fits well with the phenomenological aim of explicating a deeper more essential meaning to phenomena.

One of the benefits of using photographs in the interview is that they provide a focus for both the interviewer and the interviewee. Kvale (1996 p.50) talks about the differences between literary texts and interview texts in hermeneutic research. Whereas literary texts are 'eminent' in that they are usually well-articulated and containing concise expressions of meaning, the interview text may be vague, containing areas of digression and repetition, which may require an "extended process of clarification and condensation" in a search for the meaning intended. The artful use of photographs potentially aids in the reduction of such 'noise' by providing a focus for the interviewee.

It is hoped that the use of photographs in the research text helps to contextualise the hospice for the reader, painting a picture of how it is to be within this particular individual and unique environment. The photo hopefully allows the reader to interpret for themselves how they would feel in such an environment, but also provides a deeper understanding of how the participants may have felt when the photographs are accompanied by the quotes of that person. As Harper (2005 p.748) suggests, photographs within research articles help to adequately describe the phenomena under question, helping to "subjectively connect the viewer to the argument." This connection is useful in that it helps the reader to more easily cognate the descriptive information about places, but the photograph must also be recognised as a limited form of data in its validity status. The photograph itself is subject to the same criticisms as that of 'essence' in phenomenological terms and all other quantitative and qualitative data. As Harper (2005 p.749) states, the photograph is both true and constructed:

"It is true in the sense that it reflects light falling on a surface, but it is also constructed by the technical, formalistic, and other selections that go into making the image and by the contexts (from historical to presentational format) in which it is viewed."

The photographs of the hospice show snapshots of the hospice rather than a complete truth, though it is intended that this adds towards the illumination of a more complete form of relative truth.

### Observation

Observational methods as developed from anthropological traditions are often seen as the essence of qualitative fieldwork (Clark 2001). These methods position the researcher deep within the research setting, enabling the recording of events and details within the natural setting such as “conversations, encounters, non-verbal communications, spatial arrangements and the physical environment” (Clark 2001 p.59) I chose to use observation to try and gain some insight into what happened within the therapy room and how that space was used. Essentially the encounter between a patient and a therapist is a private encounter behind closed doors. No other way could have elicited as much information as a direct observation of what happened behind that closed door.

In observation, the researcher must choose what role he or she wishes to adopt within the setting, as this has a bearing on not only how the observation will be conducted, but potentially what the observer will be privy to. Most field research adopts a role somewhere between the polar extremes of ‘complete participant’ or ‘complete observer’ (Hammersley & Atkinson 1995). I found it difficult to choose what role to adopt. Creswell (2007) talks of pre-designed observational protocols, similar to interview protocols, that enable the researcher to organize thoughts on what it is that will be observed. I was suspicious of such protocols, perceiving them as constraining much like a structured survey. Van Manen (1997 p.68) talks of a “close observation” that differs from the more experimental or behavioural observational techniques, reducing the distance often created by these methods. Rather than observing participants through a one way mirror or by means of observational schemata and checklists Van Manen talks of entering the lifeworld of the participant by participating in it, while retaining a hermeneutic alertness that allows us “to constantly step back and reflect on the meaning of those situations” (Van Manen 1997 p.69). Whilst Van Manen’s close observation appealed more to me in the sense that he used no checklists

or schemata, I did not actively engage with the participants as he describes. My observational method involved less involvement with the participants as I did not participate in giving the therapy, nor did I actively try to engage those I was observing in conversation during the observation. I had asked that the individuals being observed try to think of me as “invisible” whilst I observed the therapy session from a quiet corner of the room. I hoped that because I already knew the participants in some sense my presence would not affect their behaviour too much, especially as a relationship had already been established during the interviews. I hoped that they would have become familiar and comfortable with my presence and that this might encourage a more natural atmosphere. In hindsight the fact that I had already spoken to the participants in the interviews and they had a good idea of what I was studying, may have affected their behaviour even more if they thought that they could “give me something” in terms of data. The possibility of creating an unnatural situation in terms of the observation will be discussed in later chapters.

### *Postcard Diaries*

Although diaries have been commonly used in health practice settings and in particular nursing practice settings, there is little exploration of this method within the social science and health research context. However, there is evidence that this narrative method can yield invaluable insights into the health behaviour of individuals, and how this is enacted over time and space, often revealing hidden aspects of the participants’ daily lives (Milligan, Bingley, & Gatrell 2005).

As qualitative methods have enjoyed a period of growth in health research, so too have narrative methods. The diary has proved to be a useful methodological tool, and it has been adapted in many forms to suit varying research designs. Besides the traditional “pen and paper” diary, there are now other types of diary tools available to the social science researcher. Electronic personal diary assistants (PDAs) are a sign of advances in communication technology. In a systematic review of studies using both pen and paper data collection methods and PDAs, Oystein and Hagen (2007) found that PDAs seemed to be the preferred method with some subject groups, in terms of protocol compliance, reduced data handling time and subject acceptability. However, most of



the studies involved patients with chronic health problems, and I felt the use of such a method with often elderly terminally ill patients may have yielded different results. In a study evaluating techniques used in measuring high-risk sexual behaviours in adolescents, automated telephone interview diaries and written diary calendars were compared. The telephone diary was preferred by subjects as an alternative to the written calendar diary, eliciting a more accurate reporting of contraceptive behaviour (Minnis & Padian 2001). Structured diary cards have also received interest from researchers in respect to data collection for quality of life studies in cancer patients undergoing treatment (Caffo et al. 2003; Gower et al. 1995; Richardson 1994).

These examples all use structured diary methods requiring participants to log specific items over time, according to predefined questions, health actions or behaviours. What links the favoured methods I feel is the reduced amount of time and effort required from the participant. It is also noted that predominantly diary techniques consist of logging data over time in structured formats and therefore closely resemble survey techniques (Milligan, Bingley, & Gatrell 2005). Such methods have been contested as Burgess (1984) and Richardson (1994) acknowledge that structuring may force the participant into a narrow view of their life events potentially limiting the spontaneity that may otherwise be achieved.

Research using open or solicited diaries is rare in qualitative health research. The term 'solicited diaries' refers to diaries that are "constructed with a specific research purpose in mind and completed by participants in the full knowledge that the contents will be analysed and written about by the research team" (Milligan, Bingley, & Gatrell 2005 p.1883). The advantages of using unstructured, open or solicited diaries are that they can accommodate different response modes so that participants can write in a manner comfortable to them. They have the potential to capture the diarists' own priorities and to reveal aspects of health and healthcare that are important to them (Elliot 1997). Furthermore, as diaries have the capacity to capture events close to when they occur, there is also the potential to trace these events across space and time, providing a landscape of an ever changing present (Elliot 1997; Milligan, Bingley, & Gatrell 2005). I felt that some form of diary method would be useful in an exploratory study, where the researcher wished to capture a wide range of experiences and perceptions from participants in a particular setting. It was felt that this method would also be potentially

useful in an area that is particularly under-researched as there are few studies of complementary therapy use in a hospice and fewer still with a geographical aspect.

The diary provides a freedom of expression and potentially provides as Freer (1980 p.281) states “more of the social aspects of a person’s day to day health, which are important for a holistic appreciation of health”. It is this holistic appreciation that I wanted to capture with this particular method. The unstructured and small format of a blank postcard diary was intended to present a less burdensome task than a more traditional diary.

### **Trustworthiness and Validity**

Although there are well established guidelines for judging validity in quantitative research, there is more debate about what constitutes validity in qualitative research (Langdridge 2007). According to Johnson, Long and White (2001) there is no ‘pure’ form of phenomenology that is capable of having its procedures rigidly adhered to and there is often a level of flexibility in qualitative research, which while often criticised must be accepted as a reality. While I am not claiming to be a pure Heideggerian phenomenologist, I have tried to be as explicit as possible about the methods I have used and to maintain an audit trail.

A reflexive diary was kept to monitor my own thoughts on the research process and to note any troublesome issues so that I could then take these to discuss with the supervisory team at the university. The diary also enabled me to keep a record of the progress of my own thoughts and to monitor events that I felt were important to the context of the research. Supervisory meetings were also held regularly to reflect and discuss events and ideas and to ensure that the quality of research was regularly reviewed.

Involving others in the coding of data (inter-rater reliability) in order to ensure quality was not attempted. As a subjective endeavour, involving others in the process of coding may be considered unnecessary, as phenomenologically this was my interpretation of the data, rather than that of anyone else. However, the coding process and examples of

coding and thematic maps were discussed during supervision meetings to ensure that what I was doing was appropriate and rigorous, and to seek advice on the coding method.

I did not return the transcripts to the participants for member checking. Partly because it was difficult enough to secure the interviews in the first place and time did not allow for this. Furthermore, I felt that I was already asking a great deal of the participants in terms of their time and effort. Also, the interpretations of the data were my own interpretations which I have confidence in and a willingness to take responsibility for. There are as many arguments against validation as there are for it, and in particular Kvale (1996 p.252) notes that a “legitimation mania...” may “...further a corrosion of validity...” requiring that “...the more one validates, the greater the need for validation.” Kvale (1996) also asserts that the nature of scientific discourse means that the generation of new arguments can always invalidate earlier knowledge, which further weakens the argument for validation as strictly necessary. Richardson and St.Pierre (2008), using the central imagery of a crystal, which combines multiple facets, multidimensionalities and angles of approach, propose a “crystallization” rather than a validation of knowledge:

“Crystallisation, without losing structure, deconstructs the traditional idea of “validity”; we feel how there is no single truth, and we see how texts validate themselves. Crystallization provides us with a deepened, complex, and thoroughly partial understanding of the topic. Paradoxically, we know more and doubt what we know. Ingeniously, we know there is always more to know.” (Richardson & St.Pierre 2008 p.479)

This new imagery although developed by Richardson and St.Pierre in an ethnographic context, is still applicable to the interpretive tradition as a whole. In essence, however I interpret the data, someone else will always interpret these data differently, adding to a partial understanding which in turn can only be added to.

Beyond methods and audit trails, I also acknowledge that there is the possibility that the participants’ responses may not reflect their real opinions due to a noted reluctance existing among patients to criticise health care providers, and that respondents may feel

under pressure to provide socially desirable answers, particularly in face to face interviews (Wilkinson 1999). I can only say that I believed that the patients answered openly and honestly, and I accepted their answers as their truths. Subsequently, I tried to make sense of those truths through my own interpretation.

## **Generalisability**

Concerning generalisability, it is noted that there is an extremely high variation in the models of organisation in palliative care (Salisbury 1999). In recognition of the notion of essences in phenomenological research I acknowledge that the findings of this study reflect my interpretation of the perceptions of a certain group of participants who were unique to this site at that particular time. However, the hospice is not atypical of UK hospices in general and there may be recognition of certain themes within other organisations. The strength of this study is in part the detailed description of the findings which increase the transferability of the conceptual and theoretical conclusions. It is certainly possible to use the three existential modes of being as an exploratory and conceptual framework to further explore other hospice and palliative care settings and wider health care settings. This will be discussed later within the recommendations in Chapter 8.

## **Conclusion**

In this chapter, I have located myself within a constructionist epistemology, which sees all knowledge and meaningful reality as neither subjective nor objective, but as constructed out of the intentional relationship that exists between human beings and the world they live in. I planned to use an interpretive hermeneutic phenomenological approach to studying the relationship between peoples' perceptions and experiences of complementary therapy, and the hospice as a place in which these experiences are contextualised. Such an approach supports the explication of the essential meanings of these perceptions and experiences, allowing for the investigation of the effects of space and place upon these and vice versa.

As I have discussed, knowledge is always emplaced and embedded in the world, and as human beings we live through places as profound centres of human existence (Relph 1976 p.43). In exploring any phenomena that is under-researched it was useful in my opinion (though not easy), to try to gain as wide a picture as possible in the initial instance. By combining a number of research methods, I hoped to gain as full a perspective as possible.

In the next chapter, I discuss how these methods were used and how the study was conducted.

## CHAPTER 3

### CONDUCTING THE STUDY

“The way to be is to do” Tao Te Ching

In this chapter, I will discuss how I gained access and the ethical implications of conducting the study in light of the strong opinions that often accompany palliative care research, and the issues raised by doing such research with a vulnerable population. In the previous chapter, I discussed the ‘why’ of methods – why methods are used and why I chose to use a particular set of methods; in this chapter, I will discuss ‘how’ these methods were used and how I organised and analysed the resulting data.

#### Access and Ethical Considerations

Palliative care research is in part characterised by its own tumultuous ethical and moral landscape. Palliative care populations consist of terminally ill patients, patients with life limiting diseases, and their carers and families. Ethical dilemmas over how to conduct research in order to best serve, maintain and protect this population’s best interests still continue. Some have even suggested there are no moral justifications for researching this population (de Raeye 1994), while others have strongly argued against such extreme perspectives (Mount *et al.* 1995). I agree that there is a case for well designed and rigorous research. Indeed as Mount *et al* (1995 p.166) point out the origins of the hospice movement grew out of Dame Cicely Saunders efforts to establish a home for the dying based on “patient care, teaching and research”. St Christopher’s Hospice in London was the culmination of twenty years of observation by Saunders who had intended it to be used not just for in-patient and homecare but “for research into the relief of distress” (Saunders 2001 p.431). Indeed one of Saunders regrets was that the research and educational base that she had aimed to develop at St Christopher’s was not

developed or rigorous enough (ibid p.432). As von Gunten and Ryndes (2005 p.656) point out it was the first “modern academic hospice where research and education were inextricably conducted as part of meticulous patient care.” In light of the moral and ethical issues surrounding the conduct of palliative care research, I approached it with careful consideration.

Before applying to the Local Research Ethics Committee (LREC) I settled upon one particular hospice as a site for the research and approached its Head of Care. I spoke to the therapists and a number of staff before deciding that this was the site I wished to conduct the study at. After my proposal was considered by the hospice board of governors, I received an official agreement to the research from the Head of Care in December 2006. The hospice was enthusiastic about the research and offered whatever support they could. After submitting my application to the LREC I received final written approval from the LREC committee on 28<sup>th</sup> June 2007. Final approval from the NHS Research and Development Directorate was granted on 9<sup>th</sup> July 2007, and final approval from the University Faculty of Health Ethics Committee was granted on 24<sup>th</sup> July 2007.

The vulnerability of the patients was taken into great consideration in this research. I had previous experience of working with vulnerable populations, working for two years in the mental health sector. I have qualifications in communication and counselling skills, touch, presence and tactile therapies and training as a complementary therapist. I undertook a period of working as a volunteer at the hospice, which consisted of sitting and talking with the patients, eating meals with them, serving them tea and biscuits, relaying messages between patients and nurses and making sure that the patients were comfortable and happy. The role of volunteer was never to constitute any form of data collection but it helped me to foster a greater sensitivity to the patients and the setting, and I felt I was giving something back to the hospice. I volunteered for approximately 18 months throughout the data collection phase, until it was no longer feasible to continue due to time limitations and workload. I was mindful of maintaining a sensitive and informed approach to all interactions with participants at all times, and due care was taken to ensure that the rights of the patients and participants was assured. All the day care patients and staff at the hospice were fully informed about the study by the day care sister. As I was working at the hospice as a volunteer, I felt that all those with

whom I was working should know that I was conducting research at the hospice, so I openly informed people of this. I felt that it would create tensions if I did not mention this, even if people were not taking part. I also felt that it could potentially put unnecessary pressure on participants if they felt they could not talk about the research to others at the hospice. If participants (particularly patients) happened to mention the study to other non-participants and then began to worry about what they had said, or if they thought that they must be guarded in some way, I felt that it would essentially change their experience of the place, requiring them to be covert and uncomfortable. I thought it inevitable that during the course of participating in activities such as taking photographs, or “going for an interview”, others would see the patient participants, and questions would arise regarding the nature of their behaviour. I could not ask patients not to talk about the study, so I retained an open and honest approach.

My concerns about the research were mainly focussed on the photographs. In order to ensure anonymity, I did not want patients to take photographs of other people as I thought it might make other people feel uncomfortable. The information sheets given to participants stated that participants should be “particularly considerate of other people, as they may not wish to be recorded in a photograph” (See Appendices 9-11). When I spoke to the participants, I also asked them verbally not to include other people within the photographs unless they had that person’s expressed permission to do so. My concerns were tested almost immediately when the first participant in the study photographed a patient and various members of staff. The participant took photographs of people rather than places, as this is what he found most inspiring about the place itself. Everyone had given their permission to be in the photographs but I still experienced a tension within myself as I felt that ethical boundaries were being tested. I feel that this tension was a product of the process of gaining ethical approval, a resultant heightened sense of ethical awareness, and a wish to protect the patients from any harm or to jeopardise the ethical integrity of the study. My perception of hospice patients as vulnerable individuals was already established in the research process - and by the research application which framed them as vulnerable - and my concern was that participants would forget my requests to gain consent from those they photographed, and this did happen on one occasion. Bill (a day care patient) took images that included patients, claiming he had not known about my concerns:



“Yeah some of them were erm...might have patients on them, which er I quite appreciate is the wrong thing to do on them [...] unless you had permission from the patient [...] but erm, when you were just walking ‘round snapping things, you sort of ignore the patient [...] But none of them gave me permission, it was unknown to me that...” (Bill: Day Care Patient - Photo-elicitation Interview)

I certainly do not feel that my concerns were purposefully ignored or that Bill was aware of doing anything wrong at the time. I feel that he may have forgotten what I had discussed with him at the consent stage when I re-iterated that patients should be considerate of others when taking photographs, as they may not wish to be photographed. When giving the participants the cameras I always made sure they knew how to operate them and my concerns over photographing others. In this circumstance the photographs were left out of the study, and it was agreed between the participant and myself that I would ask whoever was in the photograph if it was ok to include it in the study.

Patients also took photographs of staff members whom they felt some connection and relationship with. It could be argued that these people were ‘therapeutic’ in a sense to the patients. As permission was granted with exception to the case above, I did not stop the patients from including people, however it was understood that these would not be used in publications unless they were completely anonymised by blacking out the person’s image.

I was aware that patients may have felt pressured with the amount of activities I had proposed and I made it clear that involvement in any number of these was optional. They also had the choice to back out of the project whenever they wished without the need to give any reason. I wanted them to feel no obligation to me. Some did drop out, and this was fine. I felt that there was no awkwardness resulting from this. One lady dropped out after the first interview as her health had begun to worsen. Another patient gave consent, but died before the first interview. Another patient died during the study, after completing the initial interview and two postcards.

In my approach to all aspects of the study I was sensitive to the way in which I engaged with the participants. Their being within a hospice meant that I was aware that their health may decline and some participants would perhaps die during the course of the study and perhaps all of the participants would have died by the time I completed my thesis. I carefully explained the study and how I would use the data and explored consent to participate in the study. I judged that discussing the utilisation of the data in the event that they died was not appropriate and I also felt that not using their data would be disrespectful. All of the participants agreed on consent that I may use anonymised quotes and photographs in publications and that this data would be stored for 10 years in a secure location. Although I did not explicitly make this clear at the time of gaining consent I feel that I was alert to nuances during the interviews and other data collection activities which meant that if this issue had been raised I would have been able to respond to this appropriately.

In regard to the ethical concerns of interviewing palliative care patients, it was never the intention or focus of the study to approach topics that the participant may have found distressing, though I was not so naïve to think that sensitive issues such as dying would not arise. Issues around dying did arise, but I did not pursue how patients felt to be dying, or how their disease affected them or their families. I let participants talk about these experiences and I listened attentively. None of the patients became upset during the interviews on account of what they had told me. In fact many seemed to enjoy the interviews and readily offered further help if it was needed. There was support available to the participants at the hospice in case they did become distressed and I also received regular debriefing from the university supervisory team. I felt that this support was needed at times. The death of patients that I knew from the research and those I knew as a volunteer on the Tuesday group affected me in different ways at different times. I was well aware that patients would die, and this was discussed in my supervision meetings at the university prior to going into the field. I found these instances upsetting, but I was also convinced that the patients received the best possible care whilst at the hospice and that their lives were certainly enhanced by their time spent there.

## **Recruitment and Consent**

Initially after a meeting with the hospice Head of Care it was agreed that a memo would be sent around to all the hospice departments to notify people of the research project (see Appendix 2). This was firstly to inform people of the nature of the research and secondly to notify people that participants in the project would be taking photographs around the hospice and that if anyone had any concerns they were to notify the Head of Care or the Senior Day Care Sister. Also a memo was sent around to all nursing staff, nursing assistants and complementary therapists notifying them of the project and welcoming any expressions of interest in the project. I received one expression of interest from an auxiliary nurse working on the in-patient wards who also used complementary therapy to treat patients. I have classed her as a staff member within the project as that is her primary role.

I intended to recruit 12 –18 hospice day care patients. The recruitment process was staggered to ensure that I had time to commit effectively and appropriately with each participant. The consent forms stated that patients could take part in any or all of the data collection activities. Most were happy to take part in all, though few attempted to fill in the postcard diaries, which will be discussed later. I found the recruitment procedure hard. I did not want to push patients into doing something they did not wish to do, but at the same time, some patients, I felt, needed gentle reminders. The LREC committee had agreed that 48 hours was enough time for a patient to decide whether or not to take part after receiving the information packs. Often they would have over two weeks as they only attended day care once per week. I did not feel comfortable visiting patients at their own home. I felt this was too invasive and wanted to keep the research as something that happened at the hospice, amongst the support and safety of such an environment. Patients who were thought to be suitable and perhaps interested, were initially identified by the day care sister in charge. She identified patients who were possible candidates based on their health status and on the inclusion criteria. If a patient was thought to be suitable she would approach them, in the first instance, and inform them of the research. If they showed interest, she gave them an information pack and they would have one week in which to read the information sheets. The following week she would ask them if it was ok if I came to introduce myself to them and talk about the research. If they agreed I would go to the hospice and introduce myself answering any

questions regarding the research. This ensured that the patient had enough time to read the information pack, to discuss the research with family and friends if they wished, to ask any questions and to consider taking part. If the patient agreed I would explain the written consent form and they signed two copies in the presence of another independent witness such as a member of staff. I would then interview them if they agreed.

I felt that if I approached patients in the first week they may have felt pressured or overawed. Often when I introduced myself on their second week, it was then that I would find out that they had not yet read the information sheets, or that they had lost them. I would give them another copy and verbally go through the research with them. I would then ask them to think about taking part, to discuss it with friends and family if they wished, and I would return next week to answer any questions, thus giving them more time. My contact details were also on the information sheets should they wish to contact me to ask me anything. No one ever contacted me. Sometimes it would be another two weeks before the patient attended day care again due to illness or prior commitments. They may have forgotten to read the information sheets. In this case I would go through the sheets with them and if they wished to take part I would then ask them to sign the consent forms after we had discussed them. Often it would be another week before I interviewed them, to allow them time to get used to the idea. By then they could have been attending day care for five or six weeks. My original aim had been to interview them in the first two weeks of coming to the hospice and taking up complementary therapy. This almost never happened.

As the pressure of time increased I became a little more astute in regards to the recruitment process. I asked the staff to remind patients to read their information sheets and to make sure they took them home. As soon as patients had decided they wished to take part and signed the consent form, I asked them if they wished to do the interview on the same day. Most often they agreed. No-one seemed to mind me recording the interviews, and some were even interested in the small high-tech digital voice recorder which also provided a conversation piece useful in establishing rapport. I was always aware of the patients' demeanour and body language. Prior to interviews if patients seemed to be having a tough time I would leave interviews until the following week. I would phone the sister in charge before coming to the hospice to see if a participant wanted to be interviewed that day. Sometimes they would decline if they were feeling

unwell. I felt that my phoning through and relaying a message was far less coercive than meeting with them face to face. Though there is evidence of what Keeley (2008 p.757) calls an “untapped altruism” in palliative care patients, I still wanted to give the patients the chance to back out if they did not really feel up to it.

Once the patients had completed their six to eight week complementary therapy course I planned to interview them again. It became almost impossible to adhere to this time frame. The difficulty in recruiting palliative patients is well documented elsewhere. I had not realized at the time how difficult it would be. Patients were often not attending because they were ill or had hospital appointments, which reflected in some ways the disruption that terminal illness can bring to the lives of families and patients. Other reasons for non-attendance included family holidays, birthdays and wedding anniversaries.

Operational concerns also surrounded the postcard diaries. I needed some kind of postal box that was secure so that participants could post their diary cards on their way in or out of the hospice for me to collect. I felt that this would make things easier for the participants and would not involve me having to make appointments for me to see them, during which I was using up more of their time. Giving participants pseudonyms and an ID combining a letter and a number helped to maintain anonymity and security. The ID was copied on the top corner of each postcard along with an entry field for the date. I made a secure box from a container I purchased from a stationary store. I cut a slit in the top and secured the lid with cable ties. The box was then placed on top of the reception desk, where it would be under the watchful eye of the reception staff. Although patients and participants were notified of this, I was often given the cards by the participant personally. I would check and empty the box regularly each time I went in to the hospice. Although the box was identified clearly with the university logo and “research project” on numerous occasions people dropped money into it, which I then had to empty into the correct donation boxes. I found this amusing, as did the reception staff, but it was also a reminder that the hospice relied heavily on the support of the local community.

Some patients declined to take part in the study. Often if patients were not interested they would inform the sister in charge who would relay the explanation to me.

Sometimes I would meet the participants and they would explain that they were either too tired, or did not feel they could manage to take part. I did not press or argue with their decision. Other patients were only too happy to participate in the study. The male patients particularly took part in the study because it would “keep them busy” or give them “something to think about”. The predominance of male patients who agreed to the research was discussed with the day care sister who seemed to think that this was because there was not enough for the male patients to do, and so they were glad to be taking part in something constructive, particularly the photography. I noted this lack of activities and wrote a letter to the Head of Care and the Day Care Sister suggesting a gardening activity for patients (see Appendix 3).

Recruiting staff and therapists posed less of a challenge. All staff and therapists had been notified of the research project and the recruitment procedure was similar to that of the patients. As I had become known to many of the staff as a volunteer those who were interested often engaged me in conversation about the study. I took this opportunity to invite them to participate in the research. I sent or gave information packs to other staff I considered to be important stakeholders. Staff had at least two days to decide whether to take part in the research.

While most of the staff and therapists were happy to take part, I did experience some difficulty with two members of staff who had enthusiastically agreed to participate, yet acted very differently once they had signed the consent forms. They repeatedly delayed taking photographs until months passed by. Eventually, when they completed the photographs and they were interviewed, they seemed to enjoy the experience immensely, commenting on how they had become more aware of spaces and places within the hospice. One member of staff also declined to take part. I did not ask why, as I felt it was intrusive to do so. However, when one of the therapists refused, I did question why, simply so that I could possibly make improvements to the study. The therapist simply felt that there was no benefit in the study for the patients. She was identified repeatedly in the interviews and I viewed her as a key figure in the study because her role was one that I would not have usually classed as a ‘therapist’. How others defined her role had implications for the way that people interpreted ‘therapy’ at the hospice, so I approached her again and explained the purpose of the study while acknowledging her concerns. I also mentioned why I wished to interview her. She was

more than happy to agree to an interview once she understood that the study could potentially help the hospice and that it was not entirely an exercise for the university's benefit. I felt that she had originally misunderstood the purpose of the study and that I should explain and clarify my position and for that reason I felt justified in re-approaching her.

I had met most of the contract therapists in my capacity as volunteer and during conversation I invited them to take part in the research and gave them information packs. The volunteer therapists were given packs by the day care sister who also acted as the complementary therapies coordinator. I spoke to the three volunteer therapists via telephone and arranged to meet them. I met two of the therapists at their own homes as this was where they preferred to meet. Most of the therapists were happy to consent to all of the activities apart from one therapist who declined to do the postcard diaries as she could not write due to personal injury.

Other incidents included a temporary breakdown of communication between the day care sister and myself. I ensured that she had a supply of information packs to give out to patients, but on one occasion she had run out of information packs and had forgotten to inform me of this. I realized it was my responsibility to ensure that she had adequate supplies of information packs. After this I constantly checked how many she had given out each time I telephoned or went to the hospice. This incident impressed on me the importance of having strict procedures in place concerning the distribution of information packs, and maintaining good communication with gatekeepers for which it was my responsibility.

I kept my roles as volunteer and researcher separate at all times. At one point in the study a female patient who had attended the Tuesday group with whom I volunteered, swapped her day care day to a Thursday. This meant that potentially I could have asked her to participate, as she was no longer a part of the Tuesday group. However I felt that it was inappropriate as she had come to know me as a volunteer and potentially this could have affected her responses. Although I was a volunteer on a Tuesday I did make some general notes and observations in my field diary as I felt that these were helping me to contextualise the study and to become sensitive to the setting.

In conclusion, I feel that the recruitment procedure was the most challenging part of the fieldwork. The target sample for patients was 12-18. I managed to consent 12, though one of the patients died before commencing the research reducing the number to 11. Only five of these patients completed both interviews. Some became too ill to carry on, and others died. Only one of the patients attempted the postcards. Time was a factor. The study required patients who were able enough to take part in the project, and many were too ill or frail. Patient numbers also decreased rapidly over the Christmas and winter period with as little as four patients attending day care on some days. I decided that as five patients had already completed both interviews, this matched the number of therapists and staff who had completed their interview, and as time was becoming a more pressing issue I decided not to recruit any more patients. There was no guarantee that if I did managed to recruit more patients, that they would complete both interviews. I considered the data from the interviews to be the main data sets as they potentially yielded the richest and most in-depth material.

### **Data Collection: How the methods were used**

This next section details how I used the methods of data collection with each of the participant groups. Please also refer to the table of participation in the appendices (Appendix 4)

#### **Day care Patients:**

*Interviews.* Once the patients had signed a consent form I asked them if they would like to do the first interview. These mostly took place in the “interview room” as it came to be known. The digital recording equipment that I used had an external microphone and was extremely sensitive to background noise and the interview room was air conditioned as there were no windows and it was a small room. The noise of the air conditioning often made the recordings difficult to decipher when transcribing, so I tried to avoid using this room and tried to use the bedroom instead, though this was often already in use. Interviews also took place in the small day care lounge and on one occasion in one of the patient rooms downstairs on the in-patient wards. In this instance



the day care patient had been admitted to the in-patient ward, however she expressed a wish to carry on with the research. All the interviews were recorded and no-one declined being recorded.

*Taking photographs.* Between the first interview and the second interview that was planned for six weeks later patients were asked to take photographs of the spaces and places around the hospice. They were asked to take photographs of areas they felt were 'therapeutic' in some way and conversely areas they felt were 'non-therapeutic'. I had given each patient a disposable camera with 27 exposures. I asked them to take as many or as few photographs as they could manage. The minimum amount taken by a patient was nine whilst the maximum was 27. When the patients had completed their photographs, I collected the cameras and took them to be processed.

*Photo-elicitation Interviews.* Once I had the photographs I would then invite the patient back for the photo-elicitation interview. The first half of the interview was used to discuss if and how things had changed since the last time we spoke, and often we would reflect on what was said in the first interview. The photographs provided the focus for the second half of the interview. Initially I took control of the photographs handing each one in turn to the participants, so that we could discuss each photograph in turn. I had also put alphabetical codes on the back so that they could be identified for the recorder. Almost immediately I realized that I was controlling the situation and that it created an imbalance of power in the relationship. The patients may have also been excited to have their photographs returned, to see how they had turned out. By controlling the photographs I was denying the participant this simple pleasure, so I began to hand the photographs to the participants, telling them that I had coded them on the back so that when we spoke about each photo it could be identified for the recorder.

Only five patients managed to complete both interviews. Six had died or left the project through a decline in health.

*Postcard Diaries.* I had also asked the patients who consented to the postcard diaries to fill them in each week for six weeks. Often patients forgot and my gentle reminders did not seem to remedy this. I even asked the staff to remind patients to fill them in. However they were most often left at home and forgotten. On reflection I feel that

perhaps some patients may have found the free format too challenging and would have preferred a more guided and structured method. Only one patient managed to fill in any of the postcards. Overall 44 postcards were collected (23 from staff, 19 from therapists and 2 from patients).

*Observations.* I observed complementary therapy treatment sessions with patients and therapists. I carried out four observations in total with different patients. Most of the patients who were available to do the observations were attending day care on the same day and so were treated by the same therapist. As I have mentioned in the methodology chapter, my observational method consisted of being in the same room as the participants, though not engaging them in conversation or participating in the therapy session. I had asked the patient and therapist to think of me as invisible while I sat and observed from a corner of the room. My seat was placed in a corner by the door, out of the way of the therapist and patient. I positioned myself in such a way so that I was sitting slightly sideways to the participants and not directly facing them in what I hoped was an un-intrusive/non-confrontational manner. I listened intently and watched passively, not staring but watching whatever caught my eye. During the observations I became intensely aware of every movement and noise that I made. I tried to write as quietly as possible with a ballpoint pen. My notepad was size A5, small and unobtrusive.

As a novice researcher, I was unsure of what I would be observing. I wanted to leave everything open, to see what would happen and what I could capture. I felt that using an interview style protocol at this stage would be too constraining and I wanted a more organic approach to get a feel for the method. I noted the subject of conversations between the therapist and patient. I tried to capture some things that were said verbatim if they struck me as significant. I made notes on silences and watched what the actors did physically, such as:

Silence for 5 minutes.

Carl's head droops increasingly toward the bed.

It occurs to me that perhaps I should interview people straight after the treatment to see what their reaction is.

Still silence after 10 minutes.

I watch Jackie working. She has a very straight back.

Carl's head is almost touching the bed.

Some of these notes would end up as extraneous material, such as the observation of the therapist's straight posture. I also noted down my own thoughts at the time concerning what was happening, such as this note on the behaviour of the participants:

Jackie turns on the music and moves closer to Jim. Jim continues to look at the wall chart while Jackie massages his foot. They are comparing the charts.

I have the feeling again that this scene is for my benefit and feel that I am affecting the behaviour of both Jim and Jackie.

The following extract from the same observational notes, include some of the things that I felt it important to capture, because they said something about how the patient experienced the therapy, what he thought about it and also the awkwardness of being an observer when their attention turned to me:

Jim: "My feet have always felt wonderful when I've left here and I look forward to it, I really do."

Jim: "I am learning, I'm beginning to understand it a bit more now." Jim talks about his understanding of reflexology.

Jim keeps looking at his chart and then at his feet and to what Jackie is doing as if trying to follow.

Jim then turns his attention to me: "Poor old Drew will be getting quite envious. His tootsies will be dancing... I could stand this all day Drew if you've got the time."

I say nothing but smile as I don't wish to encourage any more interaction as I worry that this may spoil the context.

My presence as an observer was of continual concern to me as I felt I was influencing the research environment. I feel that perhaps in a busier environment my presence would not have been noticed so much. However, sitting in a small therapy room during what I feel is an intimate exchange of care between two people, I feel had more of an effect on what was happening than I had anticipated. I noted this during the same observation:

I notice that Jim isn't asleep as he has told me he usually is. This leads me to think that my presence here has stimulated more conversation than usual and that some of the 'talk' is for my benefit.

I felt that the observations provided context and insight into the patient and therapist relationship and how therapy sessions were acted out within this space, but that ultimately my presence adversely affected the observational data.

#### Staff and Therapists:

*Photo-elicitation interviews.* Once the staff and therapists had signed consent forms I gave them a disposable camera and a pack of six blank postcards. Once they had finished taking the photographs they would notify me so I could pick up the camera and get the film processed. Once I had done this, a meeting was arranged so that we could conduct the photo-elicitation interview. The interviews were recorded and took place in various rooms around the day care area. Unfortunately there was no set room for the interviews, only what was available at the time. I often left the choice of the room to the participant in the hope that they would feel less intimidated. The interview focused on their experiences of working at the hospice and how they perceived complementary therapy before moving on to the photographs. The photographs provided a focus for how the participants perceived the spaces and places around the hospice and this

frequently led to discussions about patient care, indicating that the place is inseparable from the human events and actions occurring within it.

*Postcard diaries.* Staff and therapists were asked to fill in one postcard per week, summarizing their feelings and experiences of that week. Once the postcards were completed I collected them for data preparation and analysis. Four staff and four therapists filled in the postcards. Of these, three staff and three therapists managed to complete all six postcards. The postcards were not used within the interview as I perceived that this would be too much to cover within the intended period of time.

### **Data Organisation and Analysis**

“...the meanings we bring to the surface from the depths of life’s oceans have already lost the natural quiver of their undisturbed existence.” (Van Manen 1997 p. 54)

In this section, I will describe how I organised and analysed the data, and some of the problems I experienced. I will describe the procedure of analysis for each of the data sets. The process of analysis was not a smooth process, and here I explain how I struggled in my first attempts, as initially I tried to force the process, before eventually relaxing and finding a more natural feel for the data. In the quote above, Van Manen is suggesting that once we draw out meanings from the depths of the data, they are subject to our own interpretation. Drawing out these meanings in phenomenological analysis is I suggest, rather like fishing. When we get a bite, we struggle to reel in the fish. We might get a glimpse as it breaks the surface - just before the line snaps. As we become more successful we may land the fish, but one has to learn how to grasp it properly, lest it slips back into the water and disappears, leaving only ripples. However, I feel I have become a good fisherman.

### *Transcribing the Interviews*

All the participants consented to having their interviews recorded. Although I had originally put this as an option on the informed consent forms and everyone had agreed, I asked again before starting the interview. The interviews varied in length from 18 minutes to 94 minutes. The photo-elicitation interviews generally took longer. I transcribed the majority of the interviews.

In total there were 31 interviews and 478 pages of transcripts. Transcribing this amount of data required a lot more effort than I had expected. I noticed that although participants were often “easy” to talk to and to listen to during the interviews, when it came to transcribing some of the interviews the dialogue became verbose and laden with breaks, unfinished sentences, pauses, stutters and repeated idiosyncrasies, such as “you know what I mean?” or “to my mind” or “like”. This did not happen with all the interviews and it occurred with patients, staff and therapists. During the transcription, these idiosyncrasies became distracting at times. I found it increasingly hard to listen for the meanings in the words and repeatedly made typing errors, becoming frustrated and ineffective. Regular breaks were needed to maintain a level of effectiveness (and sanity). Though it was difficult at times, I also found great value in transcribing the interviews myself. I realised how differently people spoke, with different levels of coherence and rhythm. I began to see things I had missed previously in the words the more I read and re-read, and the more I listened to the recordings. I became more sensitised to the narrative.

Transcribing is an unnatural exercise. In a natural conversation we do not listen so extensively to the words that people say, for if we did, it would become hard to listen to and perhaps harder to decipher. Instead, we follow a “gist”, a rhythm, a flow of words, emotive nuances, intonation, pauses and body language. And yet, when transcribing the recordings I realised that during the interview I was so busy trying to think of my next question, trying to maintain an ‘open’ body language, or in some cases just too tired, that I missed many significant opportunities to question what was being said. I missed the meanings of what participants were saying at the time, because I was distracted by other thoughts, and the transcribing helped to reveal those meanings I had not caught

first time around. Over time with more confidence in my technique I became more alert and attentive to what the participants were saying.

I outsourced three of the interviews for transcription by a known reputable transcription service, and on reflection, I have to admit a level of naivety in doing so, though the experience was a valuable one. The purpose of outsourcing was to reduce the amount of time spent transcribing as it is a lengthy process. When it came to analysing these I noticed the difference between my own transcriptions and those I had outsourced. I noticed that in the transcribed interviews there was a lot of “[inaudible *[time]*” entries where the interviewer could not decipher what was said. As I was more used to the participants speech I thought I may be able to correct these when I listened to the recordings again and so fill in the missing data. When doing so, I started to notice inaccuracies in the transcript text. What was said was not necessarily what was typed. Often this was a ‘shortcut’ where a seemingly unimportant agreement or utterance such as “oh yeah” was omitted. I replaced these as I wanted to stay as faithful as possible to the data but I also noticed there were some more serious misinterpretations such as in the following example:

Bill - Oh yeah and, of course, I visited one or two people who were residents here...

Me - Yes.

Bill - ...war patients. I've always had the feeling that it was a place of no return. But I've changed my mind slightly now.

The respondents' last comment should have read “...*or patients*” Rather than “...*war patients*”. The former would infer that he is aware that ‘patients’ and ‘residents’ have different meanings within the hospice situation. The transcriber had misinterpreted this as ‘war patients’ which would suggest something else entirely, possibly leading to a misinterpretation of the participant’s past history with the hospice. Subtle nuances were also left un-transcribed such as laughing, yawning, pausing, and sighing. These all suggested something either about the interviewer (me) or the participant. Where laughing was concerned I found it useful to indicate that something was obviously funny or delightful; that the participant may have been nervous about saying something, or to communicate a sense of incredulousness. To ensure that I understood the

meanings of the interviews I recorded the nuances that I thought to be important. If there was a sigh before something was said, it could mean frustration, or sadness such as in the example of Harriet, one of the volunteer therapists as she explained how she needed to leave the hospice behind at the end of the day, lest it affect her in her personal life:

“Yeah, it’s like a passageway for me from one world to the other, does that? ... and that’s part of my bubble of protection if you like, to stop me getting ... because it’s... [big sigh] When all’s said and done people are dying here and I leave that behind.” (Harriet: volunteer therapist PEI)

Her sigh lends gravity to what I interpreted as sadness for the patients and their situation, and possibly a sense of futility that she could not do more, and a sense that the work she does is stressful work and that although she does what she can, death is an inescapable part of her work. Things that made an impression on me at the time of the interview I had made sure to record in the transcriptions, and these also lent gravity to the responses of the participant, such as when I asked Terry, a patient, how his experiences of care at the hospice compared to that of hospital:

Terry – “[made a memorable face of disdain/anger] Can’t really swear can I?  
Err.

Me – You can if you want to.

Terry – No. [sighs] Shall I put it this way...I know you’re doing me, but [wife’s name] was in one of the local hospitals. And she had a terrible time. Terrible.”

The facial expression that Terry made was one that I interpreted as anger and disdain. He asked me if he could swear and the “err” at the end of his sentence indicated that he was lost for powerful enough words to describe his experiences of care in the local hospital. I did not want to stop him from really expressing how he felt, but he respectfully declined the offer to “let loose” and sighed, which perhaps indicated frustration, anger and futility.



These were important nuances that I did not wish to miss, as they added something to the meaning of what was being said. Reviewing the transcripts also meant that I would not miss out on forming an important intimate bond with my data.

Through my naivety I have learned considerably from these experiences. As the transcriber was not privy to the context of the research and was not present at the interviews it would be a lot more difficult for them to interpret what was being said. My instructions to the interpreter were not specific enough, and so nuances were not recorded. In hindsight the interviews could be even more nuanced as some researchers record every fine detail such as intonations and lengths of pause. The transcriber had no instructions to record any of these. However, correcting the outsourced transcriptions took a lot less time than it would have done had I transcribed them initially.

I developed pseudonyms to protect the participants' identity and kept a record of these. These pseudonyms were used to identify the participants in the interviews. Other people mentioned in the participant's narrative were also given pseudonyms. If there was a brief mention of them I would indicate their relationship to the patient rather than their name, for example [nurse] or [wife's name]. Each participant was also given a code so that they could be quickly identified as a therapist (T) a patient (P) or a staff member (S). These letters would prefix a number. So Lucy (pseudonym) who was a therapist would be "T1" - the first therapist I interviewed. Later during the writing of the thesis I modified this system carefully, as the letters and numbers did not reflect the fact that the participants were most importantly human beings taking part in a qualitative study. Such codes while of benefit to audit trails, seemed to reflect only a cold quantum, bereft of any human dimension. Thus, in thesis participants are given a pseudonym and identified as a day care patient, a member of staff or a therapist. So "T1" became "Lucy: Contract Therapist".

### *Analysing the interviews*

I had considered doing a content analysis on the photographs from the photo-elicitation interviews separately, but I felt that they were more of an aid to the interview process and I did not see any value in analysing the photographs separately from the interview.

The analysis of the photographs took place within the interview between myself and the participants. In this way the participants were also acting as co-researchers. They would explain why they took the photograph and what it meant to them. I would ask questions such as “how does this photograph make you feel?” and “what is it about that place that makes you feel like that?” or “what is your favourite photograph?” So the analysis of the photographs was a part of the interview itself and the interpretations were constructed between both myself and the patient.

I wrote ID numbers and letters on the rear of the photographs prior to the interview. So the first photograph of the first therapist I interviewed would be labelled T1A, the second T1B. I asked participants to refer to the letters on the back of the photographs in the interview so that it was easy to establish which photograph we were talking about on the audio recording. The photo-elicitation interviews were then analysed in the same manner as the semi-structured interviews. The only difference being was that when I was thematising the interviews at a point where a photo was being discussed, I would have that photograph with me or in digital format on the computer screen. This ensured that I would remember faithfully what was being talked about, and that if either myself or the participant referred to something in the photograph I could visualise this directly.

### *Grappling with technique*

I had originally intended to use a phenomenological approach to analysis, though at the time I first started to analyse the data from the interviews, I had moved away from this approach as I had found it too confusing and was considering a more grounded theory (Charmaz 2006) approach. I was initially attracted by grounded theory’s systematic approach to line-by-line coding and the formation of categories and themes, as this sounded reassuringly simple to a naïve novice researcher. My first attempts were too mechanical and not insightful enough. I found that I was describing and re-iterating what was going on, rather than developing more conceptual codes and themes. For example, here Harriet, a therapist describes why she took a photograph of a tree in the garden and what it meant to her. My initial codes are in bold:

“It’s a symbol of hope of constancy, constancy is hope for me. [symbol of hope] [constancy is hope] However things change for good or bad, there’s always that constant and it’s just, it’s been there hundreds of years before me and hopefully it’ll be there hundreds of years after me and it makes me feel as if I know my place, [knowing one’s place] [perspective] [existential realisation] not just here in the hospice but in the world... [...] I need to know that the leaves are going to fall off the tree and next year they’re going to be replaced and that’s been happening for years and years and years. [looking for constants in landscape] It gives me comfort. [knowing something is constant is comforting]” (Harriet: volunteer therapist PEI)

At first the process of analysis was tentative to say the least and this showed as the codes were mechanical rather than insightful.. I was not reflecting enough on the text and I had become obsessed with trying to code everything and trying to develop themes. I feel now that I was *trying* too hard and this was forcing the data, rather than *letting* the data make sense for me. After realising that I was still uncomfortable with this process, I returned to the literature on data analysis and sought help from my supervisory team. In this way I was also ensuring validity by checking my analysis with the supervisory team.

### *Returning to a hermeneutic approach*

After reading more of the literature on hermeneutic analysis, I decided to return to a phenomenological approach. I used Van Manen’s approach to guide me during the data analysis phase because I found his explanation of this process to be the most accessible. Van Manen (1997 p.92) suggests three ways of isolating thematic statements. Firstly, there is the “wholistic” (Van Manen’s spelling) or sententious approach whereby the text is attended to as a whole and a phrase is formulated that will capture the fundamental meaning of the entire text. This approach is more open to idiosyncratic judgements. The selective or highlighting approach tends to phrases or parts of sentences that stand out and seem to be thematic of the experience described. The third approach is a line-by-line approach whereby each individual sentence or cluster of sentences is attended to, to see what it reveals about the phenomena described.

I reprinted all the transcripts and began the process of coding and thematising again. I listened to the recordings again whilst simultaneously coding the transcripts. This enabled me to get a better sense of the intonation of words, to gain a better sense of how something was said, rather than how it “sounded on paper”. I found this defined the emotional context better. I started to become closer to the interviews and to know them more intimately, getting to know the people themselves more intimately. I started to become attached to certain phrases and sentences as they sparked my imagination. I remembered who said what, often recalling a participant’s words as they were triggered by something I had read within the literature.

I used a mixture of all three of the methods described by Van Manen initially. This was not intentional but more intuitive, and I feel that all three methods have to be used as often meanings are conveyed over more than one sentence. I read through the interviews line-by-line, marking words that seemed to recur often, marking unusual words and stand out phrases, and trying to get a sense of what that particular sentence or cluster of sentences was revealing about the phenomena described (the line-by-line approach). I also put a bracket around entire chunks of text and wrote in the margin what I thought the theme of it was (the sententious or wholistic approach). I highlighted phrases in quotation marks and underlined parts of sentences that stood out. I sometimes wrote out a part of a sentence in the margin and put it in quotation marks, because I felt that it was important somehow, even if I could not yet explain why (the selective approach). These approaches seemed to me to be natural ways of coding and thematising the data.

All human experience takes place within the lifeworld. There are multiple experiences and structures of meaning that constitute each human being’s lifeworld and Van Manen (1997) suggests the use of four existential themes that are probably fundamental to all human lifeworlds:

Lived space (spatiality)

Lived body (corporeality)

Lived time (temporality)

Lived human relations (relationality)

These four existential categories enable a process of phenomenological questioning, reflecting and writing. A prime example of these four lifeworld existentials is illustrated in Jim's comment on his experience of care at the hospice:

"I get what I want and I get it at the pace I like it and I get it in a friendly atmosphere and that'll do for me." (Jim Day Care Patient - Photo-elicitation Interview)

"What I want" could imply physical needs (like a drink of water to quench thirst) and may be suggestive of an experience of lived corporeality; "at the pace I like it" suggests an experience of lived time or lived temporality; "in a friendly atmosphere" is both a comment about his experience of relationships and the space in which these occurred, which is about lived relationality and lived spatiality.

As each interview was complete I re-analysed the next, keeping in mind new insights gained from the analysis of the previous transcript. As each transcript was coded these new insights informed the coding of the next. Subsequent codes were also checked by returning to previous transcripts to see if it occurred in those too. Slowly I began to draw links between the codes that could be seen across the transcripts and developed these into tentative themes.

I grouped together the tentative themes and wrote memos to try to develop them further. Through writing memos I began to draw further links between these themes, and larger themes would begin to emerge, building into what I would call primitive concepts, not yet fully formed but promising. I used a cut and paste method, literally cutting up the printed codes and grouping them together into themes on my bedroom floor (see fig.1)

However, I was not happy with the results. I still felt that there was too much happening and I was struggling to find something that would draw it all together. I had three voices to represent; those of the therapists, those of the patients and those of the staff. Just when I felt I knew what was happening with one voice, it did not seem to fit with the other voices. I was looking for an overarching theme that would draw

everything together, which in hindsight was wholly unrealistic. I decided to concentrate on the patients' voice. I had interviewed more patients than I had therapists and staff and I felt that the patients should be represented to a greater degree although this did not mean I did not consider the narratives of the other participants. The other participants (staff and therapists) further confirmed what the patients were saying, strengthening their voice.

Adhering more to a selective and sententious approach I re-coded the transcripts again, taking a more relaxed approach to the process. I read and re-read the transcripts, hoping to get a deeper sense of what was happening overall. Each time I had re-analysed the data I had gained new understandings and interpretations of what was happening. These subsequently informed the next analysis. Stepping back from the data and taking time away from the analysis and then returning to it with a more relaxed approach, seemed to generate more insightful codes. These were then drawn into more conceptual themes.

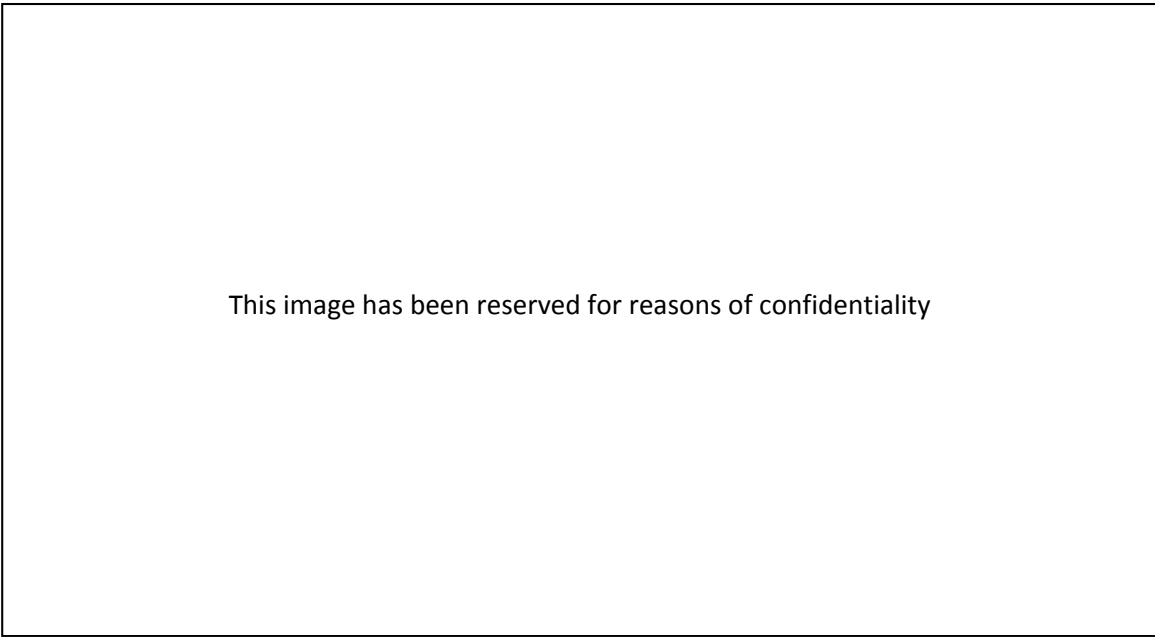


Figure 3.1 Thematic analysis and the cut and paste method

Thus, the previous example of Harriet's description of the tree was recoded:

“It’s a symbol of hope of constancy, constancy is hope for me. However things change for good or bad, there’s always that constant and it’s just, it’s been there hundreds of years before me and hopefully it’ll be there hundreds of years after me and it makes me feel as if I know my place, not just here in the hospice but in the world... **[having an anchor]** [...] I need to know that the leaves are going to fall off the tree and next year they’re going to be replaced and that’s been happening for years and years and years. It gives me comfort.”  
**[supporting / anchoring]** (Harriet: volunteer therapist PEI)

These codes eventually became “anchoring” which became part of the theme of “sustaining”, which eventually became a part of the larger conceptual theme of “sheltering”. Eventually, when I felt I could develop these themes no further, I felt there was a close to the hermeneutic circle. The sub-themes were linked by the three larger themes which resounded across the narratives of the patients, staff and therapists. These eventually became the three existential modes of being that will be discussed in the following chapters.

### *Ensuring validity in the analysis*

I ensured validity in the data analysis by constantly questioning my method and checking that the codes, sub-themes and major themes were evident across the participants’ narratives. I also remained reflexive and aware of my own pre-conceptions of hospice care, making sure that I was not ignoring my own preconceptions when interpreting the data, and making sure that the themes resounded within the words of the participants. Using the hermeneutic circle also ensured that the development of the themes occurred in an interpretive, yet systematic fashion. Also, at regular stages during the analysis I checked with the supervisory team to ensure that my findings were a sound interpretation of the data.

### *Deviant Cases*

There was a very small amount of what may be termed deviant or anomalous cases, where participants offered perspectives and opinions, which significantly differed from those of others. Because of the sampling criteria, those who did not use complementary therapy, or those who did not feel the hospice was for them, were not included in the sample. However, it may be perceived that their disinclination to take part in the therapies or to return to the hospice after their initial visit was more a function of their personality rather than anything intrinsically negative about the therapies or the hospice. Percy – a day care patient – did voice his concerns that the complementary therapy was nothing more than “a foot rub with oil” and he was concerned that rather than a vocation, the therapist may have been working at the hospice because it was something to keep her busy in her retirement. Interestingly his opinion changed after his second treatment, and he felt it was a lot more beneficial, and even reported that he therapist in question was now above question, and that she was serious about her work. He also noted that as he was such a relaxed person, the therapy was “nice”, yet it would perhaps been of more benefit to someone who was more anxious and stressed about their condition.

### *Observation: format and analysis*

The observations were planned to happen between the first and second interviews with the patients. However, I became unsure about observation as a method for the study. I felt I had enough data with the postcard diaries, the interviews and the photo-elicitation interviews. It had already proved hard to organise just the interviews with the patients and I felt that observations might have been too much for them, and for me to cope with. After discussing this with the supervisory team it was decided that I should do some to get a feel for the technique, and to see of what value they would be to the study.

The notes from the observations were transcribed into ‘Word’ documents. The analysis consisted initially of line-by-line coding of the sections of verbatim text. I intended to



use the visual and auditory notes as experiential anecdotes to support findings from the interviews as suggested by Van Manen (1997).

### *Postcard Diaries: format and analysis*

The postcard diaries measured approximately 10.5 cm by 14.8cm, the size of a postcard. Participants had the options to fill them in, in a variety of ways, in what I would call a freeform style; entries could take the form of a comprehensive account, one word, a sentence, a poem, a drawing, a photograph or a painting. However, The majority of the entries were textual. Of the nine people who filled in any postcards, only three people drew anything and these illustrations were accompanied by text meant as an explanation, which made the meanings clear, such as Lucy (Contract Therapist) who wrote “I feel happy today” accompanied by two smiling faces. I transcribed the text into a ‘Word’ document, exactly as it was laid out on the postcards, staying faithful to any use of words in upper case, or the use of exclamation marks. The transcriptions were then coded and analysed. Many of the codes were markedly different from the themes in the interviews, though some were repeated. This may have been because what the participants wrote on the postcards represented a more private perspective.

### *The Reflective Diary*

A reflective diary was kept in which I noted events that occurred during my time at the hospice, impressions and thoughts and reminders to myself. After I had interviewed someone I would write down my immediate impressions, or if I had spoken to someone I would often note things that were said that I needed to remember, or that made an impression on me. At times I found I forgot about the diary as I became ‘comfortable’ with my role as researcher, and immediately regretted not keeping it up to date as often as I should have done.

The diary served as a reminder of events that would have significance at later stages of the data analysis, helping to contextualize these events historically. It also enabled me

to reflect on my own assumptions and presuppositions about how it was for the patients or the people working there.

### *Data used*

In light of the difficulties I experienced during the data analysis there are a number of reasons I did not use all of the data sets in the final analysis. To be clear I used only the interview and photo-elicitation data sets. As I had decided to concentrate on the patients' voice I felt that the postcard diaries were so incomplete they would compromise the integrity of the analysis rather than add to it. As stated earlier, only one patient filled in any postcards diaries, amounting to two. The observational data was also left out as I felt that it had also been compromised: the therapy room was very small, making it difficult to be unobtrusive and I felt that the participants were far too aware of my presence. Also, I had more than enough data with the interviews alone and I felt the observational data and the diary sets could be used at a later date for another study.

### **Conclusion**

In this chapter I have discussed the ethical implications and concerns surrounding the conduct of this study. The vulnerability of the patient participants was considered carefully, particularly in regard to the recruitment and process of informed consent. The use of patient data in the event of patients dropping out or dying, and the inclusion of people within photographs posed some challenges, which I felt I dealt with appropriately. There were lessons learned in regard to communication between myself and gatekeepers to ensure that the study ran smoothly.

I have outlined how the methods of data collection were used and the problems encountered in their use that would seem to me to be an inherent part of becoming more aware of, and skilled in negotiating such problems.

I have described how I organised and analysed the data, paying particular attention to the process of transcribing and analysing the interview data. I showed how I grappled

with the analysis, firstly in a rather mechanical way before actually “making friends” with the data, taking time away and embracing the hermeneutic approach. In hindsight I feel I may have opted to use too many data collection methods and that the interviews and photo-elicitation interviews provided more than enough rich data. I also feel that my decision to concentrate more on the patients’ voice allowed me to make sense of the large amount of data. My decision not to use the postcard and observational data sets, but to keep them for potential future use also saved me from effectively drowning in the data, and I regard this as valuable experience, noting that interview methods alone can generate sufficiently large amounts of data.

In the next chapter, I will introduce the findings produced from the analysis of the interview and photo-elicitation interview data sets. I will also introduce the setting itself to provide more context for the reader.

## Chapter 4

### An Introduction to the Findings

Before introducing the findings, I feel it is important to discuss the location of the hospice and try to convey some of the aesthetic features and atmosphere that attracted me to the location as a site for the research. I will also discuss changes to the location of the complementary therapy room as a result of a programme of building development that I was only made aware of at the start of my fieldwork. It is crucial to the readers' understanding of the findings to present a context into which the reader can place the findings generated from the data analysis. Subsequently, I will concentrate on the three major conceptual themes of *drifting*, *sheltering* and *venturing* that form the focus of the remaining findings chapters.

#### The Hospice Location

Settled in a quiet location, in immaculately kept gardens on the outskirts of a town in the North of England, the hospice looked more like a country house than a healthcare setting. Dating back to the 18<sup>th</sup> Century, the hospice was once a grand family residence, which was developed into a continuation hospital, before becoming a hospice, providing end of life care. Subsequent developments added new modern extensions to the building, which in my opinion blend in with, rather than detract from the overall aesthetic value. The hospice is well known in the community and well supported. More than 65% of monetary support for the hospice comes from fundraising activities and voluntary donations. Just over 21% comes from the NHS.

The hospice provides specialist palliative care for terminally ill patients who require management of complex symptoms and patients with life limiting diseases. The hospice underwent changes and developments during the course of the research, but at the time of my first visit there were 19 in-patient beds and provision for up to 20 day care

patients per day to attend one session per week. Clinical nurse specialists provided care in the community, often called 'hospice at home'. The day care service provided care and support to patients who wished to continue living at home but attended the hospice for one day a week benefiting from the physical, emotional, psychological and spiritual care offered by the multi-disciplinary day care team. Services offered by day care included medical advice and support, diversional therapies, complementary therapies, hair and beauty therapy and volunteer transport. These services were also offered to outpatients. Outpatients included relatives and carers who attended for complementary therapies and family support. The core services provided by the hospice as a whole are available in Appendix 4.

Referrals to the day care service were made through the patients' General Practitioners, Clinical Nurse Specialists in the community, and other healthcare professionals. Patients attended for one day a week on a set day and had access to a specialist palliative care doctor for pain and symptom management and a team of nurses who looked after their general care and psychological needs. The day care unit itself was situated on the first floor of the original old building. From the exterior there was no hint of 'health care institution' about the place.

On entering the site there was a large car park surrounded by trees and shrubs and a pedestrian walkway that led over a bridge over the river and under the large canopies of mature trees that in summer provided leafy shade. A patio area marked the beginning of the gardens, and the front entrance to the building. The reception area was quiet, and warm. The friendly volunteer reception staff sat behind a semicircular wood panelled desk always offering a greeting and consistently helpful. Their manner seemed to add to the warmth of the atmosphere which was welcoming and non-threatening, as did the furniture and plush Chesterfield leather sofas and chairs. Often there were patients and family sitting in the chairs talking or just watching the comings and goings of others. The reception was bright enough, but not dazzling. It looked personal, and inviting. A small open fronted gift shop sold greetings cards, books, jewellery, handbags, small craft items, convenient consumables, stationary and occasionally there were clothes for sale and jams and preserves made and donated by the patients.

The entrance to day care was via a stairway or a lift leading to the first floor. The stairs were bright, with large windows overlooking the gardens and patios. Often gardeners could be seen tending to the grounds. There was a small waiting area just outside the day care office which marked the entrance to the day care unit. The waiting area was very light, with a large modern conservatory style extension, and very informal, with comfortable wicker chairs and a glass coffee table under which magazines were piled. The views overlooked the patio entrance and gardens. One had a better sense of the expanse of lawns that flowed down to the river at the far end of the gardens. The day care office door was always open, suggesting that nothing was hidden, and help was always available.

Beyond the day care office was a hallway with bookshelves and small library of books and audio cassettes which patients could borrow. Off the hallway was a dining room with two large dark wooden tables. A large window again provided views of the garden and a stone fireplace hinted at the previous residential status of the building. The floors of day care were all carpeted except for those in the kitchen and the art room. The kitchen was much like any home kitchen. There were no industrial stainless steel worktops or machinery as one would expect in a hospital or large hotel. The patients' lunch was prepared by the staff in the large main kitchen downstairs. The smaller day care kitchen was used for making cups of tea and washing dishes. Sometimes the patients could be found there baking bread and cakes. There were cupboards full of odd mugs, old dinner sets, and fancy teacups. The only suggestion that the kitchen was other than that of a family home was the paper towel dispenser. 'Tea towels' were not used for health and safety reasons.

The art room was a creative place. It had a healthy untidiness, interspersed by vivid colours, unfinished paintings, paint splattered mixing trays, muddy jars of water and every imaginable crafty item was to be found somewhere amongst the hectic shelves. There was also a small library of art and craft books, and the walls were adorned with fine examples of the patients' work, both past and present.

Further down the hallway there were two day care lounges. Firstly, the main day care lounge was the larger of the two where everyone gathered in the mornings to chat and drink tea. In the afternoon everyone gathered again before finishing for the day. This

seemed to me to be the hub of day care and it was a homely, domestic feel. The furniture was mismatched but comfortable. There were nests of low tables of various sizes on which patients could place their tea and biscuits within arms reach. There were stone fireplaces at both ends of the room, though they were never lit. Patio doors provided access to a covered balcony area overlooking the gardens, and patients and staff could often be found there in the summer, chatting or sitting and reading. There were tubs and planters full of flowers on the balcony area. This had the effect of bringing the garden up to the balcony. The covered area meant that patients had access to the gardens all year round, and for those who found it too physically stressful to go down to the gardens, it meant they could still enjoy them from the comfort and safety of day care. A door at the end of the large lounge led to the second smaller lounge in which there was a television, a laptop computer on which patients could access the internet, and comfortable chairs and sofas on which to relax. A drinks cabinet was evidence that patients could enjoy alcoholic beverages whenever they liked - another touch of homeliness. These were the main rooms of day care. There was also a bedroom in which doctors examined patients and patients could retreat there to lie down if they wished, to have some quiet time alone. The volunteer therapists sometimes used it to treat patients. There was also a small interview room, softly lit, with comfortable chairs and photographs of wildlife on the walls, which was used by patients and staff to talk privately.

### *The Complementary Therapy Rooms and the Building Development*

In August 2007, twelve months into the study and just after gaining ethics approval to start fieldwork and data collection I was notified that there was a refurbishment programme starting at the hospice. This meant that the therapy room was to be relocated from downstairs to upstairs in day care. So, the study involved two therapy rooms - the old and the new.

The old complementary therapy room was downstairs at the end of a corridor, away from the in-patient section. It was a large room, with nice views out to the trees in the garden. One-way glass ensured that no one could see into the room, yet patients could see out. There were window blinds in case patients still felt uncomfortable with this.

The room seemed warm and friendly to me and quite spacious. It was lit with soft lighting from wall-mounted up-lighters, giving a soft glow rather than a harsh light. Pictures of fruit and flowers on the walls lent a homely feeling. A large massage plinth occupied one corner on which patients could lie down for treatment. There was also a padded adjustable treatment chair and a small desk. On the desk were flowers and a mini stereo unit on which relaxing music was played. There was a sink for hygiene and a small mirror above it so patients could straighten their hair after a head massage if they wished. The room was quiet as it was situated at the end of a corridor at a corner of the building.

The new therapy room was converted from an old bathroom and was a lot smaller than the old one. Because of this downsizing, some of the equipment had to be abandoned, as it would not fit into the new room. The massage table, the treatment chair, the desk and the therapist's chair took up most of the room. There was another chair on which patients could sit. A single high window looked out onto the rooftops of the hospice. During the period of data collection this view was obscured by scaffolding, indicating further development work to the building. The room had a stark and cold feeling to me when compared with the old room.

### **An Introduction to the Participants**

Though I have mentioned the participants previously, to give a more meaningful human account of the findings and to give the participants a voice, by describing them briefly here, the reader has some idea of what their lifeworld is like. I came to know many of the participants over the two years I spent visiting the hospice, and some of the patients in particular made quite an impression on me. I have not included demographic data such as age, or what type of cancer the participants had. There are multiple reasons for this. Firstly, as this was a small sample of day care patients and staff, it would not be hard to identify them from this data, which compromises anonymity. Also, as I noted earlier in the methodology (Chapter 2) Cohen *et al* (2000 p.50) suggest that rather than seeing participants as groups of individual characteristics that can be regarded as variables, phenomenological research sees participants as “people who offer a picture of what it is like to be themselves as they make sense of an important experience”. It is



this important experience that forms the focus of the study, and while such demographic characteristics are salient at times, I felt a less demographic account of the participants was more justified.

The Staff who took part were:

Thomas: Thomas was a palliative care doctor, attracted initially to the hospice because he saw opportunities there for change and improvement. He described the people as having “a vision for the patients”. I came to know Thomas as someone who was inspired by ‘people’, and he seemed frustrated by bureaucracy as it took him away from his patients. He was supportive of complementary therapies and suggested that in some situations they had more of a place than orthodox medicine.

Penelope: Penelope was an auxiliary nurse who worked on the in-patient ward. She was interested in complementary therapies and she provided these to the in-patients on an ad hoc basis. She was very encouraging about the study and loved her job at the hospice.

Susan: As a part time staff nurse in day care, Susan had worked on and off at the hospice for over 15 years, on the inpatient wards and eventually on the day care unit. Although she had worked at other hospices and nursing homes she came back to the hospice because she felt it gave the best service to the patients.

Cathy: Cathy was a full time day care sister at the hospice. She really engaged with the study and enjoyed taking the photographs, saying it had made her really think about the hospice as a place. She was very aware of how people were affected by illness and how place and space played a part in their experiences at the hospice. She was also very aware of her own attachment to places, particularly the wooden seating area in the hospice gardens, down by the river. She had already said to me when she agreed to take part she would take most of her photos down there.

Julie: As a palliative care doctor, Julie was very busy, but always seemed to be completely composed and thoughtfully deliberate offering very insightful words. She also had a lovely smile and was very approachable. She perceived complementary

therapies as more appropriate in some circumstances than medical treatment and was very supportive of their use at the hospice and in general in health care.

**Bernadette:** Bernadette was the senior day care sister. She was very kind and cared deeply for the patients, her team and the day care unit as a hospice service. She liked a laugh and a joke but also knew how to approach difficult subjects, such as when a patient died. I felt the patients had great respect and admiration for her, as they did for all the staff.

#### The Complementary Therapists:

**Lucy:** Lucy was a contract therapist. She had a nursing background before re-training as a complementary therapist. She was very supportive of complementary therapies for palliative care patients and wanted to see them as more integrated into the NHS health care service. She felt CT was a very important part of the services offered at the hospice.

**Jackie:** A contract therapist, Jackie had worked at the hospice for over ten years at the time of her interview. She was very appreciative of palliative care and “modern medicine” which she felt relieved the patients of a lot of suffering and allowed them to retain a degree of normality for a lot longer. She felt that complementary therapies should be considered as a holistic package of care, which included the therapist, the client and the environment, as well as the therapy itself. She also ran her own practice outside the hospice.

**Harriet:** A volunteer therapist, Harriet worked in day care and on the inpatient wards for two hours a week. She had only been working at the hospice for a short while before I interviewed her. She had obviously thought a great deal about the photos she had taken and was very aware of the context in which she worked, admitting that she had taken a while to settle in, and to find her own place. She was a quiet woman who appeared to have great inner strength behind a rather fragile exterior.

Jane: As a volunteer therapist, Jane described herself as “transitory”, moving around the hospice providing therapies to both inpatients and day care patients. Though she was a therapist previously, after personal experience of cancer in her own family she chose to specialise as a therapist in palliative care.

Melanie: Melanie had worked at the hospice as a volunteer for over a decade when I met her. Initially she was a volunteer until the hospice offered to fund a course for volunteers who wanted to train in complementary therapies at a local college. Melanie was the only one left from the group who trained. However, she did not consider herself a ‘real therapist’, as she didn’t have a medical background. She used her training to offer what she considered simple “relaxation” to the patients.

Sheila: When I interviewed Sheila, she had been a hairdresser at the hospice for approximately 10 years. She seemed to have an exceptional rapport with the patients, and they spoke highly of her. Patients and staff included hairdressing as a therapy and after speaking to Sheila, she also felt that the service she provided was more aligned to a therapy.

The day care patients:

Ethel: Ethel was an elderly patient who had cancer. She had always had an interest in complementary therapies as her son was a therapist. She also attended a local complementary therapy support group for cancer outside the hospice. Ethel dropped out of the study as she became too tired to carry on. When she told me she was dropping out, I assured her it was fine and thanked her taking part. She then spoke of her family and her life and what it was like to have cancer. I felt she needed to talk to someone at that point in time.

Andrea: Andrea was the youngest of the participants. She was in her thirties, while the others were all in their late fifties and beyond. She seemed very matter-of-fact when talking about her cancer and she seemed very strong and resilient to me. She enjoyed day care and the complementary therapies and art work, visiting day care once a week even though she was an inpatient. She died not long after I had interviewed her.

Bill: Bill was a very 'straight talking' man. He had worked in the construction industry for many years and had an interest in the architecture of the hospice, which he photographed. He found the research project was something to do to keep his mind busy. He lived alone as his wife had died, and I felt that he valued the company of others at the hospice. He was particularly fond of painting and spending time in the art room.

Derek: Derek was, in his own words "a believer" in complementary therapies, as was his family. He was very interested in various special diets and he read widely around the subject. He saw no harm in trying new things that might help him or even cure him of his cancer. He also valued the chance to learn new skills in the arts and crafts room and to take part in the therapies he saw as "part and parcel" of day care.

Terry: When I met Terry we spoke briefly about his wife. She was also attending the hospice as an inpatient. They both had cancer. He insisted he was ok about taking part in the study. I remember he was very short in his replies during the interview and almost defensive of how highly he thought of the nurses and the hospice. He dropped out of the study later as he could no longer cope with the tasks.

Jim: Jim was the life and soul of the day care unit when he was attending. He was a big man, loud but not abrasive and always had a ready joke for the nurses and other patients. He read a lot, enjoyed writing stories and was often very expressive when talking to me during the interviews. He was very reflective and thought deeply about his situation. He had cancer, complicated by diabetes and arthritis, and he benefited a great deal from the complementary therapies.

Percy: Percy had cancer and felt that his recent move from hospital to the hospice was a blessing as he described his absolute joy at being moved to the hospice. He initially seemed very sceptical about complementary therapies, even though his partner was a complementary therapist. However, after experiencing them at the hospice he saw the value in them as an aid to relaxation, though he maintained he was so relaxed already he did not need them.

Douglas: Douglas had cancer and Parkinson's disease, and yet seemed completely unfazed by either of them. He surprised me with his perspective on life as despite his illness he felt that life was completely fair. He was widely travelled and very knowledgeable. I would sit and talk with him often when I was visiting the hospice and our conversations were never short but always interesting. He was interested in the study and thought deeply about complementary therapies and the hospice as a place and how he experienced them. His favourite part of day care was the Jacuzzi bath in which spent as much time as he could.

Jeffrey: Jeffrey was an elderly quiet man. He seemed quite reserved and was worried about his wife who was also ill at the time. He was not an expressive man but he appeared to enjoy the complementary therapies, though he had never had them before. He later dropped out of the study as it became too much for him.

Arthur: Arthur was a thin looking man who gave the appearance of someone who had laboured all his life. He was very approachable and had a dry humour. He was very supportive of the hospice, praising the staff and the care he received. He was also very supportive of the study and he enjoyed complementary therapies, which he said were part of a whole new world that had opened up to him at the hospice. He reminded me of one of the 'old boys' in my own village; a quick witted country gentlemen, someone that everyone would know. His health deteriorated quickly and he died later.

Carl: Carl was in his sixties and enjoyed being outside in the gardens. He seemed to spend most of his time in the art room or in the gardens. Carl had known the hospice many years before when it was a hospital and we spent some time chatting about how it had changed. He valued the camaraderie at the hospice and enjoyed the complementary therapies. Carl gave the appearance of someone who was still very active and well.

### **Three Existential Modes of Being**

Having provided some context to the location and setting of the hospice and day care unit, and an introduction to the participants who took part, it is hoped that the reader

will now be more able to connect with the words of the participants involved in the study. I will now introduce the findings from the analysis of the data.

As I have stated in the previous chapter I used a hermeneutic phenomenological approach to analysis. I concentrated on the data from the interviews and photo-elicitation interviews, combining these and treating them as one data set. The amount of data produced by these two methods was significant at 478 pages of transcripts. I felt that using any more data would compromise the process of analysis, creating too much data to handle in a meaningful way.

From the interpretation of the interview transcripts I found three main conceptual themes which as noted in the abstract I have called *drifting*, *sheltering* and *venturing*. These three themes can be classed as existential modes of being in that they relate to the patients' individual experiences of existence within their lifeworld.

The use of direct quotes from the participants' interview narratives ensures that the reader can observe directly how these conceptual themes arose and helps to convey the meanings which the participants gave to their experiences. Some of these quotes are used in the findings and discussion chapters more than once. This is because they illustrate how the participants experienced these different modes of being simultaneously. These existential modes of being incorporate other themes that characterised the experiences and perceptions of patients and staff. I will discuss each of the existential modes of being and the themes that are incorporated within them in the following three chapters, before bringing them together in the final discussion chapter.

## CHAPTER 5

### DRIFTING

“Serious illness is a loss of the “destination and map” that had previously guided the ill person’s life.” (Frank 1995 p.1)

The word ‘drifting’ means to wander aimlessly, to deviate from a set course, or to be driven by the wind into a heap. There is a sense of uncertainty and not being in control in these definitions. The Oxford English Dictionary further states it is to be carried involuntarily or without effort in some course or into some condition. I would suggest that none of the patients chose the condition in which they found themselves.

In this chapter, I will describe how patients experienced a sense of drifting in terms of how their illness had affected their life world. Patients describe feelings of isolation and uncertainty, and some had effectively lost their bearings from which to navigate their life. Some patients experienced an impending sense of fear and reluctance when entering into the hospice. There were levels of anxiety and uncertainty about what would happen within the hospice and how this would affect them. As a way of combating this *threshold anxiety*, complementary therapies were used as a means of helping patients to cross over the threshold into unknown places.

#### Losing the map

Uncertainty and anxiety about the future are common amongst those who are diagnosed with terminal illnesses such as cancer. Some of the patients who took part in the study felt uncertain about their future, about entering the hospice itself and there was a sense of how important “knowing” was to the patients. I feel that some of the patients felt lost within their own disease, as though the disease itself represented a space within which

they had lost their bearings, and without knowledge of the terrain, could no longer navigate their journey. They had in a sense lost the map that had previously guided them. The hospice represented for many a place to be feared, with implications of finality and demise. Others felt only curiosity about entering.

One of the first things that became apparent when reading the interviews was how differently patients experienced their initial entry or their 'way in' to the hospice. Their experiences varied along a kind of continuum, from sheer dread, to a sense of positive anticipation and this was directly influenced by their previous experiences and knowledge of the hospice. For those who have little knowledge of what hospices are really about, it is perhaps easier for them to relate to the experiences of the patients who experienced a sense of dread and anxiety at entering such a place. As I have stated earlier, there is no incidence of cancer in my own family and so we are not familiar with hospices. That is not to say everyone who has a terminal illness goes into a hospice. When I asked members of my own family and colleagues what they thought hospice meant I tended to get the same answer: "It's where you go to die". In my experience, the word 'hospice' has very negative connotations for many people. That is reflected in the data, both by the patients and the staff and therapists. To get any idea of the patients' experience of the hospice as a place it was apparent that I should start at the beginning of their experience with this place and to ask how they felt when they first entered the hospice.

I will first describe those patients' experiences that illustrated a sense of uncertainty and a feeling of being lost before they entered the hospice. I will then attend to how patients felt about entering into the hospice and the fear and anxiety that their idea of hospice conjured within them. The most notable of these was Jim who was attending as a day care patient. Jim had lung cancer and renal lymphoma and bone metastases as well as diabetes and rheumatoid arthritis. Despite his multiple health problems, he was perhaps the most expressive and animated patient that I talked to, the life and soul of the group. This is how he described his entry into the hospice and his fear of what he thought it entailed:

"Well I was asked to come here by my palliative nurse [...] and at first I were very reluctant, I er...I suppose I were a bit worried, a bit nervous about it not



knowing what it was, well knowing that is was a cancer unit and people that came here like had terminal illnesses and whatnot like you know? [...] But I didn't realise that there were such a thing as day care and things like that. Now when they said 'day care', I wondered what that entailed. And I mean as I say having been left up in the air since September [date] as to how my illness was doing at [city hospital], I thought well I'm going to take this opportunity to go and ask somebody how I'm doing." (Jim: Day Care Patient - 1st interview)

Jim admitted to not really knowing a great deal about the hospice and he had no knowledge of what day care involved, hence this left him with feelings of uncertainty. This seemed to add to his uncertainty about his own disease as he says he was "left up in the air" regarding his illness. Despite his lack of knowledge and initial reluctance about the hospice, Jim saw it as an opportunity to find some meaning to his disease. His uncertainty about the hospice was evident as he described a "learning process" and "finding his feet":

"Well...as I say I've got...at the moment I think I'm just finding me feet. I'm not a quick learner. I don't catch on terribly fast, and er [...] I feel I'm just finding me feet. I hope I'm a long time way from residential care here but, as I say, the one thing it's done so far for me is it's dispelled the fear and the dread." (Jim: Day Care Patient - 1st interview)

Jim was essentially talking about finding a sense of place and he was aware this entailed a process of orientation, whereby he needed to "find his feet" in the sense that he needed anchoring in solid ground in order to stop drifting. His developing sense of place was evident as he stated that "so far" it had "dispelled the fear and the dread". Jim had in other words moved through his reluctance at crossing the threshold into the hospice as his old perceptions were dis-placed and re-placed by increasing security.

I also felt that with Jim there was a sense of being lost and uncertain within his own illness, as though that illness were an imagined space in itself, and that he felt he had found a place in terms of the hospice, that *may* have the answers he was looking for. This sense of being lost was further strengthened when Jim talked about his later discoveries about the nature of his own disease:

“But of course there’s...people can’t come out and say straight to you like you know that it’s good, it’s bad, it’s this that and the other. Everybody is taken in different ways with it like you know. That was something else I didn’t realise, I thought these things run much of a general pattern, but they don’t.” (Jim: Day Care Patient - 1st interview)

At the time of the first interview it was Jim’s fourth visit to day care. He had taken the opportunity to find out more about his illness, yet the knowledge left him with the realisation that the course of his disease would not follow any set pattern, but that each individual was “taken in different ways”. Jim’s words reflect the individuality of disease, and there is a recognition that each person is different, each person being on his own personal journey. This left him with no level of certainty, no definitive path or map to follow. Jim was drifting in uncertainty rather than having any sense of direction. He further described drifting from day to day, never sure of how he would be:

“...before and after I stopped the chemotherapy and radiotherapy treatments, I could never guarantee, I could never ever guarantee how I’m going to be from day to day. One day I could be fine [...] but, there’s days when I can cope and there’s days when I have absolutely no chance at all.” (Jim: Day Care Patient - 1st interview)

Coping became difficult, as Jim had no guarantee or certainty about his health. He was essentially living day-to-day, never certain of how he would feel the next day, but drifting through his existence.

In the second interview, Jim described how the hospice had taught him to make efforts to get “out and about”, to do something constructive. Jim gained a sense of achievement from simply attending the hospice (which is discussed again in the chapter on “venturing”). The alternative to this as Jim described it, emphasised his uncertainty and he expressed a state of being lost and despairing:

“It’s taught me I think since I started coming here, that I must make the effort to get out and about. And there’s a lot more to life than just sitting at home watching the television and reading the odd book and that, and worrying about what might be. Or trying not to worry about what might be and all the rest of it.

I mean you can get bogged down in rhetoric and thought like you know. You think one thing one minute, you drive yourself crazy! Because you're thinking one thing one minute, another thing the next minute and there's no positive coming out of you. It's all up in the air, negative stuff. You're not going anywhere, you're not doing anything, you're not even enjoying the basics of your day-to-day existence. And if you're not doing that then you start slipping into that suicidal thing don't you? You know when you start thinking to yourself am I an existentialist, is it worth it, what am I doing here, why are we here? You know awww God! And then your mind starts going on and you're racing away and...and to me that's just barmy. It's no good at all. I can't cope with it." (Jim: Day Care Patient – Photo-elicitation Interview)

Jim was anxious about the future, and he talked rhetorically about existential questions such as "What am I doing here?" "Why are we here?" and being driven "crazy" if he gave in to this way of thinking. I feel that his words were born out of some personal experience and reflexivity, as he said he could not cope with such thoughts. He gave the impression of someone who was at times lost within the psychological space of his own illness. Feelings of "not going anywhere...not doing anything" reinforce a sense of drifting and being lost within an unknowable space, and that uncertainty led him to his rhetorical questioning.

I felt that Jim, wanted certainty and that he had lost a sense of order to his life. There was a strong feeling of *wanting to know* in Jim, wanting some sense of order, a direction and certainty in a practical sense, so that he could cope with what the future held. Jim was essentially describing feelings of placelessness in terms of his disease, in the sense that he was trying to find his place within the space of his illness, to find some sense of meaning and order in the chaos of drifting.

This sense of uncertainty and having no direction continued through Jim's narrative. During the first interview, he described his only reservation about the hospice to be a lack of knowledge about his illness and his constantly fluctuating health:

"If I've got any reservations about it, the only one would be is that I never seem to get to know anything about my condition and what stage I'm at and

whether I'm making any improvements or whether I'm going any worse. Now physically I do realise that without the drugs and the treatment I would be in a shocking state I know that. But having said that, there's days when I feel absolutely marvellous, and I think to myself, if I just pushed a little bit I could do anything today. I could go sightseeing, I could get on a coach, I feel like booking a holiday and all this and that. And yet I know that this euphoria will only last a day maybe two, and then I'll be back to fed up with myself and stuck in the house, and full of pain and all this and that like you know." (Jim: Day Care Patient – Photo-elicitation Interview)

"Knowing" about his illness was important to Jim. There were spatial suggestions in the words he used. He showed obvious anxiety over the "stage" of illness he was at. Knowing "...what stage I'm at..." could be interpreted as wanting certainty, to have a 'location' within the imagined space or chaos of his illness, a bearing from which to navigate the course of his disease. Jim stated that he never knew whether he was "making improvements" or "going any worse". If making improvements can be seen as progressing and therefore equated with a sense of positive movement such as forwards, then getting worse can be equated with a movement backwards. Later Jim stated that he sometimes felt a brief euphoria that lasted for perhaps a few days but then he was "...back to fed up with myself and stuck in the house". Using the words "back to" again denotes not only a sense of having moved backwards, but a regressing rather than progressing, and this was coupled with a negative lack of movement when he was "stuck" in the house again. Essentially Jim moves backwards and forwards drifting in the space of his illness, without ever knowing or having an anchor of certainty and knowing - an anchor he hoped would be provided the hospice.

Although Jim never felt that he had enough certainty about his disease, it was evident that the hospice provided a constructive environment for Jim to take part in life again and to make some achievements. I feel that it gave him something "solid" to hang on to, a bearing or anchor point in his world of uncertainty. He described how he felt better after having attended the hospice:

"When I leave here I feel so much better, I've had reflexology this morning, I've had a superb lunch. I've had good company, and I've had a chat with Polly [auxiliary day care nurse] now I'm having a chat with you. [...] And when I've

finished here at half past three I've got a few issues to resolve with the bank and credit cards, and when I go home tonight, I will feel that I've had a marvellous day and I've made some achievements." (Jim: Day Care Patient – Photo-elicitation Interview)

Having a chat, enjoying a good meal and good company and having reflexology are some of the reasons that Jim felt a sense of achievement at the end of the day. There was a severe contrast in the alternative Jim described:

"Now if I hadn't have come, if I'd have sat there this morning and thought I'm not going...at the end of today, I would have been in a deep slough of depression like you know I would have been really fed up with myself." (Jim: Day Care Patient – Photo-elicitation Interview)

There was a great contrast between his uncertainty and the sense of being lost, in how much better he felt when he attended the hospice day care unit. The hospice provided Jim with something that he felt helped him to live his life, something which gave him direction and that gave his life meaning and provided him with a place in which opportunities presented themselves and somewhere he could make achievements. He managed his day in a more positive way, helping him to feel better about his situation. Although others were not as explicit as Jim about how they felt about their illness before coming into the hospice, there was certainly evidence amongst other patients that their place in the world had been affected by the diagnosis of cancer and their subsequent association with the hospice.

### **A sense of isolation – present but distant**

There was a sense of isolation and alienation in the narratives of the patients, from those who lived alone, and those suffering from a "social death" (Lawton 2000) as their networks of interpersonal relationships began to collapse. The hospice was a place in which patients found company and a sense of camaraderie, a place in which they were present and included and yet could put some distance between themselves and their illness. Bill lived alone and enjoyed the company of others when visiting the hospice.

Just being in the company of other people made a positive difference to Bill, even if he did not speak to them. I felt that this was both a reaction to his sense of isolation at living alone away from others yet living closely with his cancer:

“A change of surroundings. I live on my own. It’s good to come in and talk [inaudible 12:19]. Not even talk but acknowledge people that are around you. So long as you keep off your illnesses and that, you’re okay [laughing]. You get enough of people’s troubles without that [laughs]. No, that’s something that is very good actually, no one seems to keep talking like, when I go to the café all I get is hysterectomies and what not going on [laughing]” (Bill: Day Care Patient - 1st interview)

The change of surroundings was important to Bill. The hospice provided the stimulus and comfort of being with others, rather than being alone at home. I perceived that Bill felt alone in his own home and being physically in the presence of other people was a positive experience, even if he only acknowledged them. However, Bill did not like ‘illness talk’ and he preferred not to talk about illness with other patients. This suggested to me that as he lived closely with his disease when he was alone, when he had the opportunity to be with others he found it therapeutic to put his disease into the background. Despite being with others who shared similar journeys, there was a sense of Bill distancing himself from the illness.

Other patients spoke of the breakdown of interpersonal networks, as friends began to distance themselves and families became smothering. Jim spoke of how he was afraid of meeting in-patients from the hospice for the same reasons that his own friends were afraid of talking to him:

“I haven’t been around to people who are like...in their last...I’ve been afraid of them people [...] who are in their last few weeks of life. I...I still am to a certain extent, but not as much as what I have been. I’ve found the same thing amongst my own circle of friends. People are scared of me now. They don’t come near me because they don’t know what to talk about.” (Jim: Day Care Patient - 1st interview)

Although Jim was in the same place in terms of the hospice, he distanced himself from the in-patients, those who were further along their journey than he was. He recognised this behaviour amongst his own friends in other places, as they ceased to converse with him. Although present in the same geographical place as them, he also felt removed from them. Similarly Arthur also felt his own social networks were beginning to change and break down as friends talked ‘around’ him, as if he were not present:

“The wife and I were out, and we were chatting, and some of the lads were saying, ‘how’s it going?’ like you know. Then all of a sudden they start talking to the wife! [disbelieving tone]. I’m stood there at the bar, sat down or whatever, and ‘how’s he going on?’ She says ‘what do you mean, how’s he going on?’ They say ‘well you know...’ She says ‘no he doesn’t sleep there!’ They say ‘does he not?’ ‘Well...’ she says, ‘...he’s bloody well stood there’. You know they’re all talking around me. [...] It’s like the old poor lepers isn’t it? [laughing] [...] You know, ‘oh he’s a leper, throw him on an island somewhere’.” (Arthur: Day Care Patient - 1st interview)

Arthur felt that his friends were treating him as “a leper” when they failed to acknowledge him, talking around him to his wife. They no longer knew how to communicate with him. I perceived that this created feelings of distance, alienation and isolation creating a sense of drifting - of being present but removed as interpersonal relationships failed in the presence of a terminal illness and friends became as strangers. The hospice provided a place where people like Arthur could find a sense of sheltering from that which had become strange, a sheltering within the camaraderie and companionship of others in similar situations who shared the same experiences. However, the patients first had to enter into the hospice in order to find this sheltering, and this brought fears of its own, as to enter into unfamiliar and unknown places also created fear and anxiety.

All of us will have experienced an anxiety at entering into unknown places at some point in our lives - a new school, a new workplace, a hospital. The point between known and unknown places may be termed a ‘threshold’ and the fear and anxiety of entering into an unknown place I will refer to as “threshold anxiety”.

## **Fear of entering the hospice**

For a patient with cancer the hospice can be an unfamiliar and disorienting place, as to many who are not familiar with the concept of the modern hospice, it exists as a place initially in the psyche, a place associated with illness, death and dying; what may be termed an “end place”. Many healthcare places such as hospitals, hospices and nursing homes have negative connotations, as simply to enter into such places implies that something is already wrong in terms of one’s health or the health of those one cares about.

Hospice is often thought of in the same context as dying and therefore already has a negative meaning for most people. This was quite evident in the data from the patient interviews. These negative perceptions of hospice are the basis of the “threshold anxiety” that patients may suffer. Even though some patients already had some positive perceptions of the hospice, when it came to entering into the hospice as patients themselves they became apprehensive and anxious. The hospice took on new meaning for them. As people became “terminally ill”, I felt that entering into the hospice was for them a confirmation that they were dying. The hospice was no longer a place where *other* people came when they were terminally ill, but a place where *they* now attended as terminally ill people. This was particularly evident in Derek’s explanation of how he had known the hospice through giving donations and through interpersonal networks within the community, and how suddenly he had become “a part of it”:

“I mean I’ve known lots of people and families that’s been involved and all you ever hear about [hospice name] is what a fantastic place it is. And it is! Yeah”  
(Derek: Day Care Patient - 1st interview)

“I never thought I would ever, you know...become part of it. But there you are, that’s life isn’t it? I think they’re wonderful people, yeah. Yeah I do. And not only me, but friends and relatives that have been involved. You know it’s like I said before in one of our interviews, you’ve only to mention [hospice] or...the amount of times it crops up in a conversation. And it’s all good. You never hear anything negative.” (Derek: Day Care Patient – Photo-elicitation Interview)



There was a sense of disbelief and resignation in Derek's words. It was as though he always thought the hospice would be a place for *other* people but not for him, though he had resigned himself to the fact that death was inevitably part of life, but often unpredictable. Derek obviously did not expect to be diagnosed with cancer, or to end up in his local hospice and this disoriented him, which would contribute to feelings of drifting. Derek gave the impression that the hospice was well known in his area of the community, and a simple mention of the hospice elicited a favourable response, noting that all he had ever heard about the hospice was positive, that it was a fantastic place and that he never heard anything negative. In spite of this, he still had a sense of apprehension. When I asked Derek how he felt after his first day he replied:

"I'd settled down. Just a little bit apprehensive." (Derek: Day Care Patient - 1st interview)

This suggests that his disorientation lasted even though he had heard it was a good place. He still experienced the anxiety of apprehension and uncertainty. Another patient, Douglas told how his initial reaction to the word 'hospice' was one of fear even though he already knew one of the volunteers who worked at the hospice. He had been told what to expect, that it was a "good place", but still the anticipation of entering the hospice was evident despite the reassurance:

"I knew a little bit about the hospice and consequently I was not coming into it cold. But the reaction to the word 'hospice'...still a sense of...what most people would describe as fear, but certainly ill at ease. But because I knew [the volunteer], because I spoke to him before I came here, I'd already had that put out of the fashion, put out of the way. Erm...and I was ready for...the sort of things that most people say after their first visit. That they were comfortable, that they were at ease. That everyone was at ease with them. But there was still that vague sense of...anticipation." (Douglas: Day Care Patient - 1st interview)

The fact that Douglas had heard testimony that the hospice was a "good place" and that he was ready to experience what he felt other people experienced - a sense of comfort and ease, this led him to a feeling of vicarious insideness, knowing the place through

others. Despite this, he still felt anticipation. This suggested it was only the direct experience, or the embodiment of knowing the place from the inside rather than the outside that would finally put Douglas at ease.

While some patients had heard about the hospice from friends who worked there, some knew others who had died at the hospice. Some had work connections to the hospice and one had attended as a patient some years before. Regardless of these experiences, most patients felt some anxiety prior to their first day. Such anxiety could originate from the patient's own imagination of what the hospice would be like; from assumptions made through a lack of knowledge about the place itself; from stories they had heard, from media representations or previous visits to friends or relatives who were in-patients. Andrea suggested that there was a common assumption about the hospice as a place where people come to die:

"I was very dubious about coming in. It's just what people think of places like this. Everybody just assumes this is where you're coming to die, and it's not, it's a brilliant place. It's the total opposite to what I thought it would be..."

(Andrea: Day Care Patient - 1st interview)

She suggested that it was everyone who made these assumptions, most probably based on her experiences of what others thought. Again, she described apprehension and feeling "dubious". Such a word gives the impression of being uncertain, doubtful and not knowing, which creates a sense of drifting in uncertainty. Ethel also saw the hospice as a place where people came to die:

"The first time I came I was a bit apprehensive. I had this... my thoughts on it were, you come to a hospice to die. But then, of course, you don't. You come here, as I've said before, you live with cancer, you're not necessarily dying with it. And I think the mind set changed my whole perspective of things."

(Ethel: Day Care patient - 1st interview)

Ethel had already constructed a psychological landscape of the hospice as a place of death. The mind set of people at the hospice changed Ethel's perspective; her sense of place changed, from a place where people come to die, to a place where people 'live'

with cancer. This mind set or way of thinking about cancer as something to *live with* rather than *die from* was one of the philosophies of the hospice day care team.

Through knowing people who had died at the hospice, Bill had already formed a negative perception of the hospice, but like Andrea and Ethel, Bill's perceptions of hospice also changed:

"I've always had the feeling that it was a place of no return. But I've changed my mind slightly now [...] most of the times that I knew it the people that came in here didn't come out successfully. But now with the care and attention it's far more advanced than that now. The attention that you get is...helps."  
(Bill: Day Care Patient - 1st interview)

Bill's previous experience of the hospice, visiting people who were patients and coming in to make donations, gave him the idea of the hospice as a "place of no return". The hospice was no longer a place of no return, and his experiences even led him to laughingly suggest a more permanent residency stating: "if I could afford it I would take up lodgings here [laughing]." Bill put his own positive experiences down to an advance in care provision. What he later called "care taking". Bill described in the second interview how his perceptions of hospice had changed:

"Well I can tell you what it used to mean, but it no longer applies. It used to mean terminally ill. But now it doesn't seem to apply to that and there's light at the end of the road. [...] In the previous day there was no light. The people that I visited here were history in about three days after I visited them. No doubt that still happens, but there's also a lot of 'care taking' now. . And like myself, they'll not cure me but life is probably extended by a couple of weeks. Bit cynical that, a couple of weeks but still." (Bill: Day Care Patient – Photo-elicitation Interview)

To Bill, hospice used to mean "terminally ill" but he described as a place of hope in the interview, using the metaphor of a "light at the end of the road", and suggested that during the times he visited the hospice before, "there was no light" and his friends died within a very short space of time. He accepted that this most likely still happened but he

also had a sense there was more of what he called “care taking”, and that this care was responsible for extending his life a little longer, though only by a short while. It seems to me that Bill perceived an improvement in the quality of care, though I feel it was more of a realisation of what care was actually provided by the hospice day care service.

Jeffrey was also wary of coming into the hospice and it was his wife who feared that he might be “sucked into” a system and operated on:

“Well I never liked the thought of it before I came. [...] I didn’t feel like coming. And the care nurses were saying “well you want to go to [hospice] you’ll enjoy it.” And the wife said “oh don’t bother, don’t bother going.” [...] And er she said “I think you better not go, they’ll sort of suck you in to the system”. [...] Well she was thinking more of the cancer system. [...] Well [hospice] is noted as a cancer hospital. Right? I have cancer in me blood, so she thought I’d get sucked into it and they’d be operating on me before I err...sort of thing.” (Jeffrey: Day Care Patient - 1st interview)

Being “sucked in” conjured a notion of being trapped into something, without a choice and Jeffrey described the fear of being operated on before he could do anything about it. There was a sense of having no choice and a fear of losing control of what was happening. This seemed to be a theme amongst some patients. Jeffrey’s experience of feeling sucked in was similar to that of Jim who also feared being “grabbed” and trapped against his will. Such a loss of control would also contribute to a feeling of drifting, a feeling of helplessness. Jim was perhaps the most explicit in his descriptions of his fear and anxiety of entering into the hospice. Initially he saw the hospice as an opportunity to seek knowledge about his illness, but his lack of knowledge at the time of his first entering into the hospice contributed to his negative perceptions of what it would be like as a place. He had constructed a nightmarish vision of the hospice, and had embodied his fear and anxieties describing them in terms of being grabbed and feeling pain. He envisioned the hospice as a place of suffering and his mental image of the place consisted of long corridors and dark passages:

“What I feared most was erm...it was one of those grab places, they get you, they take you in and er...and you never come out of these places but [...] I found that that's not true and it's...it's a different set up all together than...more relaxed. There's no fear, there's no dread, there's no pain involved in this which I thought there would be err...I suppose I've watched too many movies really like you know [...] Well I always expected long corridors and dark passages and er...people in rooms where they were er...they either couldn't come out of you know, bedridden or...and I just found the whole thing you know, in my mind very disturbing.” (Jim: Day Care Patient - 1st interview)

What Jim seemed to fear was that he would be “grabbed”, manhandled physically, against his will. There was a physicality to Jim's words that suggested he feared both physical and mental pain, perhaps based on previous experiences of care in other places. There was a strong sense of foreboding and a fearful apprehension of what the future would bring in Jim's narrative. He feared that once he entered the hospice he would never come back out. It is almost as though by entering Jim felt he would seal his fate, that he would be confirming his status as a dying person or provoking his impending death. Jim was experiencing anxiety over crossing what he thought would be the final threshold. He had constructed a psychological landscape of fear. When I asked Jim how he felt about the hospice as a place, he pointed out in both interviews that the driveway was a particular place to which he attributed negative meaning:

“[...] the only down part I have about that is the entrance. [...] It's...very wooded...and mysterious [...] because you don't see anything, all you see is this wooded area and this path and you think where does it lead to? Well what's this? And you look at the sign and it says [hospice name] and you think oh right [...] But I do find that that drive into [hospice] is wooded and dark, and it just has that edge to it for me. I don't know why. [...] you've got nothing, just this dark, well, darkened pathway leading into [hospice] and I think to myself like you know. I mean it's just that first instant when you look at it and I think whoa! Now then...” (Jim: Day Care Patient - 1st interview)

He described it as “mysterious” having “an edge”, though he was uncertain why, and again I have the feeling that uncertainty and not knowing was an important issue to Jim

and important to his sense of drifting into a place he would not return from. He described how reading the sign might have said it all, as though the very word ‘hospice’ was enough to explain the dark and mysterious entrance. His description of “that first instant when you look at it and think whoa! Now then...” summoned feelings of anxiety, warning, and fear. There is a sudden alertness to a strange and unfamiliar place and immediate anxiety over crossing the threshold, a suspicion of the dark and unknown places that seem to hide what is beyond them. Fictional places represented in media had also influenced Jim. The influences of watching “too many movies” as Jim described earlier was evident in his return to describing the driveway in the second interview. That time Jim likened the hospice to the Bates Motel in Hitchcock’s 1960 horror classic ‘Psycho’. Although Bates Motel was a fictional place, it was a place that had obviously made an impression on Jim for him to recall it at such a point in his life. The motel in the film was portrayed as sinister and menacing, and the film had powerful themes of mystery and suspense, again reflecting uncertainty. Hitchcock created a feeling of foreboding - that something terrible would happen, surrounded by the uncertainty as to how it would manifest itself:

“It was just one of those things, I don’t know why Drew, it’s a long drive... you’ve got a long driveway and you’ve got all the [...]trees and leaves and all this and that right. Now...in winter time when there’s no leaves on the trees and it’s dark or overcast, it’s raining, it kind of like put me in mind of Michael Bates’ hotel [the film character’s name is Norman Bates], where his mother sits in that room rocking and looking out you know...? [...] I find it a little depressing like when it looks like that er run up to Michael Bates hotel like.”  
(Jim: Day Care Patient – Photo-elicitation Interview)

The obvious media influences on Jim’s perceptions of the hospice showed in how he communicated his sense of fear and anxiety and the tensions that were created by the appearance of a physical landscape - the driveway up to the hospice building – that looked “dark” and “wooded”. He also mentioned that this appearance was made depressing because of the winter season. The sky was dark, and overcast and the trees were bare. In a metaphorical sense this could be analogous with his own journey towards death and the mystery that surrounded this. His experience of the hospice was therefore affected by the time of year as well as the physical landscape. As noted in the

methodology chapter, a phenomenological study must take into consideration the temporal context of the study as well as the geographical location and I will draw attention to these instances as I progress through the findings.

The data clearly suggests that not everyone shared the same sense of anxiety at the thought of entering the hospice, but rather that there existed a continuum of experience with extreme anxiety at one end and positive apprehension on the other, and the patients' experiences fell somewhere along this continuum. Terry was perhaps the least explicit about his feelings, though they left him at the positive apprehension end of the continuum:

“Well you hear good reports you know. So I wasn't, err shall we say, I was looking forward to it put it that way.” (Terry: Day Care Patient - 1st interview)

Terry obviously had a preconception of the hospice based on “good reports” or vicarious information. Terry's response lacked any deep reflection due to his state of obvious agitation at the time of the interview. Though he gave his full consent, he appeared to be restless offering short and terse answers. Another patient gave a similar response albeit in a less agitated manner. Carl was “looking forward” to visiting the hospice and felt no threat of being trapped as Jim had done, or gave any indication that he thought it was a place in which he would die:

“Quite looking forward to it actually [...] Everything had been explained. [Palliative nurse] came to see me actually at home and explained, they said do you want to go and I said yeah. [...] I wasn't apprehensive or anything you know I just thought oh well, we'll just see how it goes, if I don't like it, 'cause he said if you don't like it you don't need to come again. Well I thoroughly enjoyed it, because it was a change of scene, a nice bright sunny day, so that helped you know. If it had been pouring down I suppose I'd have had a different view of it.” (Carl: Day Care Patient - 1st interview)

Carl seemed quite relaxed about attending day care as the explanations that had been provided by the palliative care nurse put him at ease. He was immediately made aware that day care was a choice and that if he didn't like it he did not have to attend again.

The fact that he enjoyed the change of scene was bolstered by the sunny day, which again contrasts with Jim's depressing and foreboding experience of the drive up to the hospice during winter time when it was dark, overcast and raining and the driveway was lined with bare trees. The time of entry into the hospice in terms of the season and the weather, had a definite bearing on the experiences of patients.

For someone in pain and disorientation such as Percy, entering the hospice was a very positive experience in contrast to the experiences of hospitalisation. He had suffered hallucinations and paranoia related to blood poisoning and he described his experiences of care at the hospital as "appalling". He entered the hospice as an in-patient, before making substantial recovery and attending as a day care patient. His account told of his joy at arriving at the hospice:

"And when we arrived here I was grinning. I honestly was grinning with joy, because I'd escaped, really escaped, from [hospital], remember because I'd seen... I thought it was somewhere in the far east and there were guards with gun turrets and all the rest of it, and so I really felt I had escaped from somewhere weird. [...] I think I had a pretty good understanding of what hospices were about. I knew the old fashioned myth about you know "go to hospice and die!" was not necessarily true." (Percy: Day Care Patient - 1st interview)

For Percy the hospice was a place to which he had escaped. Essentially, it was providing him with a shelter (something that will be discussed in the next chapter). Not only did Percy feel the relief of "escaping" from a place where he had endured traumatic experiences but he had experienced hospices before. He knew that what he called the "myth" of hospice as a place where death is the inescapable certainty was not necessarily the truth. Percy's previous experience was centred around memories of his brother's time in a hospice. He recounted the last week of his brother's life as "fabulous":

"But in his case...he'd been suffering at home, his wife was trying to look after him at home, failing really to manage him properly, and last week of his life he was moved to a hospice, where he was cleaned up, and sorted and had a



fabulous last week to his life. So I think I had a very positive view on what hospices were about.” (Percy: Day Care Patient - 1st interview)

Percy’s positive view of hospice is in contrast to other people who had no prior experiences of hospices, experiencing a deeper sense of dread such as Jim.

Arthur was more matter of fact about why he thought he had come to the hospice, stating that he thought he had come to the hospice to die, but this attitude quickly changed to “astonishment” once he experienced what day care offered to patients:

“Astonishment. [...] Yeah the whole layout of it... And all the beautiful chairs and everything. It’s like...it’s like the Regent Hotel! [surprised laugh]. You know? ‘Cause you thought...ninety nine percent of the people thought, like bloody hell, I thought I’d come here to die! You know. And it gave you...confidence...knowing...that this is a hell of a good place... ...because the first time I came, they toured me around, and then that Rachel [complementary therapist] the therapist...she “oh come on lie on the bed”...you know, I took me socks off [reflexology treatment] and you know...bringing you drinks and fantastic food.” (Arthur: Day Care Patient - 1st interview)

Besides the physical landscape of the hospice and its hospitable aesthetic appeal, the use of complementary therapies is one of the first things that Arthur recalled about his positive experience of the place. It could be argued that this was due to the fact that he knew of my interest in complementary therapy at the hospice and therefore it was at the forefront of his mind during the interview. However, I had not approached any questions about CT at that stage and it was the first question I had asked him. I felt it was because complementary therapy was one of the first services offered to new patients to help them to relax. It made an obvious impression on Arthur and brought him particular benefits. In hindsight, it is hard to tell what Arthur was thinking at the time, but I feel that complementary therapy represented an element of care that changed his sense of place and helped him to overcome the threshold anxiety that he had experienced and subsequently contributed to Arthur’s positive sense of place. When I asked Arthur if he had been offered CT on his first day he replied:

“Yeah, she just came around and said “do you want your feet doing?” I says “you what?” “Your feet.” I says “is it free?” She says “yeah”, [...] you know it’s surprising what it does, you know. It’s not that she’s cured me. But, she’s doing something that relieved a bit of pain. [...] Well it was great.” (Arthur: - Day Care Patient - 1st interview)

Arthur seemed surprised that the service was free, and further surprised by the effects of reflexology. Though he understood it would not cure him the fact that it relieved even a bit of pain was of great value and he was impressed with this first experience. He further explained how the therapist had cut his toenails as they had become so tough he could not cut them himself. The therapist then suggested he get them cut by a specialist. Arthur got in touch with a specialist but became frustrated with the need for assessments and suggested it was time-wasting and “pointless”. When the therapist cut them for him as part of the therapy, he described the situation at the hospice as “heaven” in comparison:

“So, when I got here it was heaven! No problem, lie down I’ll cut them. You know. You couldn’t get better treatment than...in Harley Street in London! [laughing]. I’ve all faith in it.” (Arthur: Day Care Patient - 1st interview)

The hospice was a place where there was no time wasted or any pointless bother. It was a place where things happened which provided relief. He was not left to drift along wondering when he would be treated. It was a place where things got done and Arthur seemed to greatly value this pro-active approach to solving his problem. The suggestion that it was in fact “no problem” seemed to bolster his opinion of the services provided. He later described an “unknown world”, where new opportunities and possibilities for a better quality of life, seemed to open up. When I asked him if he knew anything about CT before he came to the hospice he replied:

“No, no, no. That’s what I say, it’s walking into an unknown world. All of a sudden...everything opens up. From feet, from head to toe! [laughing].” (Arthur: Day Care Patient - 1st interview)

I felt that Arthur was talking about the hospice as an unknown world, a landscape of new experiences of care such as CT, nursing care, even the built environment of day

care. His description of an “unknown world” further pointed to the possibility of new knowledge as a theme amongst the patients. As everything opened up there was a sense of crossing over conceptual thresholds as Arthur realised the possibilities and opportunities available at the hospice, thus forming a different sense of place from the one he had previously. When I asked Arthur earlier what he thought of the hospice before he arrived on the first day he explained:

“I don’t know. I’d given up! Well not given up, because err...I’m a practicing Christian. And I knew one day...I’m going to nod off. So I took the attitude of well, I’m seventy five, seventy six. I thought well, not a bad run...and then all of a sudden I started to realise you know I can...I could get some more life out of me [laughing]” (Arthur: Day Care Patient - 1st interview)

Arthur’s experiences of CT certainly helped to influence this realisation that he could “get some more life” out of himself. This showed similarities to the sense of “living with” and not “dying from” cancer that other patients and staff remarked upon. The nursing and medical staff and the complementary therapists similarly pointed out that complementary therapy was one way of helping patients to cross the threshold into the hospice, a way in.

### **CT as a way in**

As with Arthur, when a new patient arrived at the hospice to visit day care for the first time, they would be introduced to complementary therapy on that first visit as part of what was offered by the day care service. It was suggested that CT was used to help patients to relax into the unfamiliar surroundings, to calm them and to alleviate their anxiety at crossing over the threshold in an unfamiliar place. Cathy, a staff nurse explained:

“If someone’s really anxious the aromatherapy is always a good move because you know, unless they’re the sort of people if they don’t really like the massage and it’s rare that people don’t like it, but you know they’re gonna come

off...go off to that, come back and look more relaxed and, usually that's the case, so yeah." (Cathy: Staff Nurse – Photo-elicitation Interview)

In a strategic sense aromatherapy was considered a "good move" when patients were anxious, indicating that the nurses and therapists purposefully used it to help patients to relax, and to overcome their anxieties. Susan, one of the staff nurses explained that patients are often frightened of coming into the hospice and that CT is often a way of helping them to relax, providing a "way into" the hospice:

"It helps them and sometimes it can be a way into the hospice, if they are frightened of coming to the hospice, often the complementary therapies is one of the first things that helps them to relax about coming into there, because it's very frightening." (Susan: Staff Nurse – Photo-elicitation Interview)

Susan notes that CT is one of the first things to help the patients to relax. It is perhaps one of the first "treatments" that they experience as part of day care, and so leaves the patient with a positive feeling about subsequent treatments.

It was also noted that it was "rare" in Cathy's experience for patients not to enjoy massage. All of the patients interviewed indicated that they enjoyed it and found some sense of benefit from it and this was usually associated with a sense of relaxation. The patients had repeatedly stated in the interviews that they had a negative preconception of what would happen once they entered into the hospice, that they would become "sucked into a system" and "operated on" (Jeffrey) or somehow trapped into staying (Jim). CT was being used as a way of showing patients that far from being trapped or sucked into any system, day care was a place where patients had control of what happened to them and that complementary therapy was something pleasant to take part in. It was used to help to relax the patients and calm their fears of entering into the hospice, as a way of introducing the patients to a place of new positive experiences of caring in a place in which they could distance themselves from their fears and anxieties. In such a place, they could enjoy a sense of well-being and nurturing care, something distanced from more invasive procedures and treatments associated with other health care places.

Melanie one of the voluntary therapists explained that the biggest benefit she could offer to patients was that she was not there “to do anything nasty”, to “give tablets” or “take blood”. She suggested that the non-invasive approach of CT stood in contrast to medical procedures and orthodox treatments as something more relaxing and less invasive. So, it was something that was provided to induce beneficial feelings within the patient and to nurture a sense of well being and trust.

Jackie, a contract therapist at the hospice explained that sometimes patients were referred to complementary therapies as outpatients as they did not wish to attend day care. Simply being associated with the hospice seemed to be difficult for them, as if any closeness to the place would have an adverse affect:

“We have outpatient referrals, very often people who maybe don't want to take up the offer of day care, but are happy to come for a therapy. So it's quite a good way of getting them over the threshold to the hospice without feeling as soon as they're associated with it they're going to drop dead because that's what a lot of people think... ..And when they can realise that we're here to improve quality of life and help people live with cancer, not die with cancer, then often it can change their whole attitude. So sometimes, we find that once people have been introduced to the hospice environment via the therapies, then they're sometimes more willing to accept help in other ways, from the hospice.” (Jackie: Contract Therapist – Photo-elicitation Interview)

Jackie seemed to be implying that CT was used to help patients to reach a level of “acceptance”, that day care was there to help patients to live with cancer and to improve their quality of life, rather than to die with cancer. This was the mind set that Ethel had also talked about. *Living with* and not *dying from* cancer seemed to be a basic tenet of the day care service and served to change the perception of patients as “a place to die”. CT then helped to create a more positive impression of day care and hospice as a place. There seemed to be a process of realisation that hospice was not such a negative place, and this was marked by the acquisition of new knowledge, based on new and positive experiences of which CT was emerging as an important part. Jackie stated quite clearly that her therapies are used to help get patients “over the threshold to the hospice”. Patients were not just crossing a physical threshold but a psychological

threshold constructed of views, beliefs, fears and anxieties about the hospice and its meaning to individuals; a conceptual threshold that when crossed led to a change in the person's attitude and sense of place. One way of describing this might be to say there was a "re-placing" of sensibilities as old perceptions were displaced in favour of new perceptions. This occurred through learning and experiencing within the hospice, which resulted in the formation of new perceptions and new experiencing. CT changed the "whole attitude" of the patients to the hospice and this is an important point to discuss in later chapters.

Julie, one of the doctors, reinforces the notion of CT being used to help patients reach a level of acceptance. She referred patients to complementary therapy from the community. If patients were unsure about visiting the hospice day care service, (and crossing that particular threshold) complementary therapy was used to provide a way for them to experience aspects of what care at the hospice was like and what it could provide for them, safe in the knowledge that they were returning to their own home again:

Julie: "When we are working in the community, we can access complementary therapies either over at [cancer care centre] or occasionally within the oncology unit, or here, at [the hospice], where either relatives or the patient can come in for complementary therapies. That is not a large service but it's available and can be very useful. Particularly if people, haven't got to a level of acceptance of feeling comfortable about coming to the hospice. It's a way of them introducing themselves to the hospice, knowing that they're coming in for a specific treatment and heading out again. But the treatment itself can be very useful to them. [...] There is a lot of misinformation out there about what a hospice is about, and that it is about terminal care, and that if you go in you only come out feet first. Unfortunately those misconceptions are not just about the public. I know full well that medics and even some of our oncology colleagues, have made observations in the past as to why's the patient in there?" (Julie: Palliative Care Specialist – Photo-elicitation Interview)

There is a sense that the patient has power and control over their actions as Julie stated that patients "introduce themselves" knowing that they were going in for one particular reason - to receive therapy - and then coming out again once they had their therapy

treatment. Julie suggested that the process of visiting the hospice for CT changed the perceptions of patients and carers who had not yet reached a level of acceptance of entering into the hospice, enough for them to “feel comfortable” in the hospice environment. She stated that many patients were afraid that once they entered they would only come out “feet first”, again reinforcing the same sense of being trapped in the hospice that Jim and Jeffrey had described. Misinformation seemed to be part of the misconceptions that surrounded the hospice, which helped to create the threshold anxiety that many patients felt, and such anxieties could be seen as barriers to entry into the hospice. Julie believed that CT was a way of “breaking the barriers down, of introducing patients to the idea that the hospice has got an awful lot of positive things to do, and that it is not about dying.” Julie also suggested that not only were misconceptions about the purpose and nature of hospice held by the general public, but they were also held by medical staff and even some of her colleagues working within oncology.

### **CT – “trying to put things back together” – Re-creating self**

The sense of drifting could also permeate the patients’ experience of their lifeworld after a diagnosis of terminal illness. Cathy (staff nurse) explained her perceptions of how patients were sometimes “blown apart by the diagnosis” and “shell shocked” by the speed with which they had moved from diagnosis to treatment. This image of the broken body is one of disorientation and separation from the world in the sense that the body is no longer a trustworthy vehicle through which one experiences the world. Cathy perceived CT as being used to put “things back together” again, creating a sense of normality and wholeness:

“And I think there’s a really important aspect of it, particularly with the massage therapies whereby people get a sense of themselves really, as a whole and, the body image can be a problem for many people who’ve got cancer, if they’ve had surgery or they’ve had chemotherapy and lost their hair and... Sometimes you’ll find that they can become sort of almost like...shunned you know, in certain areas. They feel that some people don’t even want to shake hands with them or touch them and there’s still this like fear of cancer you

know in the general population. So I think when they come here, and... people just treat them in a normal way, and they can go and have a massage and... It kind of just gives them a sense of them being... still a person you know and still you know the massage really is, is... works on the whole body and I think it can help with self esteem and confidence and things like that as well. Together with the hairdresser that's another important part really, of that kind of therapy. The massage working on the body and then the hairdresser looking at... 'cause when they go in that salon, it's like being in a normal salon. [...] And again that's just trying to put back together that person who basically often is really kind of just blown apart by the diagnosis. There's the diagnosis, the treatment and everything tends to move along very quickly...and erm... they're quite shell-shocked really, sometimes when they come to us. And it's just trying to put things back together a little bit. [...] And I think the aromatherapy is really important in that process.” (Cathy: Staff Nurse – Photo-elicitation Interview)

CT was used at the hospice to help patients regain a sense of their own self-hood or personhood. Cathy talked about the patient as getting “a sense of themselves [...] as a whole” as they may have felt broken in some way because of their illness and the effect it had on them and their experience of the world and others within it. Patients were shunned by others because of their altered physical appearance, or because other people feared to be associated with someone who had cancer, whereas as at the hospice they were treated normally. In Cathy’s opinion massage and aromatherapy were useful in helping patients to regain a sense of themselves as whole and normal people. The psychological effects of diagnosis – being “blown apart” and “shell shocked” - conjured images of the patient’s sense of self as being scattered, incomplete and disorientated, both physically and mentally.

Jim also spoke of a feeling of being incomplete as though his feet were not a part of him. Besides cancer, Jim suffered from diabetes. This affected the nerves and blood supply in his feet and he referred to them as something almost other than a part of himself:



“like two cold slabs before I go in there [reflexology]...they’re just useless to me...these bloody plates of meat are awful.” (Jim: Day Care Patient - 1st interview)

This is not the first time Jim had referred to his feet as though they were other than a part of his self. While talking to Jim [patient] about CT before his interview he enthused about the foot massage and its effect on his feet. He stated that afterwards he felt like he owned his own feet again. I questioned him about this in the interview:

Oh I owned ‘em yeah! I were wanting to dance and all that, if I could’ve done I would’ve done but er... Oh I love it, I love it. I wish I could have it everyday that.” (Jim: Day Care Patient - 1st interview)

And then again in his second interview:

“I could feel the heat coming back, the warmth of the blood. I could feel all the tension coming out like you know and oh! [...] Oh it was so...it were lovely. And then you put your socks back on and your shoes and I’m bloody near dancing coming out of there like because I can feel everything in my feet, lovely, it’s great!” (Jim: Day Care Patient – Photo-elicitation Interview)

Although Jim was not talking about his cancer, his experience was related to a sense of being detached from his feet and regaining a sense of bodily wholeness through the massage. It is obvious that part of his ill health had such an effect on his physical self that he no longer felt it was his own body, but something “useless” and not under his “control”, and therefore not belonging to him. Jim talked of “owning” his feet again and being able to feel warmth returning to them as the tension was released. Essentially CT was helping him to be a more complete person again, becoming more at home in his body.

Douglas also recalled how his first aromatherapy massage made him feel in terms of how it brought together parts of his body that had become displaced:

“There was no doubt that I had...it was very relaxing...for three days. And it wasn’t, because that was just the way I felt. [...] Well for three days I would

say I was relaxed. My feet in general felt more comfortable. There was a sense that they'd all been manipulated back to where they should be, hadn't been stuck in a shoe or a slipper. I felt that while the cancer was saying, this, the rest of my body. My feet were saying 'No!' And lymphoma was saying 'What!' You can tell who's the creative one here can't you? Making up a story about cancer. And cancer said to me! It's just that I've had one treatment and it was a positive experience." (Douglas: Day Care Patient – Photo-elicitation Interview)

Though Douglas retained a sense of humour about his situation, it was evident that he felt a sense of separation and displacement between parts of his body, even imagining a dialogue between his feet and his cancer. He felt that his feet had been manipulated back to where they should be, re-placed or returned in a sense to the landscape of his body. I felt that Douglas's positive experience of CT helped him to feel more at home in his body, improving his sense of wholeness or completeness of self.

By putting things back together again and returning a sense of wholeness to the person, CT helped to combat the disorientation and separateness experienced in illness, particularly when patients felt "blown apart" by their diagnosis. By achieving this, patients were able to regain centeredness and a bearing on their sense of self that would help them to stop drifting, and to feel more normal and whole again, as they did before the illness. Being treated as normal people by the staff and therapists also helped patients to regain a sense of relatedness with others. This is in contrast to the feelings of being cast adrift by the perceived rejection by others.

## **Conclusion**

In this chapter, I have tried to convey how patients felt before they entered into the hospice. This analysis provides the first theme of "drifting", which describes the way that patients experienced feelings of uncertainty, fear, isolation and a sense of having no bearing from which to navigate their lives.

In these findings I have tried to show that while not every one of the patients shared these same feelings to the same extent, it is of concern to the staff and therapists that a

sense of fear and misconception about the hospice exists. Complementary therapy provided one way of introducing patients to the hospice in a more positive way. Those who did not suffer as much with “threshold anxiety” clearly had more positive pre-conceptions based on prior knowledge and experience of the hospice. The patients who did suffer with greater threshold anxiety soon changed their perceptions of the hospice, and it was clear that this process was influenced in some way by their experiences of complementary therapy.

Complementary therapy was described by therapists and staff as a “way in” to the hospice, a way for patients to reach “a level of acceptance”. This level of acceptance could be equated with a level of comfort with one’s surroundings. I also feel that CT provided the patients with a more authentic experience of place when compared and contrasted to other healthcare places where medical procedures they may have experienced added to their fear of more pain and suffering.

The data suggests that complementary therapy is used as something positive and pleasurable - what might be termed an “authentic experience”. Patients experienced a far more humanistic type of care, where they had time to relax in comfort, experiencing human contact in a caring and intimate way. This stood in contrast to their “inauthentic” healthcare experiences commonly attributed to hospitals, that were time consuming, impersonal, uncomfortable and far less pleasurable.

CT also helped the patient to regain a sense of themselves, as normal and whole people. The disorientation and separateness caused by diagnosis and illness was replaced by a reorientation with the body as a whole, and a sense that patients had a better bearing on their lifeworld, stopping them from drifting.

Although complementary therapy was used as a way in to the hospice, the fact that patients could move in and move out of the hospice, without being “trapped” helped to change the perceptions of those who were particularly worried about being “sucked into the system” or “grabbed”. There was a sense of freedom and control in this process and in the next chapter I will further attend to how complementary therapies were used to create a supportive homelike environment for the patients, and to how other facets of the hospice contributed to creating a more positive sense of place.

The organising theme for the next chapter is “sheltering”, a state in which patients were provided with support in a safe environment, where they were cared for within a community of others. This sense of sheltering enabled them to develop an “insideness” where they gained a greater sense of place and self.

## CHAPTER 6

### SHELTERING

“All really inhabited space bears the essence of the notion of home [...] the imagination functions in this direction whenever the human has found the slightest shelter” (Bachelard 1964 p.5)

The Oxford English Dictionary defines ‘shelter’ as a place that gives protection from bad weather or danger; a place providing food and accommodation for the homeless; a shielded condition; protection. As a verb, it means to find refuge or take cover or to prevent from having to do or face something difficult. It can also describe a temporary home.

In this chapter, I will discuss the ways in which the day care unit and the hospice provided experiences of sheltering. In the previous chapter, I described how the patients had experienced drifting and feelings of anxiety, uncertainty and alienation. In sheltering patients found a sense of certainty in the care provided. They sheltered within places that were characterised by supportive relationships, and a sense of community. The hospice provided a “home from home” for some patients, and creating feelings of security and safety, comfort and easiness, which contributed to feelings of at-homeness. Complementary therapies also provided a sheltering experience for patients and created a space in which patients could be relieved of the stresses and anxieties associated with their illness. Firstly, I will describe how patients felt a certainty of care.

## **The Certainty of Being Cared For**

I feel that ‘certainty’ is the right word to use in this context, as its roots suggest a place in which we are sure of something. The Oxford English Dictionary shows that ‘certainty’ is from the Latin *certus* meaning “settled, sure”. The roots of the word ‘settle’, are in the old English *setlan* “to seat, place” or *setl* “a place to sit”. To ‘sit’ can also mean “to be harmonious with”. The roots of the word ‘sure’ are in the Latin *securus*, which means “without care” meaning to be confident of receiving something, or certain one is right. *Securus* also gives us the word ‘secure’. Thus, we can take the meaning of certainty as “to find a place in which we are sure of a harmonious state”.

Many of the patients described feelings of being cared for in the hospice. A lot of the patients’ gave the impression that their experiences were un-usual or atypical of their previous experiences in healthcare – and were mostly compared by them to hospitals, where they felt that they had not been properly cared for. Time was an important theme in these experiences. At the hospice, patients were given fixed points in time when something would happen. This gave them a sense that they could be certain of the care received, at the time when it was promised, at a pace that suited them, and in a way that did not disrupt their sense of routine outside the hospice. Staff were often perceived as “going out of their way” to care for patients. This gave patients a sense of certainty, security and a confidence in the care they received, indicating an embodied care that involved *knowing* and *feeling* that they were being cared for.

### “Nothing was trivialised” - The certainty of time and place

Percy first entered the hospice as an in-patient. He moved up to day care when he improved. Previously, he had been critically ill in the local NHS hospital and he tried to convey the contrast between the two places in terms of the care he received:

“...every credit to this place because it’s just... It’s hard to explain what they do, but what they do is what all hospitals I guess should do, you know, they just do it right.” (Percy: Day Care Patient - 1st interview)

In contrasting hospice with hospital, Percy felt the hospice demonstrated how care should be given. One of the main reasons for this was that staff had more time at the hospice to care for the patients, and there were more staff per patient. He gave me an example of how when he asked for something such as a drink of water in the hospital, he was continuously passed over until eventually the staff forgot about him. He compared this to his experience at the hospice:

“[...] by the time they’ve got to the end of the ward they’ve got ten jobs. They’ve forgotten yours [the hospital staff]. And you know you can’t expect them to have done anything else. Whereas here [at the hospice], because of the amount of manning,[...] if they’ve given you something and then you say ‘and when you get time can you do so and so...’ They’ll say ‘I’ll do it now’ Or if they can’t do that they’ll give you a time it will happen. And it did happen. Often they would go outside and because there are more people around, they would say ‘Percy needs so and so’ and it wasn’t trivialised, nothing was trivialised. A glass of water wasn’t trivialised, it came.” (Percy: Day Care Patient - 1st interview)

The point I feel that Percy was making was that he was made to feel cared for. Being forgotten about led him to feel that his needs were not met and were trivialised, effectively diminishing his sense of self, and his importance in the eyes of those who were charged with his care, leaving him with the feeling of not being cared for. If the nurses at the hospice could not attend to his needs straight away they would give him a time when they could. This dispelled feelings of uncertainty and created a confidence or trust, that he would be cared for and taken seriously. This created what I would describe as feelings of undiminished value, hope and a frame of reference, in what was essentially a very uncertain time. This created a fixation in time at which a need would be fulfilled. It was something to look forward to and created a bearing or location in a space of uncertainty, so that he was not left drifting.

Jim described the hospice in a short and powerful sentence that intimated at his sense of satisfaction with the care he received:

“I get what I want and I get it at the pace I like it and I get it in a friendly atmosphere and that’ll do for me.” (Jim: Day Care Patient – Photo-elicitation Interview)

There was an assurance, a confidence, in his words, that he knew he would be cared for and not left to drift, that he had something solid to hold onto in the sense that he would receive what he needed, when he needed it and it would be given in a caring fashion. Assurance provides a sheltering sense of place for the patient - a solid structure in which they are certain of being cared for. Like Percy, Jim pointed out that he got what he wanted, *when* he wanted it, and additionally *where* and *how* he wanted it, giving him a sense of location or point of reference within time and space.

Carl also compared his experiences of hospital and hospice, and these also revolved around issues of time:

“Hospitals are a bit regimented aren’t they you know, a bit chaotic, but this is more organised and it’s more of a relaxed atmosphere. [...] What gets me is everything’s always behind time. But here you know everything’s...you know they pick you up more or less the same time every day [...] and take you home at the same time. So at least you can juggle your day if you want, you know if I want to do a bit of shopping afterwards or I’ve somewhere to go I can do it, but the hospital you can sometimes be two hours behind your treatment time. Well the days gone then you know, getting home at teatime instead of like here, middle of afternoon you know, I’m home at quarter past three. There’s still like three hours or so to go and do a bit of shopping or whatever I need to do. [...] I mean you come here and you know exactly what you can expect and what you want to do and what you don’t want to do.” (Carl: Day Care Patient – Photo-elicitation Interview)

Carl knew what to expect at the hospice, he had a routine which enabled him to find a location within time and place. He would arrive at a certain time and leave at a certain time. He knew what to expect. He had a stronger sense of place at the hospice, where he knew what to expect when he arrived, whereas he experienced the hospital as regimented and chaotic, leaving him uncertain and “behind time”. Being behind time is unsettling for someone who has a heightened sense of how much less time they have left. The hospital left Carl drifting in uncertainty as to when things were going to



happen, whereas the hospice represented a place of certainty; a place where care was given without disruption to the patient's sense of lived time. This helps to stabilise patients making them feel secure and relaxed without creating anxiety through uncertainty. This is a caring act in itself and speaks of an awareness and empathy for the patient, adding to the sense of being sheltered within the assurance of care.

### Beyond expectations of care – developing confidence

Staff and therapists at the hospice were often perceived as going “out of their way” or beyond the call of duty in their care for patients. Based on previous experiences of other healthcare places and their initial anxieties about the hospice, this level of care was unexpected and gave the patients confidence in the care provided. A simple cuddle made a big impression on Andrea:

“Yeah she’s one of the staff yeah, she does dinners and that I think as well. But she’s really nice I like her, she always comes up to me and gives me a cuddle and that when she went out of her way and she’s really nice. [...] I get on with her really well.” (Andrea: Day Care patient - 1st interview)

The small gesture had a large impact, not merely because of the physical act of touch, but because she perceived the staff member as making extra efforts to show care and affection. Terry described the dedication of the staff as “unbelievable” in a way that again suggested it was unexpected:

“Dedication of the staff, the bottle, unbelievable, you know. Can’t do enough. Can’t do enough for you. Really impressed.” (Terry: Day Care Patient - 1st interview)

Derek’s perceptions of the staff show a similar theme, though he intimated that he already knew it would be a wonderful place:

“Just like, the staff and the place itself, the people are just so caring you know? And they just go out of their way to help you, yeah. It’s a wonderful place. But

I already knew that I'd been told so often." (Derek: Day Care Patient - 1st interview)

The fact that Derek said he already knew it would be a "wonderful place" highlighted his pre-existing but vicarious sense of place, and that he knew what to expect of the place. Though later, the exact nature of the care still surprised him as he mentioned the way that the staff went out of their way to help him. He related a story of how one nurse helped his wife to come to terms with Derek undergoing chemotherapy treatment. The nurse made appointments for Derek to attend Chemo-hypnosis, to help with the side effects:

"she's said I'm going to send you for...they have a chemo-hypnosis [...] it was operated by [cancer service provider] but when [nurse] got on the telephone, it had moved and its now at [place name]. So [nurse] found this information out, that it had moved, and [nurse] went, and within an hour I had a telephone call, from [cancer serviced provider] to make me appointment for Thursday. [...] You can't believe how quickly [...] There's nothing, never a problem, everything gets sorted [...] And like I said the nurses [name] and there's been another nurse called [name] they're marvellous, absolutely marvellous. And when this chemo starts, if there's any problems, all I've got to do is ring them, just say you know I'm having a problem with this sickness or whatever, side effect. And something'll get sorted. Yeah" (Derek: Day Care Patient - 1st interview)

Derek's experience was again unexpected as he said he could not believe how quickly something was arranged for him. He had confidence that nothing posed a problem for the nurses in terms of his care and that everything would be sorted out. This confidence resulted from the actions of the nurses. They went beyond his expectations, perhaps renewing his faith that he would be cared for. Carl also described a feeling that nothing was too much trouble for the staff:

"Well I like the care...I mean I'd say out of ten it would be ten. You know I mean, nothing's too much trouble for them. You know and then I notice a gentleman who...people probably come in here that's still ongoing treatment you know, blood transfusion or whatever it is and they come here and they can

still be part of the group, while they're receiving their medication as well. I mean if push come to shove and I had to come here well I don't think I'd have any apprehension, I just feel comfortable knowing that I'm being cared for and looked after you know." (Carl: Day Care Patient - 1st interview)

Carl's experiences of care gave him a confidence that dispelled any apprehensions of becoming an inpatient. The fact that the gentleman he mentioned was still included in the group gave Carl a sense of confidence that no matter what, he would be cared for and included, without being isolated from others. I felt that the patients had a confidence and certainty that no matter what, they would be cared for. Their expectations were surpassed and this created certainty in a time of uncertainty.

Jim tried to explain in the second interview how things had changed since I spoke to him previously. He said he felt "closer" to the hospice. He revealed that the staff/patient relationship was such that he felt it was easier to communicate with them:

"I'm closer to this place, than I am with me GP, my own family doctor [...] I feel like I can talk about more things here. Like when I go to see my own doctor, [...] I'm not calling it tight-lipped, I don't believe he is, but because I don't get to know a lot from him, I won't be able to open up to him, but I can come here and I can talk to the nurses. I can talk to the doctor. Polly's (auxiliary nurse) very good at bringing stuff out of me you know, she cajoles me and all that like you know and er...but I find that pleasant and easy to deal with. I don't find it so with a doctor you know...it might be just her bedside manner I mean I don't know. (Jim: Day Care Patient – Photo-elicitation Interview)

Jim described a closeness with the place, brought about in part because he found he could talk to the nurses and the doctor at the hospice better than he could talk to his own GP. He shared closer relationships with those caring for him, communicating more easily. This was facilitated by good communication and an easiness, evident in Polly's "bedside manner". Such "closeness" was indicative of the value that Jim put on his relationship with the care staff and doctors in the hospice, illuminating close interpersonal networks and a sense of relatedness. I felt that Jim was reconnecting with a sense of hope and possibility when he stated "...but I can come here and I can talk to

the nurses. I can talk to the doctor” which he could not with his own GP. These feelings of hope and possibility were evident in his first interview:

“But this place, that's another thing I like about this place, not just for me, but it filled me with hope. That while there's places like this and people who care like this...a lot can be done I think, you know?” (Jim: Day Care Patient - 1st interview)

Jim had a sense of hope and possibility. The hospice was a “hopeful place”, which created the possibility of a better situation for patients. It is obvious to me that Jim perceived the people caring for him and the place of care as one and the same, as the closeness he felt was with “this place”. By their actions and intentions, the people within the hospice created a meaningful place of value for Jim, a hopeful place that he felt “close” to. I would equate this closeness with feelings of sheltering.

Douglas also suggested he was not used to the kind of staff he experienced at the hospice:

“It's completely new to me. The occasional people that I've met in the medical profession generally, has been, twisted ankles, car accident. So they've been in a completely different profession. That's the medical end. The people that I've met here, whilst most of them are medically trained, the key skill that they have is people skills.” (Douglas: Day Care Patient – Photo-elicitation Interview)

Douglas had noticed the more humanistic side of care at the hospice. He spoke of “people skills” as Jim had spoken of “bedside manner”. There was an evident easiness within the relationships that patients shared with the staff and Douglas thought it was “key” to his experience of care at the hospice. He differentiated between the “medical end” and the more humanistic value-based and person-centred care provided at the hospice.

Jim spoke of being “amazed” by the care he received from the doctors at the hospice.:

“Oh yeah, I've never had any trouble with them really, and that's what amazes me. [...] They've been absolutely marvellous with me like. They've never been able enough to help me. [...] If I've needed to come back and get a new medicine or something like that, you know they're willing to try it. You know, nothing's too much trouble for them. You wouldn't get that with [own GP], he wouldn't wear that one iota you know.” (Jim: Day Care Patient – Photo-elicitation Interview)

His experiences were unexpected and unusual in comparison with those of doctors he had previously dealt with outside the hospice. Again, there is the theme of nothing being too much trouble and a certainty of care.

There was a strong and complete sense of being cared for in an authentically humanistic manner, where patients felt that they really mattered. The quality of this care was expressed as unexpected by the patients, going beyond inauthentic encounters they had experienced in other healthcare situations. This care was characterised by a more meaningful approach, leading to a sense of certainty and confidence. Knowing that there was never going to be a problem in terms of their receiving care strengthened the hospice in terms of its structure as a sheltering place. If we are never certain of when or how we will receive care, we cannot shelter within its integrity as it is compromised by an uncertainty that weakens its essential nature.

#### Feeling cared for – “A sense of care without a sense of duty”

Within the theme of feeling cared for, patients perceived a ‘spirit of care’ that went beyond any sense of duty. The care was provided in such a manner that it appeared that it was an innate human quality amongst the nursing and care staff. One of the motivations for working in a hospice is often noted to be a sense of vocation. The care staff were seen to enjoy what they were doing. I felt that this had the effect of relieving the patients of a feeling of burdening others with their disease, as far from burdening they were simply the focus of the caring intentions of someone who enjoyed giving that care. In a sense, the relationship was reciprocal as they were also fulfilling the needs of the staff:

“The staff are just astonishing really. And they all look as if...and some of them have said it - but that doesn't mean anything does it often, but I believe these people do mean it – that they enjoy coming to work. They all have an attitude that says they're here because they actually like doing it, but I'm sure that a lot of them could be earning more money doing something else, somewhere else. But they choose to be here, and they're bloody good at it. They're good at what they do.” (Percy: Day Care Patient - 1st interview)

Percy's astonishment again reveals the unexpected, in terms of being cared for by people who emitted an authentic caring intention, a genuine sense of caring, that was beyond financial motivation or career goals. This sense of vocation was also felt by other patients such as Douglas who succinctly described the care he received as “a sense of care without the sense of duty”. He went on to explain this further:

“It's not the sense that it's a job [...] there's not even a sense that it's a vocation [...] But it's intrinsic to this feeling of being in a place where we will help you without feeling patronised, where people feel...it's innate, that they'll help you without question.” (Douglas: Day Care Patient - 1st interview)

Douglas talked of an innate sense of caring, so natural and intentional it was beyond even a sense of vocation. The care was so natural and focused towards people as people rather than as patients, that there were no feelings of being “patronised”. Care was given without question, and again I feel that this relieves the patients of a sense of burdening others, that it was no trouble at all. Douglas and Percy's experiences were redolent of an authentic place experience, and perhaps the best shelters are authentic places, where one is truly and unconditionally cared for as a fellow human being, as an equal person, rather than as a patient. Such a level of feeling cared for defined the hospice as a place that was different from the prior experiences of these patients. The fact that it was delivered in such a humanistic manner created a confidence amongst the patients, a faith and certainty in the strength and integrity of the sheltering experience; a faith and certainty that they were valued as human beings rather than objectified and patronised as terminally ill patients.

### Called into belonging – “everybody knows your name here” – Being known

Such values were also found in the way that staff related to patients by addressing them using their forename. Percy felt the care he received was unusual when he spoke of how the staff remembered his and his partner’s name. He sounded incredulous and remarked on his suspicions that perhaps the staff had photos of the patients, though I assured him this was not the case:

“You know people come in, everybody knows your name here. I mean I’m astonished, there’s a lady [...] who’s wandering around I didn’t catch the name on her badge [Bernadette the day care sister] I’ve met her once. [...] This morning I came up here and she says “hello Percy!” And I’m...she knows who’s coming I guess and they’ll have files, I guess they may even have pictures. I don’t remember anyone taking my picture. But they just know! [sounding incredulous] [...] Everybody knows your name. Everybody on your team at least. And I was amazed at that at first, but you just get used to it. The people on reception, they even know Dave’s name [Percy’s partner] [...] It gives him a big kick and it does, it gives relatives friends, family, it gives them the right sort of support doesn’t it, as well?” (Percy: Day Care Patient - 1st interview)

I wondered at the effect that this had on Percy. In my own experience I know that staff also use patient’s forenames in hospitals, but I noticed that the staff at the hospice knew everyone’s forenames or preferred names, including each others, using them as a matter of course. However, this seemed unusual and unexpected to Percy and made an obvious impression on him. To know someone’s name and to use it to address them in the hospice, I felt gave patients a sense of ‘being known’ and therefore being *more than* just a patient. There is a level of intimacy associated with using people’s first names, and at the hospice I feel it added to a feeling of familiarity adding to the quality of care and a sense of being sheltered within an intimate place. To be addressed by one’s name is also an affirmation of one’s existence. It is a calling into existence, an invocation, reminding someone that they are present in a certain time and place. This gives patients a sense of certainty that they are in ‘the here and now’ and not drifting. This further illustrates a sense of being cared for, not simply as a patient but as someone who is

important and unique, as someone who is part of the place itself. It creates a sense of being rooted and therefore sheltered.

### Finding a space - being smothered

Andrea suffered a loss of autonomy and freedom as her family began to treat her differently. Rather than moving away from her, as was the experience of Jim and Arthur, her family began to smother her. Andrea was a day care patient when she decided to participate in the study, but moved into the in-patient facility as her illness progressed. However, she still attended day care and wished to continue with the study. She described how she felt about the hospice and the day care unit:

“It’s lovely place to be, it is it’s really nice. [...] Erm... I like going up to the day care and doing the artwork and just...all the things they’ve got up there, the reflexology and all that. And it...it does... it helps. It just gives you that time away you know [...] From family and kids and just being, I mean at minute I feel like I’m being wrapped up in cotton wool...from me mum and me other half and kids and that, they’re all, they make it very intense...” (Andrea: Day Care Patient - 1st interview)

Being “wrapped up in cotton wool” and treated abnormally, intensified the experience of being an ill person for Andrea, leading to her feelings of being smothered. Smothering can cause feelings of being trapped or oppressed, suffocated by the care and concern of others. It is a loss of personal space, whereby the person’s world becomes smaller, leading to feelings of not being able to move, or to venture out. The day care facility was a shelter for Andrea, providing her with “time away” from the well meaning but smothering pressure of her family. It was a place to be less intense, as the focus of care was not solely on her disease but on providing her with opportunities to take part in life-affirming creative activities, such as art work and relaxing treatments like reflexology. The day care facility then provided her with the things she needed, a shelter from the intensity of her families concern, giving her time to relax and enjoy her own sheltering space. The hospice then offered her personal space.



## **A Sense of Relatedness**

Relatedness is how we are with others. It is the intersubjectivity of the lifeworld. We share places with other people, and how we relate to those people affects how we experience the place we are in. At the hospice, this manifested itself in feelings of community and camaraderie, feelings of belonging and re-interpretations of normalcy; and through intimate caring experiences, such as CT.

### “We’re a rather odd group of people” – Normality in the abnormal community

There was a sense of community amongst the patients, staff and therapists that I spoke to. This community enabled patients to support each other and to relate to one another in ways they could perhaps no longer relate with their friends and family, as there was a distance between those particular relationships created by the disease itself. There was a sense of comradeship amongst an “odd group” of people, odd in the sense that they were abnormal because of their health status. Despite this, relationships at the hospice helped to foster a sense of normality and strength in community values.

Douglas referred to the day care patients as a rather odd group of people, who still had a sense of humour despite their illness and their uncertain futures. He described a sense of normality that was still evident within this abnormal situation:

“These people, who are very ill, still manage to smile. Still manage to laugh at the odd...dose of humour that goes around, the jokes. The laughter at ourselves, the normality of the life that we lead...the fact that we’re a rather odd group of people. And all have major health problems.” (Douglas: Day Care Patient – Photo-elicitation Interview)

I felt that he was describing essentially a community of people who had bonded despite their illnesses and perhaps because of their illnesses. It was as if they sheltered within the relationships they shared. (It reminded me of penguins in a snowstorm, creating warmth amongst themselves that sheltered them from the harsh coldness of what they

faced). They shared something in common, and despite the fact that their illness may have been viewed as abnormal or “odd”, Douglas felt there was an overall sense of normality in the life they led.

The feeling of comradeship and community was shared by Jeffrey who, when I asked him how he got on with the other patients described his relationship in more militaristic terms, referring to them as “brothers” rather than “enemies”:

“No trouble. No trouble at all. In fact we’re as brothers, rather than enemies you know such a thing.” (Jeffrey: Day Care Patient - 1st interview)

Though he did not elaborate on this statement, it is a powerful reminder that many patients were facing their imminent deaths, and that cancer is still seen in terms of a battle or war. There was a commonality amongst patients in terms of their cancer and although the hospice was not exclusively a cancer hospice, the majority of patients in day care and all those who took part in the study had cancer. Jeffrey’s statement conjured strength in purpose, a sheltering in the commonality he felt between himself and his fellow patients.

The day care staff purposefully fostered this sense of community. Spaces were used in order to create a community spirit amongst the patients. The places within the hospice day care unit were places in which experiences could be shared, whether they involved doing the morning word quiz, art and craft projects, visiting the hairdresser together or simply eating together. Such communal places can help patients to feel that they belong to a place, not only in the sense that they are included by virtue of their interpersonal relationships, but also included because of their association and sense of place. One place in particular that was used to foster this spirit of community was the dining room (See figure 6.1) Bernadette the day care sister described how patients ate together and talked together, and how the staff contributed to fostering such an atmosphere:

This image has been reserved for reasons of confidentiality

Fig.6.1: Bernadette, photo S6C. The dining room (The photograph shows one of the two oval wooden dining tables with eight high backed wooden and leather cushioned chairs. The views through the large windows overlook the hospice gardens.)

"This is the dining room and I think that's a great part of the community spirit [...] I think for the patients in particular they feel community spirit, you know it's social exchange and eating with someone else [ ... ] I try and go in ... you know we serve them now and that's all we do. I do like to once when they're having their meals to sit, and listen to them having their chit chat and join in their banter as well and I think that's a big part. And then it's you know ... obviously as I talked about being professional, you do have that professionalism, but then something like having a meal and sitting and chitchatting to them that brings that community spirit into it. You know it's not an area that you'll be professional, you know, serving them meals and talking to them. So! think that's part of the camaraderie that we have [ ... ] It's not an area that I would feel that I'm in, in as a nurse capacity. I would feel that in sharing a meal or sitting with them while they're having their meal as part of a community, that I'm one of them, almost." (Bernadette: Day Care Sister - Photo-elicitation Interview)

For Bernadette, the dining room was a communal place. It was imbued with a spirit of community, evident in the social exchange and togetherness that characterised the actions taking place within its spaces. It could still be perceived as a caring place as staff “served” the patients, which can be a caring act. Bernadette also described joining in with the “chit chat” creating an informal atmosphere, where she could drop her professional role as nurse for those times when she served the patients. I feel that Bernadette was trying to construct a normal space for the patients. By joining in with the conversations and banter, the role of nurse is forgotten as staff and patients share an everyday social activity. This creates feelings of camaraderie and connection between staff and patients, evident in Bernadette’s feelings of becoming “almost one of them”.

The dining experience was also noted by Lucy (contract therapist) who felt that it was a very important element of the patient’s day and an important part of the patient’s well-being:

“I just think it’s a really positive thing that people do when they’re here, is they have this nice meal together and it is a very important element of the day. And I know Bernadette feels... you know it’s very important from Bernadette’s point of view. That they do have their lunch and have it all together. Erm, because it’s, it’s this community thing and erm... just being with one another and eating some nice food, and even if you’re not feeling very hungry or whatever. I think being with other people tempts people to eat a little bit more than if they were...certainly tempts people to eat a bit more than they would do if they were just sat on their own at home, or even sat in the next room on their own, or they will eat more nourishment there which is a very important part of their well-being.” (Lucy: Contract Therapist – Photo-elicitation Interview)

Lucy described the patients eating together as a very positive and important act. She was also aware that Bernadette liked the patients to eat together. There is a sense of togetherness and support and encouragement. Even if the patients were not hungry, the fact that they were engaging in a social act meant they could feel included. Lucy felt that just being with others who were eating may encourage those with less appetite to eat something, speculating that they perhaps ate more than if they were at home alone. The dining room is then a place to shelter in feelings of community, support,

encouragement and togetherness. It is a communal place where patients can share in a normal everyday activity. The dining room is also then part of the social landscape of the hospice, a focus of elements of social interaction and inclusion, helping to increase a sense of support and well-being.

The dining room was photographed by four of the five patients who completed the photographs, and it was a topic of conversation in most of the patient interviews. Carl enjoyed the conversation in the dining room and the social element, likening it to a “hotel”:

“It’s just like being in a hotel when you’re on holiday, your evening meal or your breakfast or whatever you know I mean everybody chats away you know, have conversations about different things. I mean you can always find out different things you know like somebody wants something, well try such and such a place they have it you know. Conversation like that you know, it’s not all about how you feel or how rotten you are, it’s totally different you know.”

(Carl: Day Care Patient – Photo-elicitation Interview)

The dining room was a place of information exchange as Carl explained, and the conversation was not always about illness, but about everyday things. There is a sense of support for one another in that it is not just food that is shared but information. The impression is one of an enjoyable social activity, unusual in the sense that the place itself reminded Carl being on holiday in a hotel, but normal in the sense that sharing meals is a normal social thing to do.

Susan [staff nurse] also suggested the dining room was a place for the patients to talk and to “bond”, and while she likened the experience of dining at the hospice to a hotel she thought it was somewhere the patients could also be “normal”:

“I think this dining room is wonderful. I like the fact that when the patients have a meal they love all getting together and they sit and they talk after they’ve had a meal, you know just like everyday things. But some of them might not have been to ... you know when you go to a restaurant, when you’ve been to a restaurant you sit and have a meal don’t you and you talk. Well that’s exactly what they do here. They sit down, they have a three course meal

and then afterwards they will sit and talk to each other, and I think it's an important bonding process and it's a chance where they can just talk and it's normal. So that's my reason for the dining room and it's got lovely views.”  
(Susan: Staff Nurse – Photo-elicitation Interview)

Susan felt that the patients enjoyed “getting together” and talking, and felt that it was an important bonding process. This strengthened the idea of a community, which had bonds, rather than a place where people were isolated. She likened the experience to that of being in a restaurant, something which will be discussed later in the section on homeliness. Although visiting restaurants is not something people do everyday, I felt that she was drawing similarities with the fact that it could be a social and normal thing to do.

### Permanence and sustaining the community

Whilst the dining room was identified as a place in which community and camaraderie happened, Lucy the therapist also chose to photograph what I will call the ‘butterfly monument’ (see figure 6.2). The structure was made with the help of the day care patients to celebrate the 20<sup>th</sup> anniversary of the hospice. It was part of the symbolic and physical landscape of the hospice. The ceramic butterflies were made and initialled by the day care patients, with the help of the art facilitator, Sally. Many of the patients had since passed away by the time the monument was finished:

“I took this because as you’re probably aware our Day Care patients made this. Er and it was a very positive thing that they were doing at the time. And still is in a way, and it was done for the twentieth anniversary, and a lot of those patients that were involved in that have now died. And er so it was quite poignant I thought. But never the less I think when people can see that, that haven’t had any connection with...can see the beauty of it and erm... what it’s about and I think the patients that were involved in making it had so many weeks of fun and good camaraderie doing it, er and it took so long to establish that er a lot of work went in to it and erm I’m glad its finally got its sort of resting place really. But that was, was, because for me and for the patients that I deal with, it has a lot of poignant memories really, because they’ve lost a lot

of good friends. But they're there." (Lucy: Contract Therapist – Photo elicitation Interview)

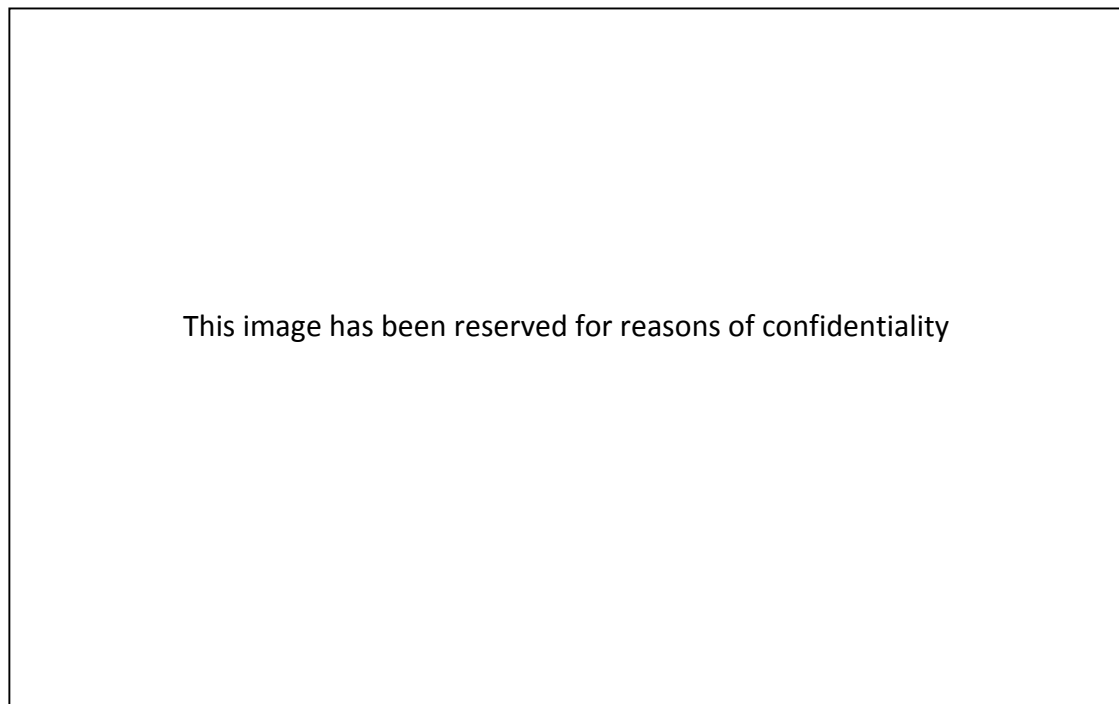


Fig 6.2 : Lucy, Photo T1B. The 'butterfly monument' (The surface of the structure was made in clay tiles, each with a butterfly bearing the patient's initials. The different coloured hands represent the multi-ethnic policy of care, opened as if setting the butterflies free.)

Lucy talked of the poignancy of the monument and the fun and camaraderie that the patients experienced in making it. It stands as a memorial, not only to the patients who made it but also to all the patients of the hospice. By drawing attention to the time and effort involved in establishing the memorial, I feel Lucy was suggesting it was a metaphor to establish something permanent, an anchor almost, to which to tie the memories of those who passed, as she said "they're there", as if their essence was in the mortar and stones of the memorial. The effort involved in making and establishing the structure was symbolic of the struggle that many patients faced, and Lucy spoke of it having found its final "resting place" as though that signified a sense of peace that she hoped for the patients. As part of the symbolic landscape of the hospice, such a memorial is not only a symbol of the communal efforts and camaraderie of the patients who worked together, but also a memorial to every soul who had passed through the hospice. I feel it provided an artefact of permanency, for the patients who built it, for all

those who passed on, for those who worked to care for them, and for those who remained, such as Lucy. There is sheltering within hope and continuity here that roots people to place – that all is not lost in this place, but forever present in its grounds and in the wider world. The monument therefore forms part of both the symbolic and psychological landscape of the hospice. It is a shelter for memories, an abiding place that speaks of not just community, camaraderie, continuity and permanence, but of rootedness and a deep sense of place.

### Creating a space to cope

The feeling of community was also evident in Carl's comment to me before his interview. He had stated that the day care unit was "like a club". I asked him about this later in the interview:

"Well it is in a way you know, it's well...when I came first time last week there was one...[interview interrupted]. Yeah, as I said we were just having a bit of a chat and then about what different people had gone through you know, what they're going through and that you know, and er... Just general chit chat about what's going on in the world type of thing you know. Yeah they're not snobbish, they're all down to earth, we have a laugh and a joke you know. We just enjoy conversation." (Carl: Day Care Patient - 1st interview)

There seemed to be a kind of bonding process between new patients and the older patients as they related to each other their experiences of illness and how it had affected their lives. Carl's description of his fellow patients as down to earth impressed upon me what I had noticed as a volunteer, that newcomers were always welcomed. There was a sense of sheltering within a concerned and supportive community. Everyone was included if they wished to be included, no one was left alone. Jim suggested that he needed someone to talk to, and that he found the day care community a "learning curve" as he became used to talking to others who had "problems":

"[...] getting on with somebody who's got problems, it's like a learning curve, you learn how to interact with them like you know and... Because no matter



what your problem is, no matter how angry or how sad you are, you still need somebody to talk to. Loneliness is no cure for nowt. Just being on your own and not knowing how to deal with people or owt like that. So yeah, I find it a learning curve in many ways Drew.” (Jim: Day Care Patient – Photo-elicitation Interview)

Jim’s statement that “loneliness is no cure for nowt” was indicative of his need to be around people and to interact with others, though he found this a learning curve. This was how he coped with what was happening to him. He learned to cope. The community of day care patients was a sheltering community for Jim, as they provided him with the opportunity to interact and to satisfy his need to talk to others:

“...I like to have a chat with everybody, even if it’s just a nod and the more they get used to you and you know what I mean, you can’t suit everybody obviously, but...my audience out there they seem to be alright with me like you know. My public love me as they say Drew [laughing].” (Jim: Day Care Patient – Photo-elicitation Interview)

I felt that a simple nod of acknowledgement meant a lot to Jim. I think he needed the company of others and found support in the community of day care. I often found him joking with the other patients and staff and he was well liked by both. I feel that the hospice provided a place where the sense of community and camaraderie was an element of being sheltered for the patients. Far from the isolation they may have felt in the outside world, they found a sense of belonging and networks of interpersonal concern that strengthened their sense of place. The hospice provided a space through which some patients learned to be with others, to develop coping mechanisms such as Jim, who coped through chatting and through relating to others.

### Walking with the patient

The doctors at the hospice play a major role in the day care patient’s care, and their relationships with patients I felt were significantly different to that of a GP, in that they had time to build up a rapport with the patients and to explore more deeply the patients’

anxieties, walking with them as it were, on their journey. Julie's [palliative care specialist] photograph of a daffodil in the hospice garden evoked her description of how illness does not need to be terribly complicated, but can be simplified with the right help and support. She described how the patients often felt that their lives were getting very complicated as they tended to focus on losses and changes, suggesting that helping patients to unpack their lives, to make sense of their lives again helped them to regain some control:

“‘E’ [photo] which is the daffodil is very much about the simplicity. I think peoples lives get terribly complicated, erm... Or it certainly feels to them that life has got very complicated. Because they're having to focus on their changes and their losses. But when you help them to start unpack it, they begin to make sense of it again, and can see that by making small changes or putting something into place they can regain some control of it and it doesn't seem quite as messy as they thought it was. Or if they know what services and support are there...it makes it easier to understand that there is a way forward that they can feel supported in. So that was much more about... The work we do isn't actually complicated. People like to tell us it's wonderful work and it's terribly complicated and no they couldn't do it, erm... I don't think that's true. [...] It is actively listening. And it's about making sure – it's about personal commitment as well – but making sure that they know you will continue walking with them wherever their lives or events take them. [...] Because everything else in their lives has suddenly become unreliable. Something, they need something there they can rely on. Even if they're bloody rude to you [laughing] they need to know that they can do it...that you'll still be there. So it's about being consistent, it's about walking with them, because sometimes they'll want you and sometimes they don't.” (Julie: Palliative Care Specialist – Photo-elicitation Interview)

I feel that Julie describes a way of being with the patient that helps the patient to cope with and manage the situation they are in, helping the patient to find meaning, to make sense of the resultant changes within their life.

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She described her work as uncomplicated, but suggested it was simply about behaving in a human way, listening and relating to other human beings. Helping the patients to make sense of their lives again seemed more of a human endeavour than a medical one. She helped patients to feel that there was "a way forward" and to feel supported while doing it. She was helping the patients to venture out whilst being supported, having confidence that the support would not be taken away. She spoke of commitment and being consistent, "walking with

Figure 6.3: Julie, photo M. A symbol of simplicity

the patient" wherever their lives took them. The patient could then develop a sense of certainty and trust in the care being given, sheltering in the supportive relationship.

### Sheltering within relationships - intimate spaces

The relationships between the therapists and the patients illustrated how deeply supportive and sheltering the hospice environment was for the patients, and how shelter could be found within these supportive and trusting relationships. Ethel described the complementary therapists as "easy to get along with", "relaxed" "kind and gentle" and her relationship with them as "reciprocal":

“Well, the therapists, all of them, are very easy to get along with [...] They are very relaxed which again, gives you that relaxation. They are very kind and gentle. I just find the relationship is sort of reciprocal really.” (Ethel: Day Care Patient - 1st interview)

There is obviously a level of trust within the relationship for Ethel to relax. She described how she felt her relationship with the therapist was different to that of her relationship with other care staff:

“Well the nursing staff are very caring and see to your physical needs. Whereas the therapists, it seems to be... just that slightly bit more personal... maybe a little bit more deeper. You build up a rapport which is, I suppose, different to the caring staff really when you think about it, I never really thought about it before in that way. But yes. That’s not to differentiate between the two because the caring staff are absolutely marvellous [...] you know. But again it is different with the therapist when I think about it. And the more you attend and the closer a relationship you tend to get. You tend to chat about things as well. Sometimes things that you wouldn’t chat to other people about, if you feel that relaxation with someone... you know? You can open up sometimes more.” (Ethel: Day Care Patient - 1st interview)

Ethel described the nursing staff as seeing to her “physical needs” which would suggest a more practical ‘doing for’ approach, whereas her relationship with the therapist was deeper and more personal which would suggest an approach more towards ‘being with’ rather than doing for. Ethel described a rapport that built up over time, different to the rapport she had with the nursing staff. The relaxation she felt with the therapist enabled her to open up and to talk about things she would not have necessarily talked about with other nursing staff. “Opening up” describes an expansion of space, as though space was created in the relationship. I suggest that because Ethel trusted the therapist and felt relaxed with her, she therefore felt *safe* enough to talk to her about personal things. In order for Ethel to feel safe and to open up there must have been a level of trust in the relationship. This provided a sense of sheltering, a protected and safe place to explore feelings. Essentially, she had a very intimate relationship and the therapy room became therefore an intimate space where Ethel experienced a deep and trusting relationship with the therapist.

Jackie, one of the therapists described how her relationship with the patients was often about talking and being with the patients as a “friend”, knowing when and when not to talk, and learning to be intuitive:

“I’m quite happy to sort of just sit and chat to some of them, almost as a friend in some ways. Which I think is still very important, I mean I can think of one chappy who has been back a fortnight, now he was discharged June 06, and he lives at home with his erm...son. [...] But his son’s forever going off [...] and leaving this poor chappy on his own. And he came back and he was really, really depressed and I said “oh how are you doing?” and he said “I’m lonely”, he said “I’m fed up and I’m lonely”. And he said...he said “it’s so nice to just come here and have a sensible conversation with somebody” and to him just sort of being able to chat to somebody, just means so much.

And some patients when they come down here, they do just want to close their eyes and sit and drift off. Others, they do want to chat and if they’ve nobody at home to chat to then it’s a very, very important part of it, and I think being able to empathise... But also sometimes [...] they’ll say “enough about me, tell me about you” and I’ll tell them [...] And they’ll say oh it’s just so nice to have some conversation that’s not about their illness [...] you learn to, not exactly be telepathic but to be very intuitive of what they want you to be like. And I think that’s all part of it. I think it’s not just like reflexology pressing the feet, it’s the whole thing the whole experience. Erm...It’s...you can’t sort off just say, it’s just the reflexology.” (Jackie: Contract Therapist – Photo-elicitation Interview)

Talking about something other than their illness was of great value to patients in Jackie’s opinion. She described essentially ways of being with patients and relating to them. There is immense value for some patients in the social contact that such caring relationships provide, and there is a sense that communicating with another caring human being whom they feel safe and familiar with, and trust provides a sheltering experience. Jackie described learning to be intuitive with the patients, describing ways of “being with” the patient as well as “doing for” the patient in terms of the reflexology. The “being with” was as important to Jackie in terms of what her therapy was about as “doing” the therapy itself. The two were inseparable as she suggested that in order for

someone to work in such a place they needed life experience and had to learn how to be with terminally ill patients. Jackie described a very human approach to the therapy that she provided, explaining that it was the “whole experience” that was important, not simply the reflexology. Jackie provided much needed human contact for the patient, creating an intimate and trusting space in which the patient could shelter and feel secure. The idea of building a trusting relationship with the patients was also evident in the narratives of other staff. Susan (staff nurse) also talked of gaining the patients’ trust, suggesting that it could take “quite a lot of time to build up a trust with the patient” enough for patients to talk about their experiences. A trusting relationship is therefore important not only in complementary therapies but within the wider sense of day care. This is evident again in the narratives of patients such as Jim who talked of being able to trust the doctors:

“But at the moment I feel like I can trust him, that I can talk to him. Now my own GP is a different kettle of fish altogether.” (Jim: Day Care Patient - 1st interview)

Jim feels that he can trust the doctor at the hospice whereas he cannot trust his own GP. To be able to trust a doctor is obviously important for Jim in order for him to feel a sense of sheltering. Patients need to be able to trust in the shelter in which they dwell.

### **A Sense of Homeliness**

Making the patients “feel at home” and the construction of homely places within the hospice was deliberate. A home is a shelter for many reasons. Home is a place of dwelling where people have a deep sense of place, a rootedness and a care for that place. There are feelings of security and safety in such places, where one feels they can be at ease and find peace. It is a place to feel normal and to do normal “everyday” things. Home is a place where one feels autonomous and in control.

### “A home from home”

Douglas described the hospice as more like a home than a house:

“Because you were aware of people knowing what you...who you were and what was wrong because you’d explained, and so on. So there was a real sense of...I suppose a sense of coming to a home, rather than to a house. [...] It seems appropriate. Because it’s err...the same feeling I’d have going into my own home.” (Douglas: Day Care Patient - 1st interview)

Douglas describes a feeling of familiarity and being known, almost as if he belongs in that place and dwells there as in his own home. There existed for Douglas a sense of familiarity and understanding between himself and the staff. He describes a sense of intimate understanding and acceptance:

“There’s a simple sense that I am here to help you, if you don’t want the help, just say so and I’ll move onto somebody else. And there’s not a sense of that being a difficult issue. [...] And that’s what I’m...when I’m talking about being at home, people at home. There’s a lot more leeway, that sort of enables people to say, if you’re happy with being left alone, I’ll leave you alone.” (Douglas: Day Care Patient - 1st interview)

Douglas again alluded to a sense of acceptance of the patients’ wishes without any sense of rejection. Thus, the patient is treated as autonomous and in control and can relax without a sense of obligation. There is a comfortableness, easiness and sense of autonomy reflective of the intimate relationships that the patients and staff share. The patient is made to feel that they can treat the hospice as their home.

In terms of the physical landscape, Douglas photographed the kitchen (Photo P9S), which for him was a symbol of domesticity. He compares it to the hospital, believing that the same room in the local hospital would be full of stainless steel. He uses the kitchen as one example of homeliness:



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Figure 6.4: Douglas, photo P9S. The kitchen in day care

"It's clean, it's domestic. And you look at that [photo P9S], and you go and look at the same room in [town hospital] I'll show you a pile of stainless steel, with as many corners as there are doors [ ... ] That was my point, is that it's bright, well lit, decent. Nice and neat. But it's homely. [ ... ] That to me doesn't say hospital [photo P9S]. In the same way as the picture of the three chairs [photo P9K: small living room] says now you've got over the shock of finding out that you've got everything in an ordinary house, and ordinary kitchens, come and sit down in an ordinary living room." (Douglas: Day Care Patient — Photo-elicitation Interview)

Douglas seems to be surprised that the hospice as a place of healthcare has "ordinary" or "homely" looking places. There is everything one would find in an ordinary house whilst still remaining "bright, well lit, decent. Nice and neat" as one would ideally expect in a healthcare place. Whilst realising that the hospice is still a healthcare place he perceives that it is constructed in a very different way, with ordinary homely things:

[ ... ] whilst a lot of the places are medically generated, they're not medically enforced, they're more homely. [ ... ] And you know you get that idea



throughout the place. It's not been put together by going for the best possible stuff, to keep the cleaners happy, to minimise the occurrence of bugs what are nasty for you. [...] what they've ended up with is a place that for me has some very positive vibes." (Douglas: Day Care Patient – Photo-elicitation Interview)

The homeliness and ordinariness of the hospice create for Douglas a very positive sense of place, despite it being “medically generated” and this generates “positive vibes” for him. These positive vibes can be associated with a positive sense of place.

Carl also used the word home describing the hospice as a “home from home”. We had been talking about the gardens and the balcony in day care that overlooked them (see figures 6.5 and 6.6). These were places in which Carl liked to “chill out” and “relax”. They were places to escape from the “hustle and bustle” of his own home, and somewhere he could access nature, admire the garden and listen to the birds:

“Mmm, that's the garden yeah [Photo P12F], that's peaceful, back to nature, you and the birds, and it's nice for a...well weather permitting, sit out there and get a bit of fresh air [...] So as I say if I feel up to it a bit of walking when I just walk around the grounds [...] You know normally what I'll do is times in the morning in between art and er just after lunch, just go and sit out in fresh air and digest me dinner and go back, and then when Sally's had her lunch we'll carry on in the art room. (Carl: Day Care Patient – Photo-elicitation Interview)

For Carl the garden is a place to find peace, which suggests he found a kind of shelter there, where he could sit or walk in the fresh air, listen to the birds and “get back to nature”. Experiencing nature in this way is known to have healing qualities, and the garden formed part of the natural landscape in which Carl and other patients could find relaxation and peace. I noticed that when I visited the hospice he would often be found in the garden. Carl had a personal routine where after lunch he would go and sit or walk in the garden to digest his dinner and then return to the art room when the art co-ordinator [Sally] had returned. Homes are full of routines that deepen our sense of place, such as getting up and cleaning our teeth, reading the morning paper over breakfast or eating a meal in the evening, prepared for us at the same time everyday by

Our loving partners (if we are lucky). The fact that Carl has his own routines at the hospice indicates a deeper sense of place, and a feeling of “at homeness”.

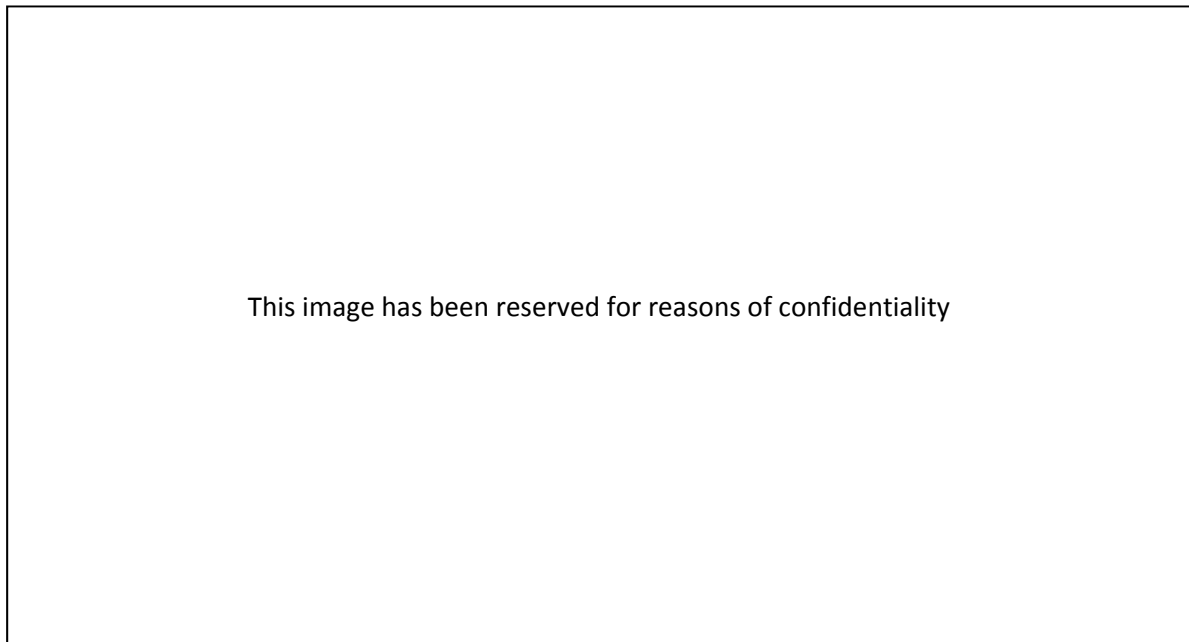


Figure 6.5: Carl, photo P12G. The balcony in day care overlooking the garden

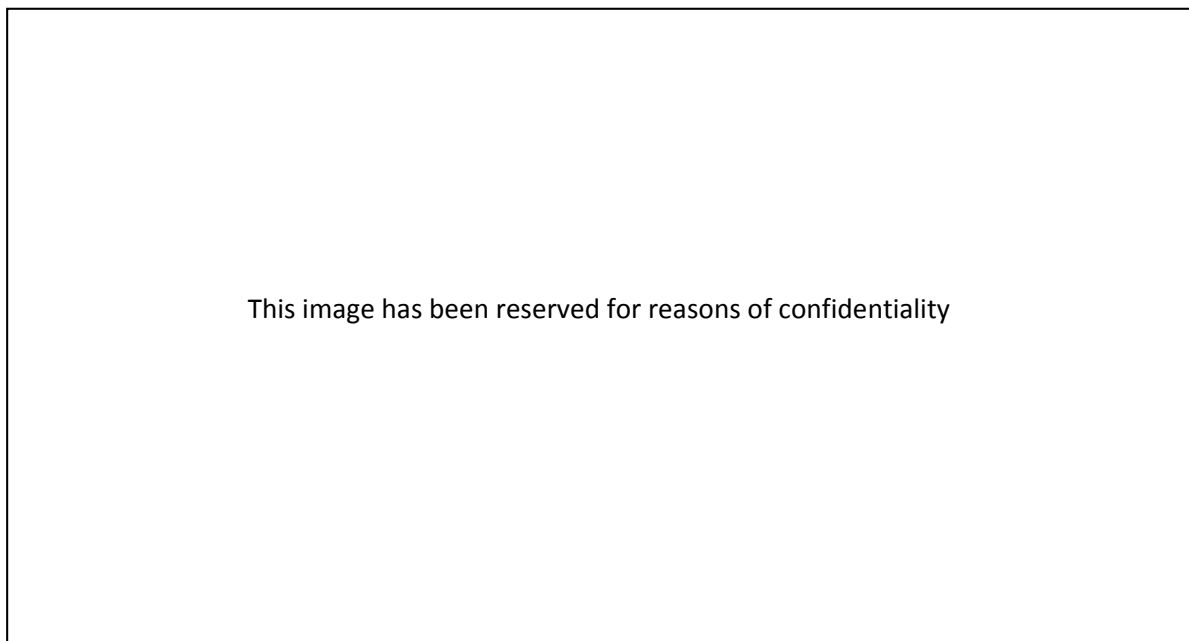


Figure 6.6: Carl, photo P12F. The gardens as viewed from the balcony in day care

Carl also mentioned that places like the balcony and the gardens gave him a sense of a “home from home”:

“Oh that's the balcony, yeah. That's another place where you can just chill out if you like. You know even now when it's raining it's still covered so you can still you know admire the garden and hear the birds and one thing or another. [...] It's peaceful and it's er I mean me granddaughter lives with me and that's a bit of hustle and bustle you know but [laughing]. It's just I feel like I'm doing what I want to do you know for a change, you know I just enjoy it. As I say, I have a garden, a big garden at home, and it's like anything else, weather permitting I'll sit out in there you know. [...] In a way it's a bit like home from home when I'm on me own you know and just chill out and relax.” (Carl: Day Care Patient – Photo-elicitation Interview)

The balcony provided physical shelter from the weather while still allowing access to the garden enabling Carl to relax while still benefiting from the natural landscape. Carl sat out in the garden in his own home as he did at the hospice and so this was a familiar thing to do and created the sense of being in “a home from home”. The hospice also provided an escape from the “hustle and bustle” he experienced at home; it was a place where Carl felt autonomous, doing what he wanted to do, relaxing in peace. It provided a shelter from those things which did not allow him to do this in his own home.

This sense of autonomy appears again in Carl's narratives. When I asked him if there were any places he felt were negative, he explained that there were none, saying that he was made to feel “at home”:

“As I say it's a nice place, it's er...they make you feel at home. And if you don't want to do it you don't need to do it, it's not like your pressurised into it you know, like if they had games or anything it's not like they say oh come on like you know in party mood you must get up and dance you know like. I don't like being pressurised like that, I like to do it at me own pace you know.” (Carl: Day Care Patient – Photo-elicitation Interview)

Part of Carl “feeling at home” was linked to the sense of choice and control he had. He was comfortable without feeling any pressure to do things. He also felt that he could do things at his own pace, which again is indicative of having a sense of control and being comfortable, as one would be in an ideal home situation.

### Caring for day care and maintaining the home

While the study progressed, the hospice underwent building development and the Day Care Unit and other areas were to be refurbished. On one occasion, day care was moved downstairs for two weeks into a single large conference room, while the area upstairs was refurbished. After two weeks, day care moved back to find that the living rooms had not been touched. This caused upset amongst the patients and staff as they felt their place had been neglected. This showed how they had become attached to the place and concerned for its maintenance and care, as one would for a place that had positive meanings and significance. Patients considered the day care unit as a ‘home from home’ as Carl had expressed, and Susan [staff nurse] suggested that things must be updated, as they would be in one’s home:

“I think the patients were really upset and I think it is awful that...there has been some work done in day care and they were moved out of day care for two weeks, and I think it’s a shame that they’ve put back old curtains up. [...] We need to maintain day care and I think it’s a shame that new things weren’t got in the time that they were out [...] a lot of the patients could not believe that the lounges hadn’t been done and updated. [...] They felt upset actually. Because like home you’ve got to maintain the update of things, and even though this is really nice and lovely it does need updating...” (Susan: Staff Nurse – Photo-elicitation Interview)

The fact that the patients were upset shows that they cared for the places in day care as they formed a part of the sheltering environment in which they received care. Susan referred to the importance of maintaining a home drawing parallels with the day care unit. There is an evident care for the place amongst both staff and patients. Derek, one

of the day care patients also voiced his concerns about the development and hoped that it would not affect the hospice:

“I’m always...you know a lot of people need help. Erm...but sometimes things grow...and they like... When you go to [city hospital] you go in the ground and you’ve to find a parking place, it’s chaos. You know. And [hospice name] will probably have to go bigger because there’s a demand. But I don’t like to see things go out of control. And I’m sure they wouldn’t. I’m sure they wouldn’t. (Derek: Day Care Patient – Photo-elicitation Interview)

When I asked Derek if he felt protective over the hospice he replied:

“A little bit yeah, mmm.” (Derek: Day Care Patient – Photo-elicitation Interview)

Derek feared that things would “go out of control” and that the hospice would lose something of its essential nature, becoming more like a medical institution. When I asked him if he felt protective of the hospice he said that he did, indicating a sense of attachment and care for the place itself. He saw the development essentially as a threat to the sheltering qualities of the hospice.

#### Placing day care – “An extension of their own home”

The placing of day care and its construction as a homely place was deliberate and reflected a desire to create was essentially an extension of the patients’ own homes. Bernadette told me that the placing of day care was considered carefully and that she wanted it to be in the old part of the house. The hospice was built around what was originally a residential building. As a healthcare place, it had undergone modern extensions over the years:

“...twelve years ago when they built the extension, where the therapy room is now [...] and all that, there was talk of putting the day care down there [...] and that corridor and all that being day care. But I actually ruled against it and

fortunately they listened to what I said because...I know that you can make a place look homely, and the atmosphere will still be there because I think that's the overall atmosphere of the hospice, but I just felt that this up here was special. And the patients felt the same as well. So, we had up here refurbished and some structural changes etc up here.” (Bernadette: Day Care Sister – Photo-elicitation Interview)

Bernadette describes a sense of rootedness and a spirit of place. She is obviously attached to the “special” place of day care as she fought to keep day care upstairs in the old part of the hospice. It was where she and the patients felt a sense of dwelling and shelter. At the time of the interview, the hospice was undergoing refurbishment and development, mostly around the in-patient areas. Day care was expected to be refurbished the following year. She described the day care unit as it stood at the time as “tatty” yet homely:

“When you go in day care at the moment now it is tatty. You know curtains aren't right, you know we've got mismatched furniture etc etc, but I wouldn't want it to be too sterile. I wouldn't want it colour co-ordinated etc I think it's nice having the odd footstool that doesn't match, you know and things like that. But I would still want to keep it as homely as possible, so that erm...I've always told patients to treat it as an extension of their own homes. That they can do what they please in their own homes. And then you know obviously...within reason. You know they can't erm...for instance one of the things in the admission policy is that if they are disruptive we won't have them which is...you know...” (Bernadette: Day Care Sister – Photo-elicitation Interview)

The “tatty-ness” Bernadette describes creates a “lived in” feeling. The mismatched curtains and furniture created a more “homely” feeling, and Bernadette intimated that if they had all matched it would create a more “sterile” place. I felt that *sterile* in this way was taken to mean cold or perhaps medical, both undesirable notions in a place that was caring for the living.

Bernadette told patients to treat the day care place as an extension of their own homes, creating a sense of continuity for the patient. She warned that disruption to this home

place was forbidden, and so the home was protected by those who would run it, creating for me a sense of the matriarchal figure who while caring for her children would not stand misbehaviour and disruption in her ideal home. It was a home place, but never the less it had rules as home places do. Not only was the hospice day care facility constructed as a home place, but its ideals were protected, ensuring it was a happy and peaceful home place.

Bernadette took a photograph of flowers on the balcony in day care. She felt it was a bit of "homeliness" for the patients, even if some of the patients lived in flats and did not have access to balconies overlooking grand gardens or flowers in their own homes. Bernadette was aware that however day care was constructed as a home place it would not be an exact reflection of the patients' homes, but she was trying to capture and generate the essence of what "homely" was in her ideal world (See figure 6.7).

The flowers were also relaxing for Bemadette and for the patients and the photograph generated further discussion about the day care unit as an extension of the patients' own homes:

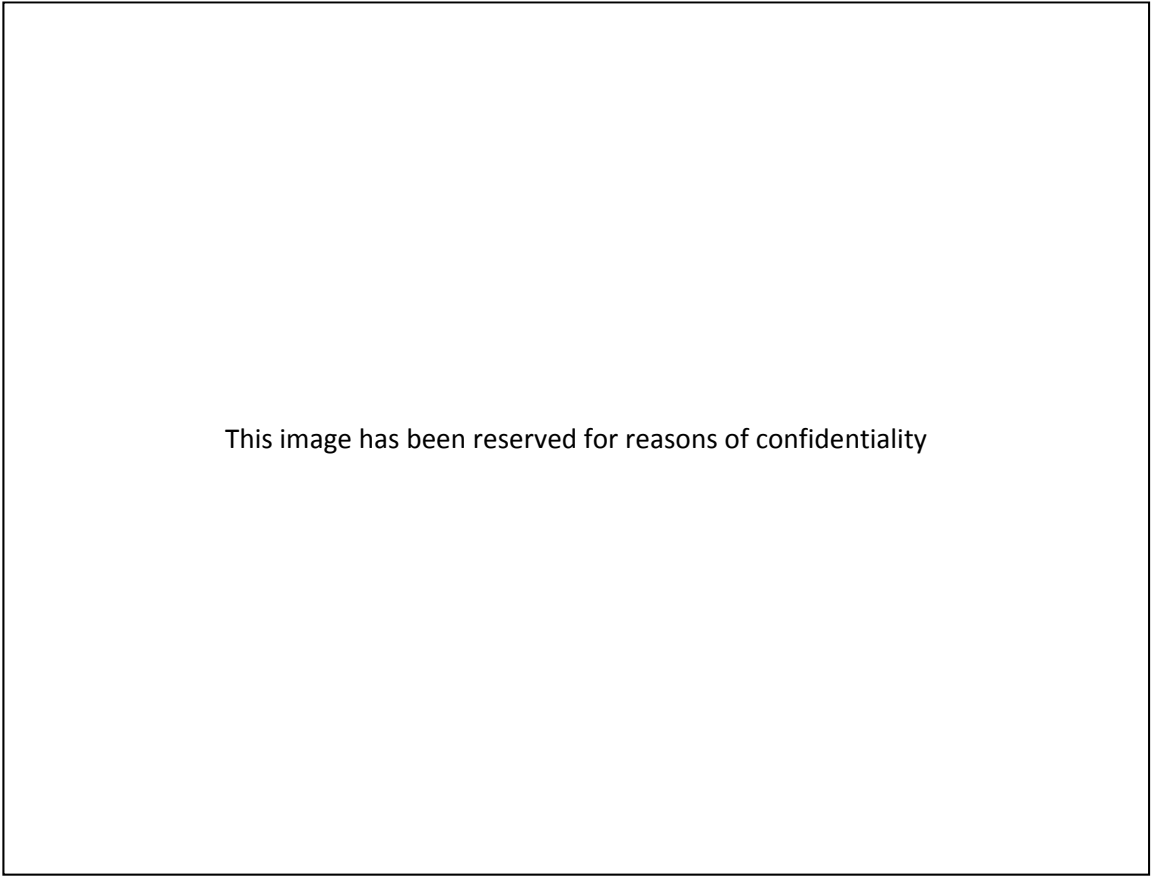


Figure 6.7: Bernadette, photo SoB. Flowers on the balcony in day care.

“And this one is of another view of the balcony on day care, and I think that the way that we’ve got all the bulbs and etc, is very relaxing. For myself and from what the patients say as well, you know it just gives it a bit of homeliness to it. That’s why it took that one, because I like flowers [...] whenever a patient first comes to day care I think it’s important to spend that initial time with them, you know making them welcome. Telling them what there is on offer so they have the choice, and also I always say to try and see day care as an extension of their own homes. So if they want to put their feet up and watch the world go by then we’re quite happy with that, you know just to treat it as just part of their home. So I think anything that goes towards that end is good. Like flowers on the balcony etc. [...] And a lot of people live in flats and they don’t see flowers really, and they might see trees, but flowers in particular I think is important. Colour.” (Bernadette: Day Care Sister – Photo-elicitation Interview)

Bernadette encouraged patients to view day care as an extension of their own homes, and yet she also acknowledged that the patients homes could have been very different from the day care unit. They may have lived in flats, without access to flowers and nature. So what she described in essence was her ideal of what a home place would be like. The hospice day care unit was somewhere that patients had choice, where they could watch the world go by and put their feet up. Regardless of how the place itself was constructed I felt that it was not just the physical attributes of the place itself that made somewhere homely, but the sense of autonomy and choice.

The physical attributes and landscape were also important to Bernadette. She changed the day care place when she took it over as Senior Sister and made it less institutionalised:

“...when I first took over day care, it’s different from what it is now [...] when I came, there were things that I needed to change. And other day cares that I visited as well to make it less institutionalised, so that you know, you have coffee tables that you can trip over, although health and safety will say it’s not what we go by the by with that [laughing]. And erm odd chairs and you know, which make it more like home, and clutter to a certain extent although we, you know you do try and make things so that it’s less risk. But I think you know, homes are full of risks anyway, if you want to treat it as an extension of their



homes there has to be some clutter and...you know.” (Bernadette: Day Care Sister – Photo-elicitation - Interview)

Bernadette was trying to make the day care facility as homely as possible and less institutional by introducing risk. Allowing patients to be exposed to the usual (but not excessive) risks of home creates a sense of autonomy, an antithesis of the controlling institutional environment where risk is minimised at all cost, such as in the hospital. Bernadette felt the added value of the coffee tables to the homelike atmosphere outweighed their potential danger as a trip hazard. The use of odd furniture and clutter extended the domestic and the inherently risky, creating a more informal space.

The patients also noted how the furniture was odd and how homely the day care unit was. Douglas photographed the day care living room to show this (see figure 6.8).

“Yes I mean there’s no...there’s three arm chairs I think it is that are pink. It doesn’t look to me as though they’re from the same suite. You look at it you’ll probably find that someone’s donated a suite. [...] The general impression I get is humble jumble of bits and bobs. [...] The key thing is, is that most of us have got houses, or lived in houses, or know people who’ve got houses, in which their living room is identical [to this one]. That to me has a warmth. A comforting feel of home about it. And it’s clean, it’s tidy, it’s neat. It’s a place where you can go and sit and enjoy the atmosphere. So the furniture in its way doesn’t interfere with the palliative care concept, if that’s the right word. You’re here to look after people and you want them to relax. So what you don’t do is give them a load of polypropylene seats. Which says things like order; sameness; industrial reasons for existing, like easy-to-clean.” (Douglas: Day Care Patient – Photo-elicitation Interview)

Douglas described a “humble jumble of bits and bobs” that is at once informal and disordered, yet does not interfere with the care provided. He describes a common sense of domesticity, a familiarity with homelike places as he suspected most people knew of living rooms that were identical to the day care one. This left him with feelings of warmth, and “a comforting feeling of home”. Because it was neat, clean and tidy, Derek was able to sit and relax within its spaces. The antithesis of this situation, would

be the institutional uniform plastic chairs so often seen in institutions like schools and hospitals, things that have no place in a home.

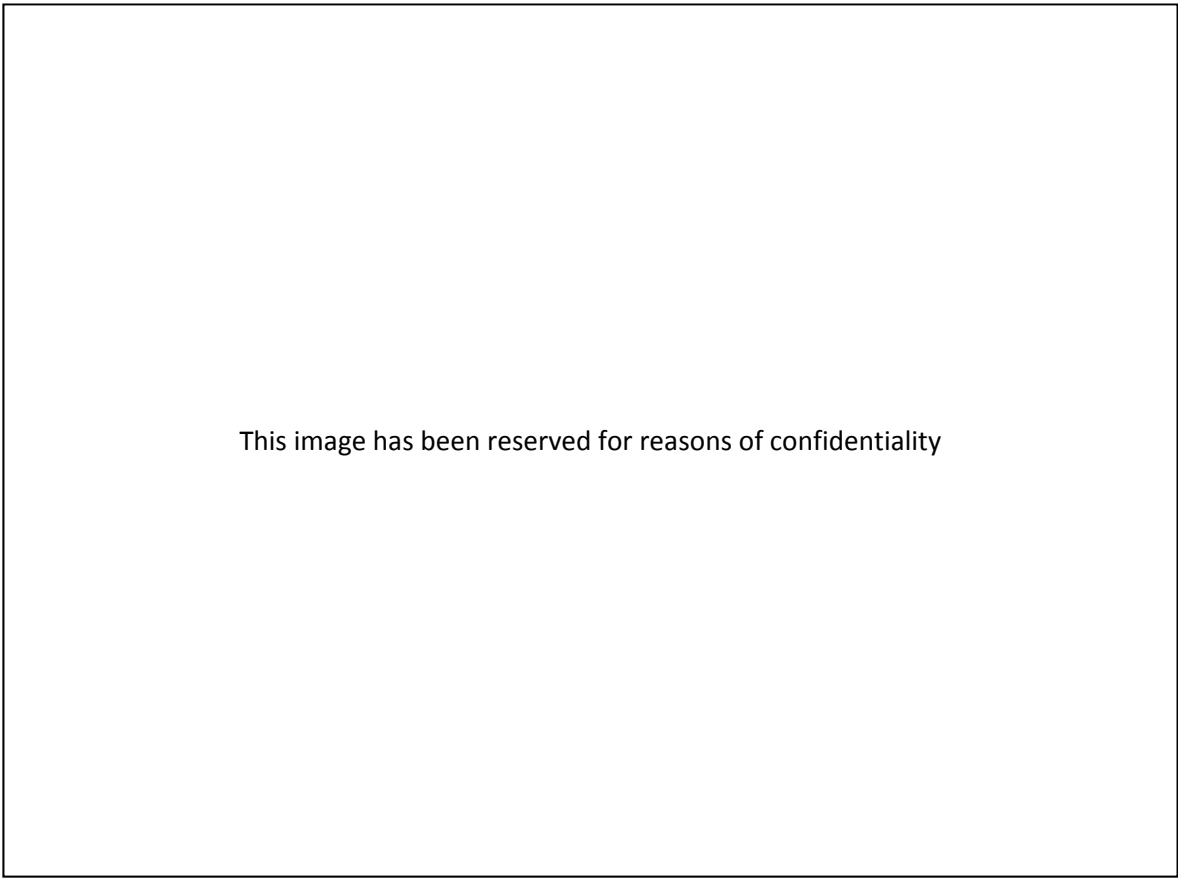


Figure 6.8: Douglas, photo P9A. The day care living room (note the various mismatched furniture, and small coffee tables.)

Susan, a staff nurse in day care also described how important it was to have a homely environment, including mismatched furniture and difficult couches:

"I think the lounge is an important aspect that we keep it looking homely. [.1 I know some patients do struggle getting up off the couch but I think it's nice to have couches in as well because it makes it more homely rather than all the chairs. I mean we have got chairs that patients do need like this one, it can come up and stuff, it's electric so we can put peoples' feet up and stuff if we need to and it can also help people to stand but there's also ordinary chairs and stuff so I think this ... I think the lounge is important and that we maintain it and make it look homely." (Susan: Staff Nurse - Photo-elicitation Interview)

In Susan's opinion, a homely environment includes some element of risk. There is a theme of potentially negative traits in the participants' narratives as they describe the living room as risky, difficult, mismatched and tatty, though essentially these are

important in the participants' eyes to the creation of a non-clinical, non-institutional and ordinary homely environment. Such traits make the place more like a real home.

Despite these risks, these were feelings of safety that patients and staff attributed to the hospice as a place of security and more particularly as a place of shelter. As Jim stated, he felt safe and relaxed in pleasant surroundings:

“But here, I feel very relaxed and I enjoy coming here. And I think everything they do is geared to that, to the enjoyment of your day. I mean I’m not saying we have parties, there’s not bloody rolls and rolls of laughter echoing through the place, but it’s pleasant it’s relaxing and you feel safe. And that to me is the most important thing. [...] That...you do feel safe you know, you feel like you can talk about owt. You feel like you’re amongst friends [...] But yes that’s the main thing here, is that you’re relaxed and it’s friendly and you feel safe.” (Jim: Day Care Patient – Photo-elicitation Interview)

Jim expressed an overall feeling of security, being in a relaxed, friendly and safe place; somewhere he could relax and enjoy himself amongst friends. There was an awareness that the staff consciously focused on creating a relaxing and safe atmosphere. The most important thing to Jim was that he was in a pleasant, relaxing and safe environment. Somewhere he could find shelter. Jim felt he could be about anything and that he was amongst friends. This adds to a feeling of being at home. There is a sense of rootedness in this experience as Jim later described jokingly that he would come everyday if he could do:

“I miss it when I don’t come. In fact if I could I’d come everyday, and that’s the way I feel about it, I think it’s great.” (Jim: Day Care Patient – Photo-elicitation Interview)

In missing day care when he was not there, Jim shows that he has an attachment and affection for the place. He has a sense of rootedness belying a strong sense of place. Sheila the hairdresser also felt that the hospice was a “safe home” for the patients. At the end of her interview I had asked her if there was anything she would like to add, she then voiced her concerns over plans to open the hairdressing salon to the public. I

mentioned that I felt that such plans could be a threat to the idea of the hospice as a “safe place” for the patients and she agreed saying:

“...this is a safe home for them absolutely yes it is. [...] You know I...sort of dealing with the public, I’ve got nothing against the public and that, but you know what I mean, I want to work with the patients. They’re the ones who take priority in my eyes. And like you say this is a safe home, it’s a safe environment when they come in here. They feel safe and secure and it’s lovely for them to be like that, you know for them to have that security. You know, take that away from them and I think your stealing from them you know.”

(Sheila: Hairdresser - interview)

Sheila called the hospice a “safe home” and a “safe environment” where the patients felt safe and secure, implying that they did not always have this outside the hospice. She felt that the plans for opening up the hairdressing salon to the public would be “stealing” away that sense of safety from the patients, and I feel this would impact their sheltering experience. This again shows a concern for place and a sense of attachment and rootedness. It is concern also for the patients’ “safe home”, and I would suggest that Sheila does not see the patients separately from the place in this instance as to affect one would affect the other. The patient’s sense of shelter is under threat if security and privacy are compromised by plans to change this “homely” environment by opening it up to the public.

### **Complementary Therapies: Sheltering/protecting/relieving**

Creating a sense of safety is important for any place that would be a shelter or a homelike place. In the previous chapter, I described how patients often had a fear of crossing over the threshold to the hospice. Complementary therapy was one way of helping patients to overcome this barrier by creating a sense of safety.

### CT as an invitation to shelter

Staff and therapists felt that one of the most valuable effects of complementary therapy was that it helped the patients to relax, helping them to adjust to unfamiliar surroundings that were at the time loaded with negative meaning for the patients. CT helped to create a more positive sense of place for the patients. Julie, one of the doctors, suggested it was a way of helping patients to “feel safe”, when their misinterpretations of what hospice is about had made it difficult for them to accept attending:

“It makes them difficult to accepting patient stays, it makes it difficult for them to attend day care [...] So, it’s a way of breaking the barriers down, of introducing them to the idea that the hospice has got an awful lot of positive things to do, and that it is not about dying. So it can be very useful, that the small service we have available can be very useful for just opening the door, letting someone come into the hospice environment and feel safe and then know that they’re heading home again.” (Julie: Palliative care specialist – Photo-elicitation Interview)

Julie talked about CT as “opening the door” for the patients and “letting” them come into the hospice, to experience positive things like CT that were not about dying. Within Julie’s explanation, there was a sense that the patients had control over the situation, that the door was opened for patients to come in and try CT, in the knowledge and assurance that they were going home again afterwards, without being trapped into staying. This openness I felt helped to create a sense of safety and trust.

The physical placing of the CT room itself was also chosen to protect people who came for CT, but who were fearful of the hospice and the meanings they had attributed to it. This came to light when I asked how Jackie felt about the complementary therapy room moving from its location downstairs and away from day care and the inpatient wards, to upstairs in the day care unit:

“I think one of the reasons that this room was...when this extension was built which I think is ten years now, they decided that they would like us downstairs

and away from the wards and in some ways away from day care... Because particularly as I mentioned before, if we get people who are reluctant to accept a place in day care but will come for therapy, they're not actually having to go anywhere where they can sort of see other patients. So it's protecting them from that, there's just sort of a corridor and hopefully a relatively pleasant room [...] and then they might take another step to accept day care.

Now with us moving upstairs any outpatients are going to have to come through a bit of day care to get to the room. Now whether that's going to have an adverse affect or not, I don't know, it probably won't really but that was one of the reasons this room was put down here in the first place. And also, for it to be quiet." (Jackie: Contract Therapist – Photo-elicitation interview)

By placing the CT room in a quiet location away from day care and the in-patient wards, it was hoped that people visiting for therapies would not have to encounter patients. It was felt that this might have deterred them from coming. Visiting outpatients were in effect being protected from encounters with in-patients who may have had visible signs of deterioration that could have shocked or upset them. It was hoped that CT would provide a stepping stone, to familiarise patients with the surroundings and the positive experiences of CT. However, with the move upstairs to day care, Jackie was uncertain that the protective element would be retained. However, day care patients were often considered "well patients", though physical signs of cancer could still be obvious, particularly as patients deteriorated over time. Cathy [staff nurse] also commented on the old CT room as being sheltered, though more in terms of its aspect:

"I like it because it's big and...it's quiet in there so that... and when you go in it always makes me feel...calm. I don't know why. I think it's the smell of the oils. And it's just a little bit, sort of... It's not a sunny room, it's quite sort of sheltered really, 'round there isn't it. But I must admit, I do like that room." (Cathy: Staff Nurse – Photo-elicitation Interview)

Cathy's positive sense of place is obvious as she described the qualities of the room and how it smelt; it's quietness and how it calmed her. She referred to the position of the

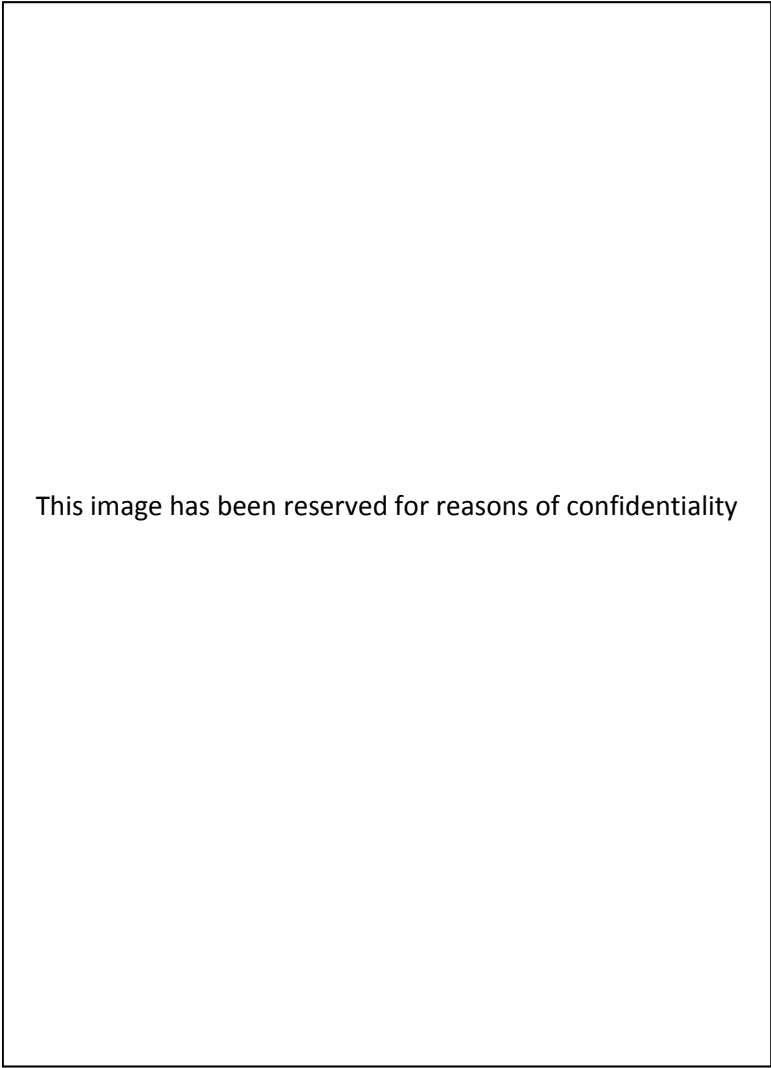
room as “sheltered”. I feel that that the sheltered aspect of the room reflected also the nature of what happened within the room in terms of the care provided there.

### CT room as a homely environment

Therapists shared the view of the staff, that the hospice environment should be as non-medicalised as possible and closer to an extension of the patient’s home. This was evident in the way that the old complementary therapy room was purposefully constructed to create a sheltered, non-medicalised, and homely environment. Jane, a volunteer therapist photographed both the physiotherapy room (see figure 6.9) and the CT room (see figure 6.11) to attempt to convey how she felt about both, describing one as therapeutic and one as non-therapeutic:

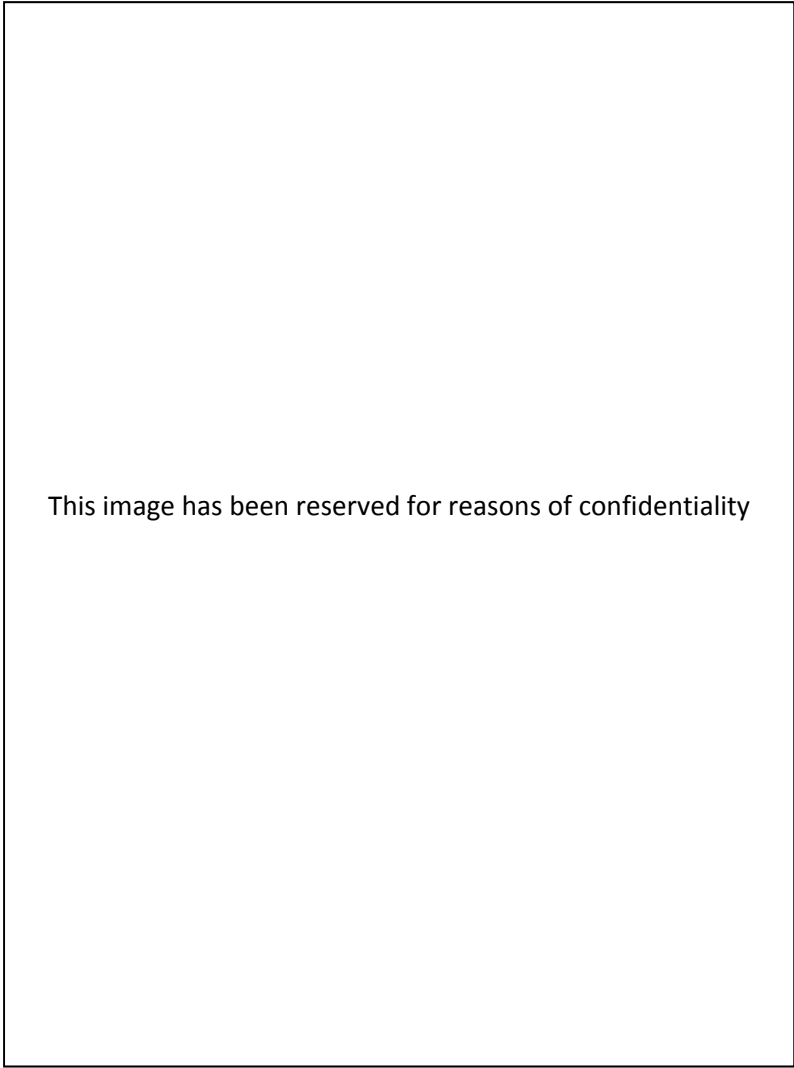
“This isn’t one of my therapeutic spaces [physiotherapy room: photograph T4I]. This is my non-therapeutic space. [...] Don’t know. It just feels...it isn’t one of my spaces. [...] If I was there, fit and well, say apart from having a broken arm and I was being treated for a broken arm, I wouldn’t care. But if I was wanting to be transported into a relaxed state I don’t think it does...it’s not a relaxing place to me. [...] The lighting, the equipment, the beds, they’re very hard, when you sit on them. It’s just...they made an attempt by having the covers on but...it’s a minimal attempt. But you know it’s the posters, it’s the clutter on the ceiling etc [...] The computer sat in the corner. It feels very medical, very technical, and that’s what it is you know, it’s a treatment area for people.” (Jane: Volunteer therapist – Photo-elicitation Interview)

Jane described the physiotherapy room as “harsh” “very technical”, “medical” and “non-therapeutic”. The objects associated with medical technology did not create feelings of relaxation for her. As a place to be transported into a relaxed state, the physiotherapy room did not create a positive sense of place for her. However, it is not used for that purpose. Although she described the CT room as homely, some objects such as the reflexology chart seemed out of place to her:



This image has been reserved for reasons of confidentiality

Figure 6.10: Jane, photo T4K. the reflexology chart, the picture of flowers and fruit and the light box.



This image has been reserved for reasons of confidentiality

Figure 6.9: Jane, photo T4I. The physiotherapy room (Jane's "non therapeutic space")



This image has been reserved for reasons of confidentiality

Figure 6.11: Jane, photo T4L. The complementary therapy room

"Erm, just the difference, although they've got the reflexology chart on the wall, they've also got an old picture [flowers and a fruit bowl], I don't think! would choose to have a reflexology chart on the wall. I would prefer to have it just as a normal, relaxed room.

The difference between picture land L, they've both got desks in it but one's a clear desk space with flowers and a music centre on compared to a computer an typewriter etc, fax machine. It's just the difference, the fact as well is that the therapy room has got curtains and the physiotherapy room doesn't. It's just the difference between making it look like a normal room and a treatment room. [ ... ] Because it is a normal thing of daily living to be touched. [ ... ] it is just to make it as normal as possible.[ ... ] More homely, less clinical and erm, softer and gentler. [ ... ] You can just leave the blinds open, it just ... er pull the curtains slightly. Just as you would at home. [ ... ] It just helps you to relax more. This is a relaxation room. That's a treatment room." (Jane: Volunteer therapist —Photo-elicitation Interview)

The reflexology chart seemed incongruous to the feeling of what she considered “normal” and “relaxed” to Jane (see figure 6.10). It has implications associated with disease and is symbolic of something being out of place in terms of the patients’ health. It hints that something is wrong, as do the “diagrammatics” charts in the physiotherapy room. This was more pronounced as it stood in contrast to the picture of flowers and a fruit bowl, which is more suggestive of something that would be found in a home. The presence of elements that may be found in the home such as flowers and music, stand in contrast to the technical and medical objects of the physiotherapy room. Even the presence of curtains suggests a more homely feel. Jane suggests that being touched is a normal thing of daily living, in the sense that physical contact is part of a basic human desire, and a more “normal” or “homely” environment would reinforce such values. Whereas the physiotherapy room had lights that were harsh and perhaps as Jane suggests more suited to the examination of an objectified human body. As a place, the therapy room seemed to be designed as a more homely, relaxing, normal and less clinical environment, where one could shelter in more familiar, or at least less clinical surroundings.

Contract therapist Jackie described efforts to make the CT room less clinical, using artefacts such as a quilt made by the volunteers to create a “peaceful atmosphere”:

“ they’re made by volunteers and there’s an awful lot of work and care gone into them. And I think it does...having things like that around it does just add to the...the peace and the tranquillity of the room, which I think is important [...] It’s just that we’re aiming for a peaceful attitude...atmosphere rather than a clinical atmosphere I would say [...] we try to keep it as non-clinical looking as we can...in some ways because I think people feel more relaxed. In a more homely environment if you like.” (Jackie: Contract Therapist – Photo-elicitation Interview)

The quilt was used as a cover for the treatment couch and to keep patients warm. It was symbolic of the efforts, care and good will of volunteers and whilst also being an object likely to be found in the home. Thus, it added to the peace and tranquillity of the room, creating a space that was “more homely” rather than clinical.

Music also played a big part in the creation of a relaxed and sheltering environment, providing ambience. It was commented on by a lot of the patients and was commonly associated with a relaxing atmosphere in the CT room:

“Very good, very good. This is my third treatment of eight. And it’s very... she has good music down there. Have you heard it? [laughing] [...] It’s not what you’d have on at home I think but in here it’s really relaxing. [...] we were talking about it today and she gets it through a Russian agency or something. Yes, on the internet. But this one was a particularly relaxing mood, you know.” (Bill: Day Care Patient - 1st interview)

Bill’s description of the music as something he would not listen to at home, but something that is relaxing during CT, suggests that the music is part of the place and the treatment itself. The music is also a big part of the therapy for Bill as he is sceptical about the effects of the manipulation and oils, he does however enjoy the music. Carl called the music a therapy in itself:

“And she had some nice background music on. That were therapy in itself, relaxing you know? [...] Semi-classical stuff, not the opera you know but er...I forget who she said it was, but it was er, some pipes, pipes of pan type thing you know [...] and very relaxing.” (Carl: Day Care Patient - 1st interview)

The CT room was constructed as a less clinical, relaxing and sheltering place through the use of objects, sounds and nature. The therapies used within the CT room also provided a sense of sheltering for the patients.

### CT as a shelter

I felt that CT was a sheltering experience for the patients because of its therapeutic intent. It was predominantly used to relax the patients, to provide a space in which they could either discuss their problems in a safe and supportive environment, or to forget them for a while. Jackie described patients as being able to “leave their problems at the door”:

“People can come in very, very wound up. I had a lady in this afternoon, and she said ‘oh I just feel like you’ve taken all the worries of the world off my shoulders’, certainly while she’s in this room. [...] So hopefully they can almost leave their problems at the door, and come in and feel indulged. And hopefully go back upstairs you know, in a better frame of mind, I wouldn’t like to say how long it lasts, it might only last while they’re in here. It might last the rest of that day.” (Jackie: Contract Therapist – Photo-elicitation Interview)

The patient was sheltered from the experience of having the “worries of the world” on her shoulders, at least while she was in the room. The therapy room was a place in which the patient was protected from anxieties and problems, somewhere she could feel “indulged”, taking pleasure in being relieved from the stresses and burdens of her illness. This helped the patient to then venture out of that place in a better frame of mind, to go back to the day care unit where she could enjoy a better quality of life for however long the effects lasted. I asked Jackie if she had any indication of how long the effects lasted. Though she could not be sure, she told me about an earlier research project at the hospice:

“It’s quite difficult to actually remember and we once did try to do a bit of research project [...] but it was too...analytical. They don’t want to have to think back and think “well how many hours did I feel like that” that’s really not what they want to do and I think by asking them too many questions it can put stress on them. Because they’re just having to think too much and what they want to do is just let go, and just forget all the why’s and the wherefores and just sort of let somebody else take responsibility for a little while, so it is quite hard. [...] And I say to some people it’s almost like if you can get a really deep sense of relaxation... It’s first of all reminding your body what its like to feel relaxed like that, because when you’re very poorly you’ll feel very tense nearly all the time. And you forget what its like to just feel normal and not have those butterflies in your tummy so...” (Jackie: Contract Therapist – Photo-elicitation Interview)

I felt that Jackie’s statement about taking responsibility for the patients for a while was very indicative of a protective or sheltering intention. Jackie was providing a sheltering

environment in which the patients could relax, “let go, and just forget all the whys and wherefores”. In her opinion, the anxieties and worries that patients felt were not part of what they would consider feeling normal, and Jackie’s aim was to remind the patient’s body how to “feel normal” again.

Patients often spoke of how relaxed they were by the CT treatments regardless of what treatment they had. Derek spoke of his initial uncertainty about the reflexology and how talking to the therapist helped him to feel more laid back. He found reflexology relaxing, stating that the longer it continued the more relaxed he became:

“...anyway you know lie back and it’s really relaxing and the more it goes on, the more relaxed you become [...] I were iffy at first, but of course when you get sat down and you get talking to the person, and then they start, you’re just totally laid back, and relaxed, and it was nice, very relaxing.” (Derek – Day Care Patient - 1st interview)

Jim related to me how the reflexology relaxed him so much he fell asleep:

“Oh I love it. Absolutely...I fell asleep this morning it was so relaxing, oh it really was. I was out of it.” (Jim: Day Care Patient – Photo-elicitation Interview)

There was no uncertainty that Jim felt very positively about CT. Douglas also found great benefit in terms of the relaxation that CT provided, but he suggested that it added to the wider experience of the hospice and a feeling of being cared for in a safe and relaxing environment, where care was provided without condition or obvious effort:

“At the moment what I’ve been involved with directly is the massage. That has been a boon in relaxing me and unwinding me [...] I mean you’re talking about someone who’s come out afterwards...feeling as though someone has been able to talk to you through their hands. And you’re able to relax away those areas of tension. [...]

But it’s that sense of relaxation, and unwinding. And even if it only lasts half an hour a treatment and an hour or two of benefit, that’s two hours of benefit

that I wouldn't have had before. And I always had this sense that each time I go, and have another massage, that the first one builds on the second one, builds on the third one builds on the fourth one.

It's a little bit like trying to get the maximum out of [hospice] facilities is to say ok, I can sit here and enjoy a massage and get the maximum out of it, but what can I do to retain the feeling of good will and also the feeling of benefit."

(Douglas – Day Care Patient - 1st interview)

The feelings of relaxation may have been stronger in Douglas in particular as he suffered from Parkinson's disease as well as having cancer. He described the massage as someone "talking" to him "through their hands", which gives a sense of a more intimate embodied relationship, where the body takes part in a conversation of sorts. In situations, such as Douglas', where the diseased physical body has become more objectified and separate from the mind, massage in this case seemed to reconnect the physical body through what I would term a physical conversation. I felt that Douglas was describing a sense of embodied care, where care was *felt* both physically and mentally, or holistically, in an intimate and very human way.

Douglas valued the feelings of relaxation and unwinding, even if they only lasted for a short while because it was a benefit he would not have otherwise have had. Any sense of relief seemed important, no matter how small or for how long. He also felt that the effects were cumulative, one building on the other in a beneficial manner. He then tried to retain this benefit and "feeling of good will". This feeling of good will is a very humanistic concept and a strong indicator of the humanistic value driven care that CT and hospice care both provided. Jeffrey also talked of a similar feeling of good will as he stated: "I felt as if she [the therapist] was trying to make me feel well and strong, that sort of thing." Jeffrey describes a therapeutic intention, a feeling of good will and being cared for.

Derek also described a belief or 'faith' in complementary therapies, saying "I've always been a bit of a believer, in complementary therapies, and medicines." I do not think that he felt massage or reflexology would cure him, but he took shelter within the belief that it was doing him good in some positive way. He then told me of a magazine article that

described how a woman was cured of stomach cancer by drinking large amounts of carrot juice, and that there was now research in this area. His prior “involvement” in CT and his faith in such evidence adds to the sense of sheltering within hope:

“It really when you read it, it sounds like a miracle [...] But it’s a true story. So now, I’m drinking carrot juice (smiling) [...] So I’ve always been very involved, yeah. And I’ve had a lot of friends who’ve been very involved.”  
(Derek – Day Care Patient - 1st interview)

I feel that Derek was sheltering within hope and a belief that dietary supplements like carrot juice may do him good - that the chance was enough to justify trying it. In the second interview, I asked Derek if his opinion of CT at the hospice had changed or not:

“I’ve always been this way. You know people can be sceptical of things like...but I’m not [...] anything therapeutic thing like that, I would always try it [...] Yeah. I’ve always been that sort of a person [...] Yeah, but you know you can meet sceptical people, oh no I’m not bothering, well that’s just them isn’t it.” (Derek: Day Care Patient – Photo-elicitation Interview)

There is a definite sense of hope and faith, that “anything therapeutic” may increase his chances of survival, and therefore is worth trying. I feel that complementary therapies at the hospice certainly added to a sense of sheltering for Derek, in the hope that it may do some good.

### CT as part and parcel of sheltering

Complementary therapies were often described by patients, staff and therapists as “part and parcel” or “part of the package” of care. This suggests that it was an integral part of the landscape of care for day care patients and staff:

“I see it as an integral part of that package...very much an integral part erm for the... supporting all that the ethos of the hospice is there to do is to give our patients the best quality of life that they can have, at this time of their life. And

I see it simply as that, as part of that package” (Lucy: Contract Therapist – Photo-elicitation Interview)

As a therapist, Lucy feels that the benefits and values of CT are reflected in the ethos of the hospice and integrated into the landscape of care. Jane, a volunteer therapist, considered complementary therapies to be far more than restricted to massage. She believed that when nurses talked to patients, when they hugged patients or held their hand, then this was complementary therapies:

“So complementary therapies is much wider than massage, it’s the whole care package.” (Jane: Volunteer Therapist – Photo-elicitation Interview)

Derek also spoke of complementary therapies as part of a wider package of care. Derek suggested that it is just part of his day:

“I think it’s just part, particularly with this day care, it’s part and parcel of that day. And when you come in, in the morning they will just ask you, you know, if you want to have this done today or that done, you don’t have to do it you know, but they will say yes, will do. And it’s just part and parcel of what’s happening that day and I just like being part of it.” (Derek: Day Care Patient – Photo-elicitation Interview)

The fact that CT does not stand out as different in any obvious sense to Derek from other activities and therapies available shows, that in the context of the hospice it is an equally valued part of the whole care package, complementing other modes of care. CT essentially is part of the sheltering experience, a part of the fabric of the sheltering structure, as are other elements of care.

As noted earlier, complementary therapies at the hospice are seen to incorporate much more than massage and reflexology. The context of the hospice certainly had an impact on how complementary therapies are perceived when juxtaposed with other elements of care. This became more obvious when patients and staff began to talk of hairdressing as CT:



“I think that the other complementary therapy, and I class this, is the hairdressing. I think that’s an important aspect we offer particularly for the ladies, if they’ve not had their hair done in a long time it gives them a sense of well-being [...] It’s important to them. It helps with their body image particularly if it’s changed a lot due to the medication and stuff or weight loss.”

(Susan: Staff Nurse – Photo-elicitation Interview)

Susan classed hairdressing as a complementary therapy because it helped with body image and created a sense of well-being, much like Cathy’s comments in the previous chapter regarding re-creating a sense of self. Like CT massage there is also a physical conversation of sorts as mentioned earlier in regards to Douglas’s comments about massage. As the hairdresser massages shampoo into the scalp, the hair is touched, the face is touched, there is physical contact:

“Yes, yeah. Because whilst you’re having complementary therapy, whilst your having your head massaged, you know as I do Indian head massage as well, so it is part of the complementary therapy.” (Jane: Volunteer Therapist – Photo-elicitation Interview)

Jane equated the massaging action of washing hair with an Indian Head Massage, a form of CT. So both CT massage and hairdressing can be delivered through an embodied sense of care. A haircut can also transform a person’s appearance, often for the better, particularly if they are ill:

“[...] he’d got hair down here, a beard and he went home sort of beardless and his hair all cut and his...his face...he was a different man, because he could see, ‘that was how I used to look you know?’” (Lucy: Contract Therapist – Photo-elicitation Interview)

Lucy was describing how some of the gentlemen also benefit from the hairdressing service. The man’s image was transformed and there was a sense of transforming this man’s sense of self as his image returned to how he used to look, prior to his illness. It also helps the patient to look normal, as often people will maintain a certain personal appearance, yet when illness takes over this appearance can become severely changed. The hairdresser enables patients to “look normal” as Jane explained:

“Carers in particular are just so pleased that their relative looks normal and you know, looks pretty and beautiful.” (Jane: Volunteer Therapist – Photo-elicitation Interview)

When I asked Jane if she considered hairdressing as a complementary therapy she replied that she did, because it produced feelings of well-being:

“And if you feel clean, cosseted, pampered, it boosts you’re spirit and that’s you know a big part of a placebo effect. You know, people who’ve had their hair done, tend not to in my opinion be as in desperate need of having a pill.”  
(Jane: Volunteer Therapist – Photo-elicitation Interview)

Jane suggested hairdressing may help to reduce the need for pharmaceutical interventions, which implies there were therapeutic effects produced by hairdressing, which could reduce pain via a placebo effect and an overall sense of well being. Because of the context in which it was set, the nature of the provision was changed and its effects were more directly related to the health of the patient. This became more obvious when I interviewed Sheila, the hairdresser:

“And it’s very, very different because you can’t sort of talk to the patients here like, ‘have you booked your holidays?’ Or you know, ‘what were you doing at the weekend, did you go anywhere special?’ You know it’s just a different...a different ball game altogether [...] It’s not the run of the mill things that you can talk about. Because...and obviously it’s not always me that’s doing the talking, it’s the listening aspect when you’re dealing with the patients. [...] and you’re sort of an earpiece for them really, because often they just want to offload and they’ll talk about everything! [...] They’ll talk about their home environment; they’ll talk about their illness. They’ll talk about the problems they have with families.” (Sheila: Hairdresser: interview)

Sheila perceived her role as hairdresser at the hospice as different to her role as hairdresser in the local town where she still worked part-time. She could not pose the same questions to patients as she did to her high-street clients. She suggested the conversations within the hospice salon were different and she acted more as a

counsellor to the patients, providing a listening ear in which they could confide. As a non-medical figure, she also found that patients confided in her things they would not tell the healthcare staff or their own families:

“I think sometimes they won’t discuss things with say the nursing staff. [...] I think sometimes the nursing staff are too close, and also their families are too close. And coming in here I’m not attached to them in any way [...] and I feel that they can just offload and tell you anything. [...] If they want you to see anything they’re quite brave about saying have a look at this and you know I’ve had this done and so on you know [...] They’re treated as a human being and it’s normal for them to come into a salon isn’t it, and be pampered and things like that.” (Sheila: Hairdresser: interview)

Patients saw Sheila as a part of their normal everyday world. They treated her as an independent confidant, trusting her and showing her the results of surgery and treatments that may have disfigured them in some way. Her work was essentially to do with image management and the maintenance of the patients’ public and self-image. The salon was somewhere patients could be treated normally, as normal people despite their physical appearance or disfigurement. They could shelter in the everydayness and normality of doing something they could perhaps not do outside the hospice anymore. In feeling and looking more normal, the patients self-image was restored and this also represents a sheltering experience as they could shelter within feelings of security produced by a more ‘normal’ or healthier looking image of themselves.

When I told Sheila that I got the impression that a lot of people classed hairdressing at the hospice as complementary therapy she tentatively agreed with this:

“I think I do agree with it really. Because it’s all about making the patient feel good about themselves. And I think that that’s what the complementary therapists do. [...] it’s all part and parcel of making them feel nice about themselves. And that’s where I think it fits in to being a complementary...in a way a complementary therapy. But it’s not medical is it? It’s not a medical thing. Would you class aromatherapy as a medical? ...it’s hard really to put it into a category like that.” (Sheila: Hairdresser: interview)

Anything that makes the patient feel good about themselves seems to be the defining trait of complementary therapies for Sheila. However, hairdressing does not have a historical basis in healing. She questioned this, as though fundamentally she was not sure herself. However, in the context of the hospice, Sheila's hairdressing is significantly different in that she acts as a kind of counsellor or confidant to people who wish to discuss their illness in a safe and secure environment. This adds to feelings of sheltering. She also helps patients to manage and come to terms with their self-image, helping them to feel normal despite the effects of their illness and treatment, in the same way that complementary therapies were seen to help patients to feel normal and to regain a sense of wholeness again.

I feel that interpretations of what constitutes CT at the hospice are formed mostly under the influence and ethos of the hospice itself. Each element of care and each person uses their particular skills to help patients to feel normal, to encourage a sense of well being, and to mediate feelings of fear and anxiety. Anything that helps towards this end is seen to be both therapeutic and complementary to the goal of helping patients to achieve a better quality of life.

## **Conclusion**

In this chapter, I have explored how hospice day care provided sheltering experiences for the patients. The patients had a confidence and faith in the care provided, certain that they would be cared for not in the best possible way. A community spirit was evident in places like the dining room, which added to a sense of support and belonging, and provided a way of coping for the patients. Relationships between patients and the staff and therapists were often characterised by trust, friendliness, intimacy and easiness.

The physical landscape was designed to create feelings of homeliness. Rooms like the living room, kitchen and the dining room created a sense of being "at home" for the patients. Patients had a sense of autonomy and felt comfortable and at ease within these places. The social landscape was also characterised by notions of easiness and trust. The way in which staff, therapists and patients related to each other also created a sense

of security and homeliness. A sense of safety was also evident amongst the patients, further contributing to feelings of being sheltered within a secure and supportive environment. The natural landscape of the gardens also provided a sheltering environment where patients could wander and sit, further creating feelings of at homeness. There was an evident sense of care for the place itself, as shown in the concern over the refurbishments. The home is our foremost shelter. It is our first protection from all that is threatening and uncertain.

Complementary therapies at the hospice provided one way of helping patients to accept a place at the hospice if they were particularly anxious about attending. It helped to foster a more positive sense of place, helping patients to feel relaxed and cared for. CT also provided a sense of embodied care as patients began to experience a deep physical relaxation whilst experiencing a positive healing intention that strengthened feelings of being cared for. CT's aim was to help patients to leave all their troubles at the door and to forget their stresses and anxieties for a short period. CT was in a sense a shelter, as was the hospice and the places of care within it. The boundaries of what constituted CT at the hospice also became blurred as the context shifted the focus of other elements of care such as hairdressing towards a more caring and therapeutic practice.

## CHAPTER 7

### VENTURING

“Human beings require both space and place. Human lives are a dialectical movement between shelter and venture, attachment and freedom.” Tuan (1977 p.54)

Venturing is a shortening of the word “adventure”. The Latin meaning of the word *adventurus* means “about to happen” from *advenire* to “arrive”. There is a sense of foreboding, of risk, and of new discovery and understanding. There is also the notion of movement, towards an event.

There is always risk in life, whatever we do we risk ourselves, we risk disappointment, pain, our health, our happiness, our security, our love, our friendships, money, time etc. To live is to always risk something of ourselves. We can shelter for a while, protected by people and places, but to live we must risk venturing outwards from that shelter.

Venturing also implies discovering, finding meaning. It infers that the person who is venturing has made a choice, a personal decision. We cannot venture under duress, as then we would not be authentically open to exploration. If we are not open in our minds, how can we see to explore? We must have a sense of control, to determine for ourselves which path we take. In the quote at the beginning of this chapter Tuan (1977) implies that human beings naturally move between sheltering and venturing, and that while sheltering fosters attachment, venturing necessitates freedom.

Once patients had found shelter, day care provided them with a way forward, by providing positive opportunities to explore their disease, and to have control and take part in a range of activities and therapies aimed at improving their quality of life. These opportunities gave the patients a chance to venture through physical, social and

psychological landscapes. It enabled them to carry on with their illness journey, to live a fuller life, learning new skills and accessing new experiences of healthcare. In venturing, there is a sense of movement outwards, towards the discovery of new meanings and values, though these meanings were not always positive. What was evident in the data was that in venturing the patients discovered physical, symbolic and psychological boundaries or thresholds they would not cross. These thresholds defined the limits of their venturing and some places remained un-explored for fear of what they would reveal, further strengthening the day care as a shelter.

### **The opportunity to live**

When speaking of their own GPs or receiving treatment in hospitals, patients often spoke of being left in ignorance in regards to their disease, of doctors having little time for them and having neither the interest or knowledge of their situation. While this may not always be the case, the hospice provided a place in which time and greater expertise could be found as Bernadette [day care sister] explained:

“But normally they see the same doctor each time they come and there’s TIME. They’re not rushed in and out. You know there’s time to see the doctor and talk to him about things.” (Bernadette: Day Care Sister – Photo-elicitation Interview)

“Time. I think that’s the biggest thing of all that we can offer the patients, is time; Time for them to...to explore their own disease and where they are with it.” (Bernadette: Day Care Sister – Photo-elicitation Interview)

In the two quotes above Bernadette describes a sheltering experience where patients essentially had time, and a consistent point of support, thus allowing them to venture and explore their disease, enough to find “where they are with it” – a sense of orientation and location. Patients had a chance to locate themselves and regain a sense of themselves in terms of their disease and their new status as ‘terminally ill person’. Whereas before they may have been “left up in the air” as Jim pointed out:

“I didn’t realise that there were such a thing as day care and things like that. Now when they said ‘day care’, I wondered what that entailed. And I mean as I say having been left up in the air since [date] as to how my illness was doing, at [city hospital] I thought well I’m going to take this opportunity to go and ask somebody how I’m doing. But of course there’s...people can’t come out and say straight to you like you know that it’s good, it’s bad, it’s this that and the other. Everybody is taken in different ways with it like you know. That was something else I didn’t realise, I thought these things run much of a general pattern, but they don’t.” (Jim: Day Care Patient -1st interview)

Jim saw the hospice as an opportunity to know more about his disease and to gain a sense of direction through learning about his disease, rather than being left drifting in uncertainty without bearings with which to guide himself. He ventured in the sense that he was exploring his situation or place in the world, and how this was effected by illness. What he found was that there would always be a level of uncertainty because of the nature of his disease, though even that provided a sense of moving forward in his understanding of his relationship to the world. His venturing in this sense therefore included elements of discovery and learning.

Discovery and learning were themes that occurred regularly in Jim’s narratives and often he made distinctions between the known and the unknown. Learning or discovering was unavoidably part of the process of venturing. In this way Jim’s venturing helped him to develop his knowledge around his illness. In the previous two chapters, some of Jim’s quotes were interpreted in the contexts of drifting and sheltering. These same quotes viewed in the context of venturing reveal that Jim also ventured in terms of his own personal development, by visiting day care and finding a community of people that he had to learn how to interact with, in particular people who shared the same terminally ill condition:

“Well you get out of that habit do you not think Drew, like you know, you’ve lost your partner, you’re living on your own. No matter how good you think your people skills are, if you don’t use them everyday, they could count for nothing because you’re not learning anything, the day to day rule the day to day news that... How do you deal with this person, because they might look jovial and sociable and all this and that, but when you get talking to them you realise



they're all full of nerves and stress and all this and that, and you've to learn how to interact with these people as well as the easy type, which are happy jovial ones who don't really give a toss. Anybody can get on with them. But getting on with somebody who's got problems, it's like a learning curve, you learn how to interact with them like you know and... Because no matter what your problem is, no matter how angry or how sad you are, you still need somebody to talk to. Loneliness is no cure for nowt. Just being on your own and not knowing how to deal with people or owt like that. So yeah, I find it a learning curve in many ways Drew." (Jim: Day Care Patient – Photo-elicitation Interview)

For Jim the hospice was a place to learn how to interact with others who shared the same fears and anxieties, who were in the same place, geographically and possibly psychologically in terms of which place they were in within the space of their illness. Also, I felt that Jim was talking about interacting in a wider sense, with people outside the hospice as he described his home situation as living on his own having lost his partner, and as a result he had lost the skill of interacting with others. He further stated that the hospice had "taught" him to make an effort to "get out and about". I feel he was referring not only to getting out of his home and visiting the hospice, but more generally in his world-view, that there was a lot more he could be doing in terms of living a fuller life. He described the resultant antithesis of this - his loneliness - as "no cure for nowt". I felt that he was describing a re-learning of how to be in other places with other people. This was his venturing, that helped him to continue with his life, however much was left. It was venturing psychosocially in terms of exploring how to be with other people and physically in terms of how to be in other places:

"It's taught me I think since I started coming here, that I must make the effort to get out and about. And there's a lot more to life than just sitting at home watching the television and reading the odd book and that, and worrying about what might be. Or trying not to worry about what might be and all the rest of it." (Jim: Day Care Patient – Photo-elicitation Interview)

Jim learned to make an effort to get out of his situation. He discovered there was a "lot more to life than sitting at home". He was in effect describing two different situations

or places: his home, in which he was not really living to his full potential, and the hospice in which he had discovered a fuller sense of life.

When I asked him if the hospice was the place in which he really lived his life he described a situation of not being “taught”, but somewhere he could learn at his own pace:

More or less yeah, yeah, yeah. I mean they don't teach me...I don't particularly care now for arts and crafts and all that you know but...there's no lessons. There's no...I mean when I were in rehab they used to [indecipherable 9:56] from ten until two were usually like classes in how to rebuild your life you know. But they started like it were a school curriculum you know. You will attend at ten o'clock, you'll all sit in here and you get pens and paper and...now we'll start with the eldest and I'm like oh God here we go! But I just couldn't cope with that, but here... I get what I want and I get it at the pace I like it and I get it in a friendly atmosphere and that'll do for me. (Jim: Day Care Patient – Photo-elicitation Interview)

The contrast between ‘rehab’ and the hospice revealed a difference between a process of being taught without a sense of autonomy, whereas in the hospice there was more of an informal process of exploring and discovery at a pace that Jim felt comfortable and in control of. Jim was under no pressure and discovered for himself the opportunities that could afford him a better quality of life.

### **Making achievements**

Visiting day care afforded the patients the opportunity to make achievements they may otherwise have not been able to accomplish. Jim reflected on his time at day care and what he had accomplished during his day:

“...I've had reflexology this morning, I've had a superb lunch. I've had good company, and I've had a chat with Polly, now I'm having a chat with you... When I go home tonight, I will feel that I've had a marvellous day and I've

made some achievements.” (Jim: Day Care Patient – Photo-elicitation Interview)

Having a “marvellous day”, and taking part in activities such as reflexology, social dining and social interaction gave Jim a sense of achieving things, and this was severely contrasted by what he described as the alternative:

“Now if I hadn’t have come, if I’d have sat there this morning and thought I’m not going...at the end of today, I would have been in a deep slough of depression like you know I would have been really fed up with myself. But this is...and I’ll be alright now. As long as my health holds up and I can do something for myself I’ll be alright. I know I will. So that’s how it goes for me Drew.” (Jim: Day Care Patient – Photo-elicitation Interview)

By visiting day care and venturing out of his own home, Jim was doing something for himself and remaining independent. This was obviously important to Jim as he said he would be alright as long as he could do things for himself. He felt in control at day care and the place itself offered him the opportunities to do other things he would not have done had he stayed at home.

### **“A vastly more interesting way forward”**

The hospice provided the patients with the opportunity to see dying in a more positive light. It helped them to endure what was happening to them and to dispel the anxieties and sense of foreboding that thoughts of the future and end of life care brought about. Douglas pointed out, there were people and opportunities to help him to see beyond his sphere of illness, and to him it was a way forward and a new start in life. He described how he coped with knowing he was dying and that how he coped with it was crucial to himself and to others around him:

“But I think it’s fair to say certainly from my own point of view, that when you are faced with life threatening things you do change. [...] But there’s no doubt that it can be a big issue for people. And how you cope with it is crucial. Not just for the people around you but for yourself. And if you can be drawn into a

circle of people who are positive and encourage you to look out beyond your...your sphere of nine to five then you can make the experience a positive one. It's up to you. [...] But you know there are opportunities there that can make you a positive person. Erm...and that to me is a way forward. Vastly more interesting way forward than sitting here moping day after day."

(Douglas: Day Care Patient - 1st interview)

Being drawn into a circle of people who were positive and encouraging again shows the sheltering experience of the hospice. These same people helped Douglas to see beyond his "sphere of nine to five" - what I interpret as the difficulties of trying to live his everyday life – and to venture forward taking opportunities and making the journey of dying a more positive one. He described opportunities that provided him with "a way forward". There is a sense of really *living* despite the constraints of his illness, and a sense of venturing in a new and more positive way beyond the static alternative, "sitting here moping day after day".

### **"The opportunity to make a new start"**

When I asked Douglas how he spent his time at the hospice he described how he had taken up painting again, something he had practiced as a child. He talked about how the hospice had given him the opportunity to take up painting again and to make a new start, to learn new skills and new ways of thinking:

"What [hospice] has given me is the opportunity to make a new start. Which is actually almost more effective than chemotherapy. [...] that to me is as much complementary therapy as massage, or anything else that might be termed complementary therapy. But it's...it's one of those things, where there's the opportunity to learn these skills, new ways of thinking and so on." (Douglas: Day Care Patient - 1st interview)

I felt that Douglas was talking of much more than painting when he talked of learning new skills and new ways of thinking. It was almost as though he was talking about being "equipped" with something to help him to venture and make a way forward, to progress, moving out from the shelter of day care to start living again. Making a new

start created the sense of not just having a new opportunity to live life, but to live it in a different way by adapting to his circumstances. Not as before, as a person who was healthy, but as a person with a terminal illness, with newly acquired skills and opportunities to live and manage his disease and to cope in a more effective and life affirming way. He valued such opportunities, perceiving them as more effective than chemotherapy, because I think they offered more meaning to his life.

Day care provided a place in which Douglas could as he put it – live his life and not his disease, a place in which he could “play”. He did not wish to let the disease itself define him or his life and he described day care as affording him the time and opportunity to make achievements whilst being sheltered from the pressures of “everything else”:

“ [...] one of the nurses at the [hospital cancer ward] came up to chat to us and after some moments, she said ‘Just remember one thing. Live your life, not the disease.’ Yep, yep, yep, I’ll buy into that one. [...] And it comes back to this thing of...I’m not going to let it rule. There’s a tendency I think with...various cancers and they become of overriding importance and everything is lashed around the [indecipherable 34:21] of disease. Whereas in reality if you get off your backside, you can still actually achieve quite a lot. And that’ll then help them to help you help yourself. [...] And virtually it’s the opportunity to really...‘play’. [...] And without the pressure of everything else being on top of you, there’s an opportunity to just sit here and ‘play’. And also to take your time [...]” (Douglas: Day Care Patient - 1st interview)

The opportunity to “play” suggests an enjoyment of life affirming activities. He described a motivation to achieve things and an unwillingness to be ruled or defined by his disease, which he felt could potentially take over his life. *Play* in this sense is a life defining quality. It suggests vitality and easiness, resonant with an innocent energy, such as the boisterous and enthusiastic antics of a child. I felt that ‘playing’ was part of venturing and exploring new possibilities, finding a way to live more fully. This often took the form of learning new skills such as painting and craftwork as Douglas mentioned before when he suggested it was a new start for him.

## **Venturing on common ground**

The gardens at the hospice represented a place where patients could venture out of the hospice building to enjoy time alone or with loved ones, or a place where patients could talk in a more relaxed manner with the staff. Susan related an instance where she suggested the use of the garden to a relative who was having difficulties talking to his uncle who was a patient at the hospice.

“...Somebody once approached me...whose uncle was in the hospice, and his uncle loved outdoor spaces and was working out in the garden his whole life had been outside doing gardening and stuff. And he came into the hospice, and the person said I want to talk to my uncle but I don’t know how because being in the hospice I’m finding it very difficult. And I suggested that they went out for a walk in the garden, because it’s something that they enjoyed together, they worked together, and he came back to me and he said that was one of the most loveliest things I’ve ever been able to do and he just pushed him round and he felt that they could talk naturally. And I think he’ll have that memory now, because you know you might be scared inside but sometimes if you’re able to get out with people it gives them a chance to open up. So, I think that we’re very lucky and I think that the gardens we have here are fantastic and people can go to escape if they want to.” (Susan: Staff Nurse – Photo-elicitation Interview)

The hospice was a difficult place for the nephew to talk to his uncle. It was uncommon ground. Conversely, the garden was common ground for both of them as they had often shared experiences of gardens. Such common ground allowed the nephew and his uncle to talk “naturally”. Susan suggested that people may feel scared inside the hospice whereas being outside the hospice allowed people to “open up”. Furthermore, she felt it was an “escape”. It was an escape from the meanings that people attribute to the hospice building itself. The gardens represented a symbolic landscape to the uncle and his nephew as it represented the familiar, common ground to both of them, as they had enjoyed and worked together in garden environments. Such an environment would feel ‘safer’ and there would be a deeper sense of place. Such a place would encourage a more authentic experience, whereas inside the hospice perhaps the unfamiliar environment represented inauthentic experiences of place for the nephew in particular,

Symbolic of death and illness and a reminder that he would eventually lose his uncle. Thus, the garden allowed a venturing for both the nephew and his uncle, a place where they could go out to, escape from, and share common ground.

**The Garden: A part of place and a place apart**

Besides using the gardens herself to relax and read during her breaks, Cathy stated that she used the gardens occasionally to help patients to talk. She used the natural and physical landscape to create the space and opportunity for the patients to talk about their anxieties and worries, helping them in a sense to venture out in terms of expressing themselves, and to explore their own illness (see Figures 7.1-7.3):

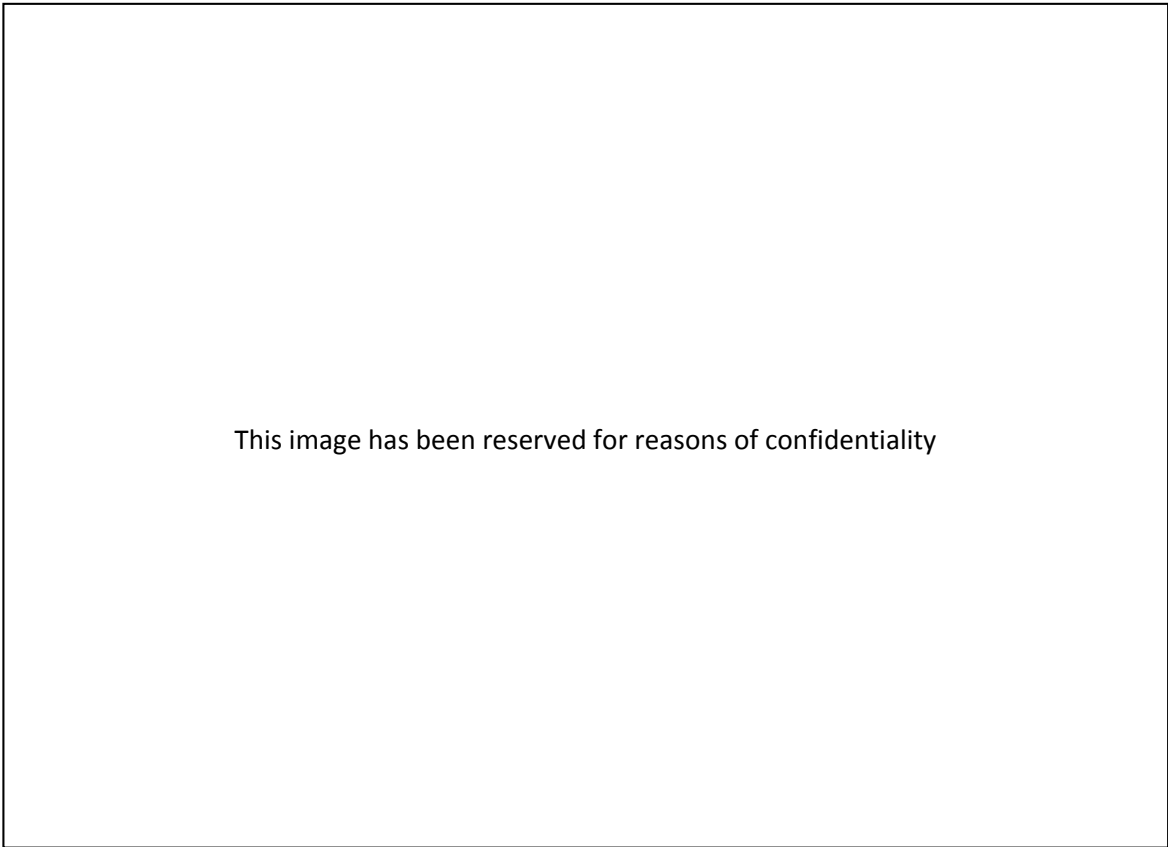
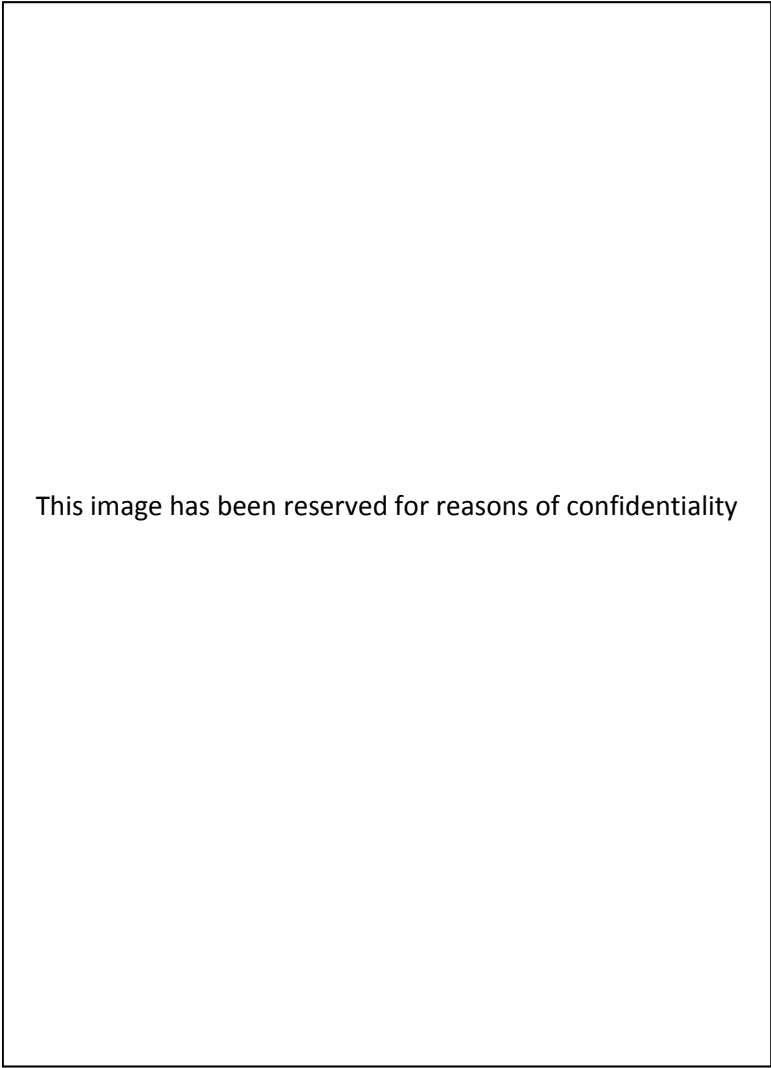
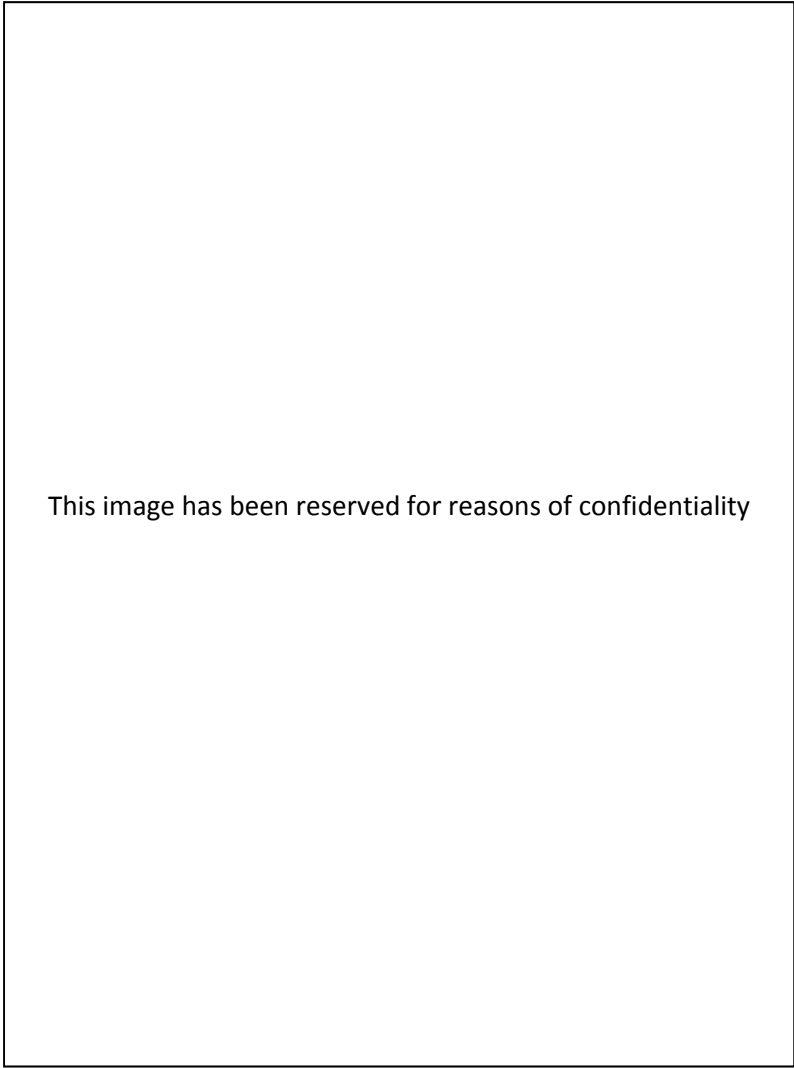


Figure 7.1: Cathy, photograph S4M. The river at the bottom of the garden



This image has been reserved for reasons of confidentiality

Figure 7.3: Cathy, photograph S4B. A view of the garden from the dining room in day care



This image has been reserved for reasons of confidentiality

Figure 7.2: Cathy, photograph S4H. Cathy's reading place



“I have used it really successfully with a young man who...[...] came on a Thursday. [...] He was one who would walk the garden. And he...he was restless anyway, you know, and there was certain reasons for that, but I said “right come on do you want to go for a walk in the garden?” and I knew then that he’d probably start talking as he walked and he did.

And it worked really well. So I used it for him and then he came down there one day after that, I don’t think specifically to find me but I was sat there doing my reading and I said “oh just sit down” and again he chatted to me out there. ‘Cause I think sometimes when you’re building up a relationship with someone, the kind of...where you see them might be important, I don’t mean, to me it’s not important but to the patient. If they’ve been in the bedroom and we’ve chatted in there, they kind of like to go back to that place, and for him it was being outside so that was fine.” (Cathy: Staff Nurse – Photo-elicitation Interview)

Cathy used the garden to help her patient to express himself more openly. She used it because she knew he liked to walk in the garden, so she used a space that was known to have meaning and value for him and in which he felt more relaxed. He obviously felt some kind of affinity with that place, and Cathy spoke of the attachment to places that patients formed once they had spoken in one place, often wanting to use the same space in which they first talked openly. She was describing places of significance to the patient. Such places allowed a process to occur whereby the patient opened up and ventured forward in talking about their illness. There is a sense of movement and progress in such places, particularly in Cathy’s following explanation:

“Another man I took out into the garden, ‘cause I was completely stuck about where to go with it. It was just like you know it was someone who I’d put lots of time in, and we didn’t seem to be getting anywhere, he was so angry, all he could think of was how he was before this had happened to him which was years and years and years ago. We just couldn’t move on anything and it was like...in desperation one day I said “shall we go out in the garden?” ‘cause he was like “oh I need to talk.” You could almost feel when you were... I think we’d been in the bedroom or wherever and the walls were feeling like they were closing in on us, and there just seemed no space in this and no

development. And we went 'round to the garden and he was going through his problems and suddenly stopped by the river and the fish were there and I said "oh look" and it just set him off on a completely different tangent and he...he just lifted and talked about other stuff and his grandson and he liked fishing and it was brilliant, it just worked an absolute treat, [...] But it can be that kind of area, but most of like the work that we do is up here, within these walls really. [...] but I mean it doesn't really matter to be honest where you are, it's how you are with someone that's important. But sometimes the environment can help definitely...can help people feel more relaxed." (Cathy: Staff Nurse – Photo-elicitation Interview)

Cathy talked of not being able to "move", "stuck about where to go" and not "getting anywhere" as though she was talking about trying to reach a new place with the patient. She wanted to move, to venture forward to make progress. The open and natural spaces of the garden helped the patient to venture in his thoughts and to expand on these further exploring his illness and the issues that it created. Whereas, in the hospice the confining structure of the rooms would not allow for such movement or venturing in this manner for this particular patient. Cathy described how in the confining spaces of the bedroom the walls were "closing in", and there was "no space and no development". It may be suggested that both Cathy and the patient needed space, both physical space and psychological space and that there was a relationship between the two. The garden was the place in which this relationship was evident, outside the confines of the physical structure of the hospice walls.

The gardens also represented both a place as part of the hospice and a place apart from the hospice. Despite the hospice being constructed as a more homely and less institutional place, I feel that patients still associated it with the medical establishment. It was a place of care, where they saw the doctor to discuss their illness, where they had treatments and where there were others that reminded them of their own demise. No matter how homely it was, or what therapeutic relationships were fostered there, it was not a home in the sense that people would experience their own home, as the central residence of their being in the world. The gardens offered a place that was far less associated with any act of caring and simply allowed the patients to be in a 'normal' environment, in the sense that it was not associated with medicine or care in terms of

their treatment. The garden is about a shared sense of domestic value. It is about nature and life, a place where people spend time regardless of their health. The hospice is somewhere where people go when they are ill. Thus, the garden as a place represented something separate from the hospice, allowing patients be in an environment where they could be alone with their thoughts or discuss them with a member of staff.

Cathy stated that environments such as the garden helped people to feel more relaxed. I suggest that such open spaces allow for the expansion of thoughts and contemplation. The relaxing effect of knowing that particular place was a normal, natural place, open and yet reassuringly full of life. I suggest the physical appearance of open space had a psychological effect, in that it would seem there was room to let thoughts free in such a place, to let them go, without the fear of them piling up around the patient. To experience such openness was for the patients perhaps an invitation to an active expansiveness of thought. Sometimes we hear people say, "I have no space to think" - in the garden I felt there was certainly space to think.

Derek also photographed the garden (Figure 7.4) and when I asked how he felt when he was out there he replied:

"Peaceful [...] You think about the position you're in and what's happened to you and what's happening in your life. And I think I tend to be, if I'm out, I contemplate more on what's actually happening in your life you know, and what's going to happen." (Derek: Day Care Patient - Photo-elicitation Interview)

The garden for Derek was a place where he could find a sense of peace, and yet he described a state of introspection, wandering and wondering, through thoughts about the past, present and future, in relation to his illness. I feel that he felt peace in the sense that such a space provided him with a place in which to think without the fear of such thoughts bouncing off the confining walls and the nearness of physical and human reminders of the situation he was in.

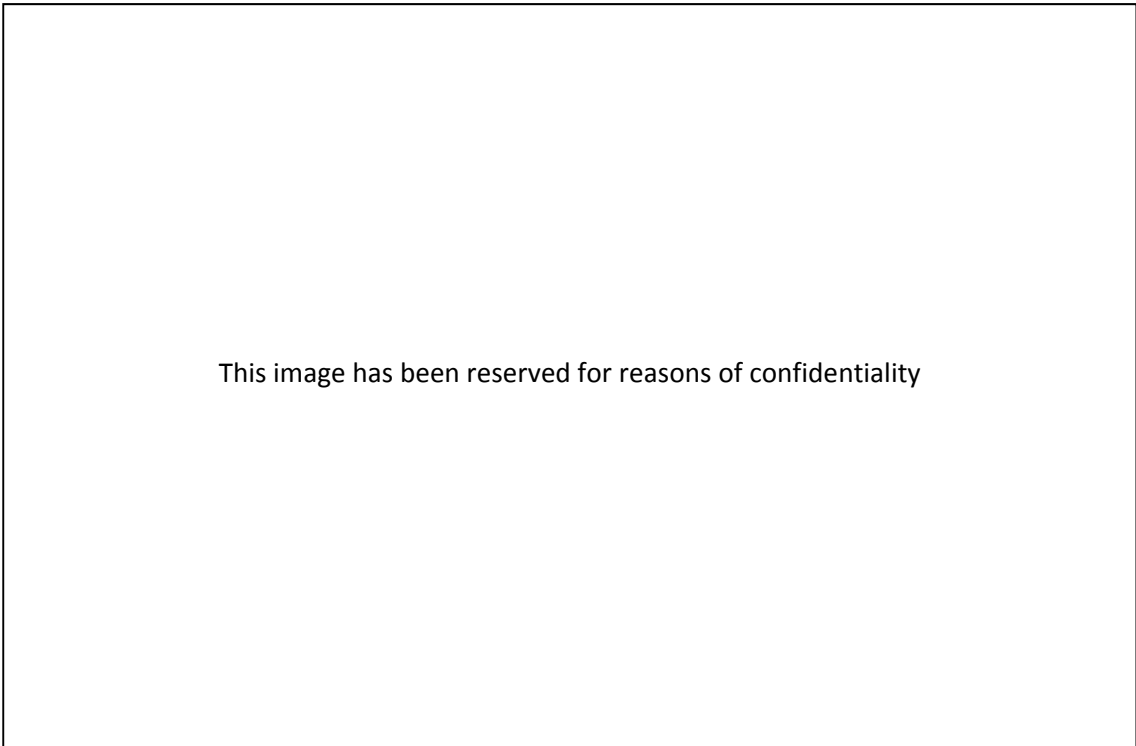


Figure 7.4: Derek, photograph P4G. The expansive top lawn of the hospice gardens

The garden in a way is more of an introspective and transcendent place for Derek, and his contemplation of his own position in life led him to venture in his thoughts, from the past to the present, and on to the future. He was in effect exploring his position in life in a place that allowed him to do so.

**Expanding spaces**

Julie [palliative care specialist] also acknowledged the importance of expanding the patient's world in terms of physical and psychological spaces and places. She talked about helping the patients to overcome limits they had placed on themselves due to fear of being hurt, or because they thought they were going to die imminently. She spoke of how the patient's world could get smaller, becoming more medicalised, and how they often needed help to see that they were in control of venturing out and expanding their world:

"I've often, especially with patients that come from hospital or you've seen them getting less well, their worlds get smaller and smaller and smaller and

smaller, until in fact their world is the bed. And if that is an acute event that is reversible, they need to be making their lives bigger again.

So it becomes the bed and then the room and then the hospice and then going home into the big wide world. [...] That it's actually within their power or [indecipherable 34:29] convalesce, but sometimes it's in their power to make that world bigger, but it has to be made bigger at a rate that they're comfortable with.

So it's helping them look at what's happening in slightly different ways, that will help them reach their full potential, because they will sometimes...put limits on it, and they put limits on it because they're afraid. But they may be afraid of completely the wrong things. [...] If things went really badly at home [...] they tripped or they fell or they broke a bone because the bone was damaged or weak, their fear is that although that is eventually sorted out if they get up and walk again they're going to have another fall that is going to land them back in hospital, that may have been a very frightening experience. So sometimes it's very practical things that stop them. [...] It's safer to stay here and not do anything than it is to actually do something because if I do something it goes wrong. Or when I try to do something it's done wrong so it's actually easier to stay here. Or that...sometimes it's actually because they believe they're dying and that death is actually really quite close within the next week or two [...] it may be an infection which is totally unrelated to their cancer [...] And you've got to help them understand that in fact it wasn't the cancer that made them so unwell. Although the cancer is still there, they're actually able to do more, and to do more they've actually got to make their world bigger again. Staying in bed and waiting to die is not really living.”  
(Julie: Palliative Care Specialist - Photo-elicitation Interview)

Although Julie was talking mainly in respect to in-patients I felt she was also including day care patients to some extent. Julie described the patient's world as becoming smaller and more medicalised as a result of hospitalisation and worsening health. She described her role as helping the patients to see that it was in their control to expand their world by helping them to perceive their illness in a different way, in order to reach their full potential. She described the situations in which patients put limits on themselves, on what they could and could not do, on where they could and could not

go. These limits were self imposed for various reasons, though the underlying reason was fear and the consequences were that they stayed confined to a particular place. Thus their perceived world shrank to the extents of their room or their bed. Fear had created thresholds that the patients would not cross. It had stopped them from venturing, from living to their full potential. It was Julie's goal to help the patients to venture beyond such thresholds, helping them to expand their world, increasing the limits of the places they would venture.

### **“They don't have to be here to get all this...” - moving out of the safe haven**

Julie talked about helping patients to move on from the hospice, a place that for the patients she felt represented “a world where everything is supplied within this space.” She talked about getting patients to move on and to “make their world bigger” When asked about the meaning of the hospice itself as a place Julie's reply was:

“It's about, if you think about hospice itself, it's about people who...care. It's also about...if you think physically about the in-patients and to a certain extent the day care patients, it's about somewhere that is safe, that is a haven for patients. Then along side that is... helping them to engage with or be aware of the support that is available outside of here, that it isn't all here. That something very similar to this is available out there. So they don't have to be here to get all this. There are ways of achieving this out there. But you can't do that unless you are aware of those services and know how to engage with them. So it's about integrating...we're part of...a support structure that hopefully will integrate the support in the community so they can actually feel well out there just as hopefully as they can feel well inside here.” (Julie: Palliative Care Specialist - Photo-elicitation Interview)

What I felt that Julie was describing was a supportive and sheltering place where the patients were helped to venture out from the hospice, making their world bigger by engaging with support available outside the hospice. The services available then helped the patients to venture out of the confines of the sheltering place to find similar shelter and support in their wider world, finding other places in which they could feel well outside as well as inside the hospice. She was in effect talking about a transition, and as

such the hospice as a place becomes transitory, a sheltered way station on a journey with multiple ends. The patients could move out of day care and back to the community, or into the in-patients or their own homes where they ultimately come to the end of their lives.

### **CT as expanding the patients' world**

Complementary therapy offered an opportunity for patients to experience being cared for in a way that they had some control over. They had a choice to partake. Once patients had experienced one complementary therapy, they became interested in other complementary therapies. The experience opened up new possibilities for care, and patients took the opportunity to venture and explore this new landscape of care:

“But I’ve never had that foot therapy or anything like that. Now somebody mentioned...now I can’t remember whether it was here or not, but somebody mentioned something about ‘an Indian Head Massage’, now I’ve never had one of them, and I thought if they’re anywhere near as good as that job they do on your feet, that lady does on me feet here, I thought I’ll have one. I’ll try everything now. [...] You know but I mean that...I mean I suffer with erm what d’you call it...diabetes. I’m on insulin for that and me feet are terrible. They’re the worst thing on me. And when that lady’s had er put them oils on me feet and worked her magic, the difference is unbelievable. Really is, it’s terrific. I wish I could have it everyday!” (Jim: Day Care Patient - 1st interview)

Having never tried complementary therapies before, Jim was impressed by the effect of the reflexology on his feet. It was a new and positive experience for Jim and he wanted to explore other kinds of CT to see if they were as effective, again enabling him to venture into new possibilities to feel better. He stated that he would “try anything now”, illustrating that his world had expanded significantly because of the new experiences he had with CT. He did not pretend to understand them as he suggested the therapist “worked her magic” but the effect seemed profoundly positive and it seemed to be a herald to the new landscape of care that he wished to explore.

Similarly, Arthur was also keen to explore this new landscape after his first experiences of complementary therapy. He commented on how it had opened up an “unknown world”. When I asked him if he knew anything about complementary therapies, he replied:

“No, no, no. That's what I say, it's walking into an unknown world. All of a sudden...everything opens up. From feet...from head to toe! [laughing].”

(Arthur: Day Care Patient - 1st interview)

Walking into an “unknown world” perfectly described a sense of venturing, and an exploration of not just the hospice and what it had to offer, but of the inner self as it opened up from “from head to toe”. CT was a new discovery for these particular patients and represented new possibilities for experiencing care in a more positive and life enhancing manner.

It also helped patients to think in a different way, venturing in thought. Complementary therapies were often described as helping the patients to become more relaxed. Pam suggested that they relaxed her so much she forgot about her anxieties and pain:

“You know, you forget your pain and everything when you're having these therapies. [...] I think it relaxes you so much and that your concentration changes. Instead of maybe thinking inwardly you're thinking outwardly.”

(Pam: Day Care Patient - 1st interview)

The relaxing effect of the therapies changed Pam's thought pattern, from thinking “inwardly” to thinking “outwardly”. I have taken this to mean a venturing in thought, whereby she relaxed enough to forget her pain and to “forget everything” leaving her anxieties behind as she progressed with her thoughts, moving into a another mental place or ‘way of being’ for periods of time. Essentially these therapies took her to a different place psychologically, away from her illness.



## Autonomy and the freedom to venture

In order to venture there must be a sense of autonomy and freedom. These were evident within the narratives of the patients and the stories of their venturing. Jim was aware that without the treatment he was receiving at the hospice he would be in his own words “in a shocking state”. The hospice enabled him the freedom to venture, it sustained his sense of self, as an autonomous and able person. He described days when he *felt* well enough to travel or to go on holiday yet he knew also that this feeling would not last:

“Now physically I do realise that without the drugs and the treatment I would be in a shocking state I know that. But having said that, there’s days when I feel absolutely marvellous, and I think to myself, if I just pushed a little bit I could do anything today. I could go sightseeing, I could get on a coach, I feel like booking a holiday and all this and that. And yet I know that this euphoria will only last a day maybe two, and then I’ll be back to fed up with myself and stuck in the house, and full of pain and all this and that like you know.” (Jim: Day Care Patient - Photo-elicitation Interview)

Jim’s words created a sense of being confined by his illness; bounded in place, in this case his house. I noted that he used the word “house” instead of home. It was not the psychological *home* of personal safety, comfort and warmth, but a *house*, a physically restrictive boundary, in which he drifted felt “full of pain”, “fed up” and “stuck”. The hospice on the other hand represented somewhere he could both shelter and venture within, knowing that he would be safe and cared for. Hospice represented a place where patients experienced freedom and movement. They could escape from their own homes, from feelings of confinement or smothering, as mentioned earlier by Andrea. For Jim, day care was somewhere he could explore his own disease; somewhere he could experience new kinds of enjoyable relaxing treatments, such as CT, and somewhere he could socialise and enjoy good food. He also felt a sense of control over his time at the hospice; he had a personal rhythm that sustained his sense of freedom and autonomy:

“... I mean I can go out, I go out for a smoke, there’s nobody, there’s no restrictions and nobody telling me what to do, what I can do, what I can’t do

everything's laid back, it's easy. And you've got all the help you need here."

(Jim: Day Care Patient - 1st Interview)

Jim described an informal and laid back environment where he could enjoy a sense of freedom and autonomy whilst being supported. He could at any time "go out" for a smoke, with "no restrictions" on his movements. Though he did not go on holiday or any sightseeing trips, the hospice was a place in which he ventured, foremost by getting him out the house in which he felt "stuck".

Carl similarly felt that there was a focus on choice at the hospice, which allowed him to feel control, but which also created an atmosphere of informality:

"They make you feel at home. And if you don't want to do it you don't need to do it, it's not like your pressurised into it you know [...] I don't like being pressurised like that, I like to do it at me own pace you know. [...] it's are you sure you want to do it? [...] it's not like you're regimented into it. It's everything seems to revolve around us, you know as the day patient, you know, not what the staff want us to do, it's up to the patient whether they want to do it, you know." (Carl: Day Care Patient - Photo-elicitation Interview)

The fact that Carl said he felt "at home" gave some indication of the level of comfort and control he experienced. Doing things at one's own pace shows that his personal rhythm was not disrupted by any formal (regimented) routine. He felt autonomy and freedom in the sense that he was the centre of care, in an atmosphere that made him feel at home. The informal routine was also noted by Douglas:

"Yeah. I enjoy the...initially I enjoyed the lack of routine. [...] But as I've stayed here longer, the time has passed. There is a routine there. There is a feeling that we're protected from it. [...] But for me, there's a sense that people come here to get away from...get out of the house. Get away from being locked in all day. Particularly for those who aren't physically able to move around. Get away from same old, same old. And that's becoming reaffirmed. There's a loose regime. Otherwise I think you wouldn't get anything done." (Douglas: Day Care Patient - Photo-elicitation Interview)

As Douglas's sense of place deepened, his first impression of a lack of routine was replaced by a sense of informal routine, though he felt "protected" from it. My impression is of an informal atmosphere, fostered to create a certain type of place in which patients felt free enough to develop their own personal rhythm. Thus sustaining the self, whilst escaping from the restrictive "same old, same old" routines, such as those experienced in the house as a restrictive boundary. The informal approach of day care fostered such opportunities to "get away from being locked in all day" affording the patients opportunities to move around, to have control and freedom, creating a sense of venturing.

### **Illness and venturing: the journey into new places**

For Douglas the photographs of corridors (see figures 7.5 – 7.8) represented patterns of movement that were influenced by his disease, and his journey through places within the hospice. In a positive sense Douglas described the corridors as "places to go, where you get another crack at getting you involved in an organic process of taking care of yourself", which implied a sense of autonomy and a venturing, where the patient had the opportunity to be involved in all aspects of their own care. With further discussion, it soon became apparent that the corridors meant much more in a metaphorical sense. They showed the journey, or adventure of the patient:

"So I mean that the whole concept of the photographs of corridors was that there are places to go to, there are places to go from, there are places to go up, places to go down, places to go up and down. Sometimes have this concept of going to places as part of your care, and there are other places that are places you go to because of the disease that you have. And sometimes you just have had enough. And you go down the staircase. Or if you had a photograph of it, up in the lift. So it can be like that. [...] But as far as making out that there's a deep psychological thing, then the key to it is the fact [...] that you're travelling. You're on a journey [...] in a place which is about a sense of stillness." (Douglas: Day Care Patient - Photo-elicitation Interview)

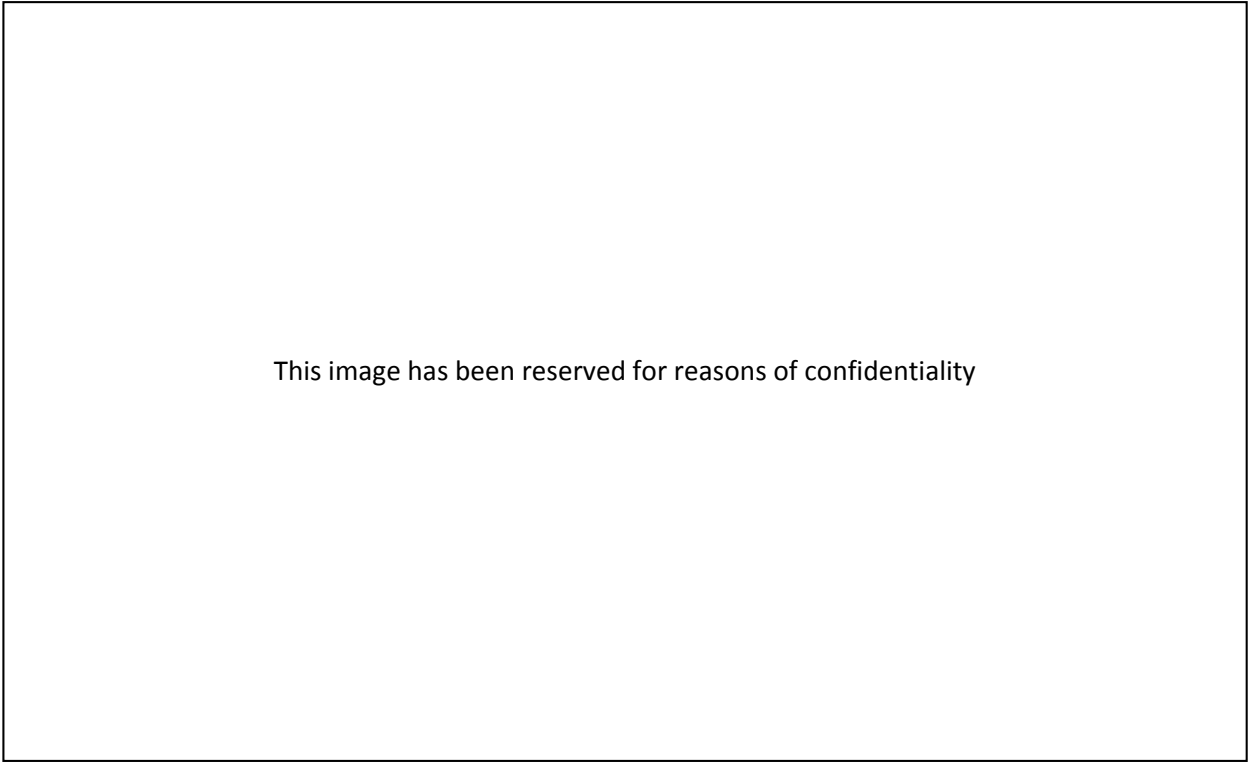


Figure 7.5: Douglas, photo P9E. The front entrance and reception (showing the shop and the corridor that led to the old CT room and the physiotherapy room)

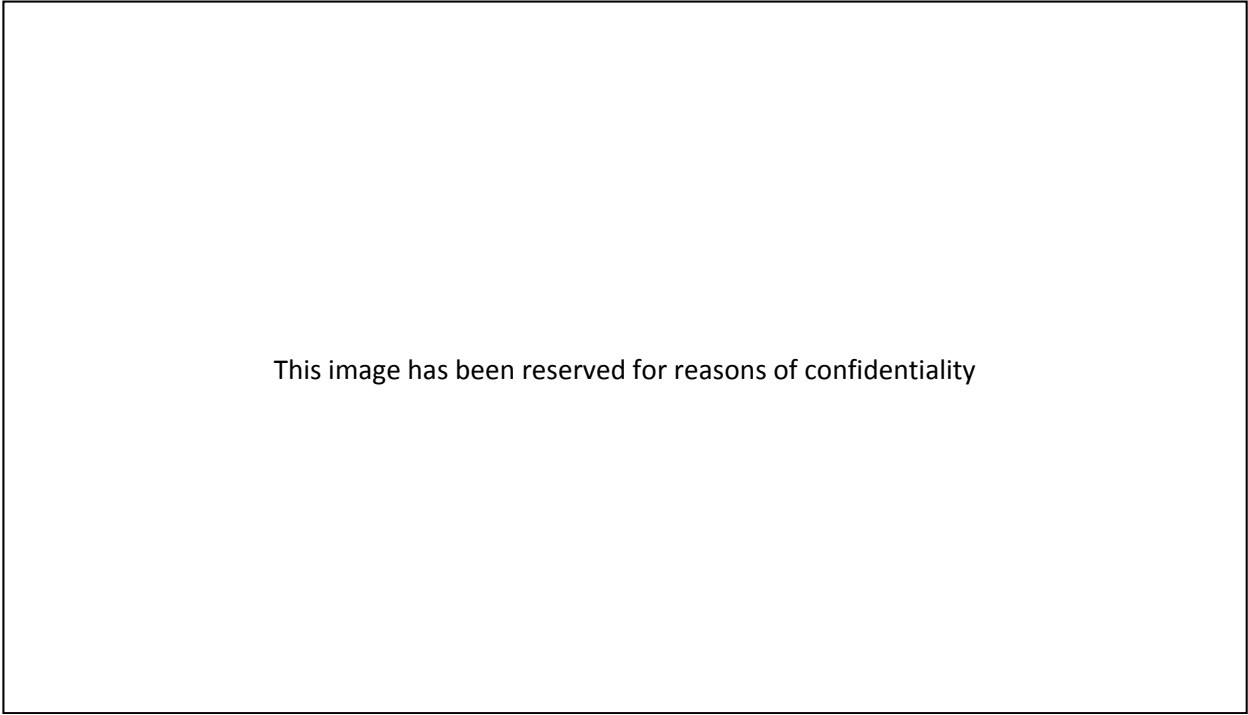
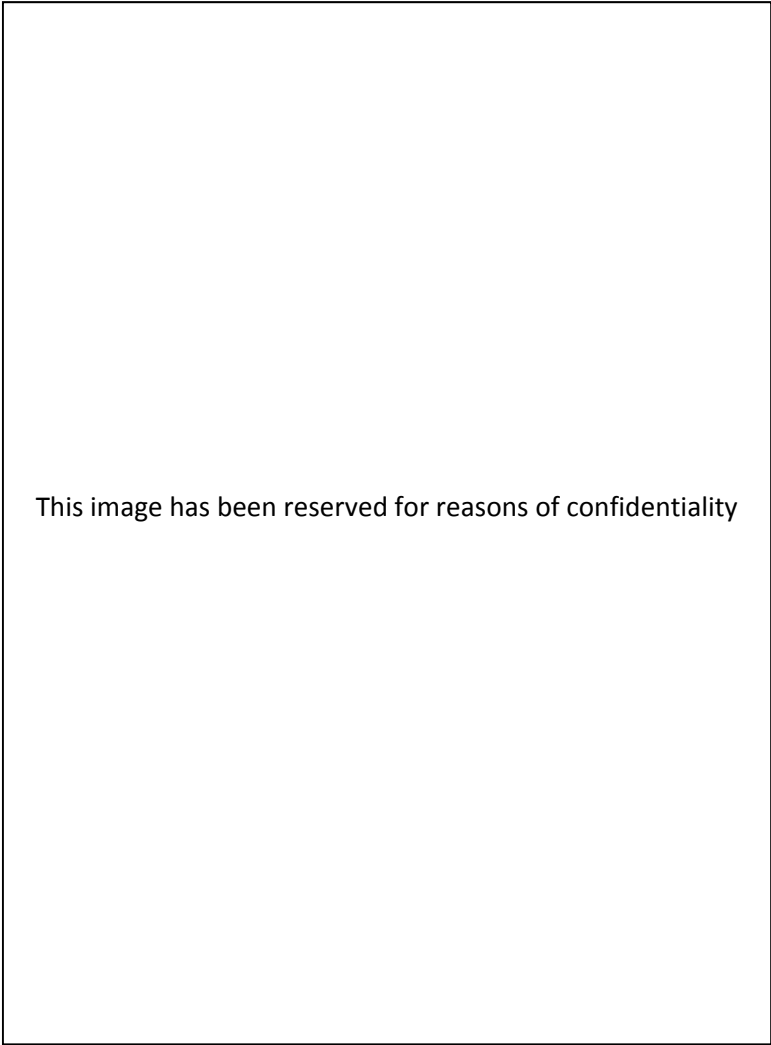


Figure 7.6: Douglas, photo P9F. The reception and corridor looking towards the in-patients wards.

Douglas stated that there were places he travelled to which were specific to his care as a whole person and places which were specific to the treatment of his disease. There were other places symbolically specific to dying, such as when patients had “had enough” of struggling with their disease, going “downstairs” to the in-patients to die, or metaphorically heavenwards in a kind of celestial lift. He described “travelling”, and identified the process of dying at the hospice as being “on a journey in a place which is about stillness”. I suggest that the patients were on a journey that had brought them from a state of drifting to a state of sheltering and venturing. The implied “stillness” I feel was a sense of security and certainty of care which allowed patients to be still psychologically, whilst at the same time they could venture out or travel to places within and without the hospice, in the exploration of their disease. There is a paradoxical element here of being still in a place, yet being able to venture to other places. Douglas’s “sense of stillness” could be equated with a calmness, as opposed to a chaotic uncertainty of care and uncertainty of one’s self.

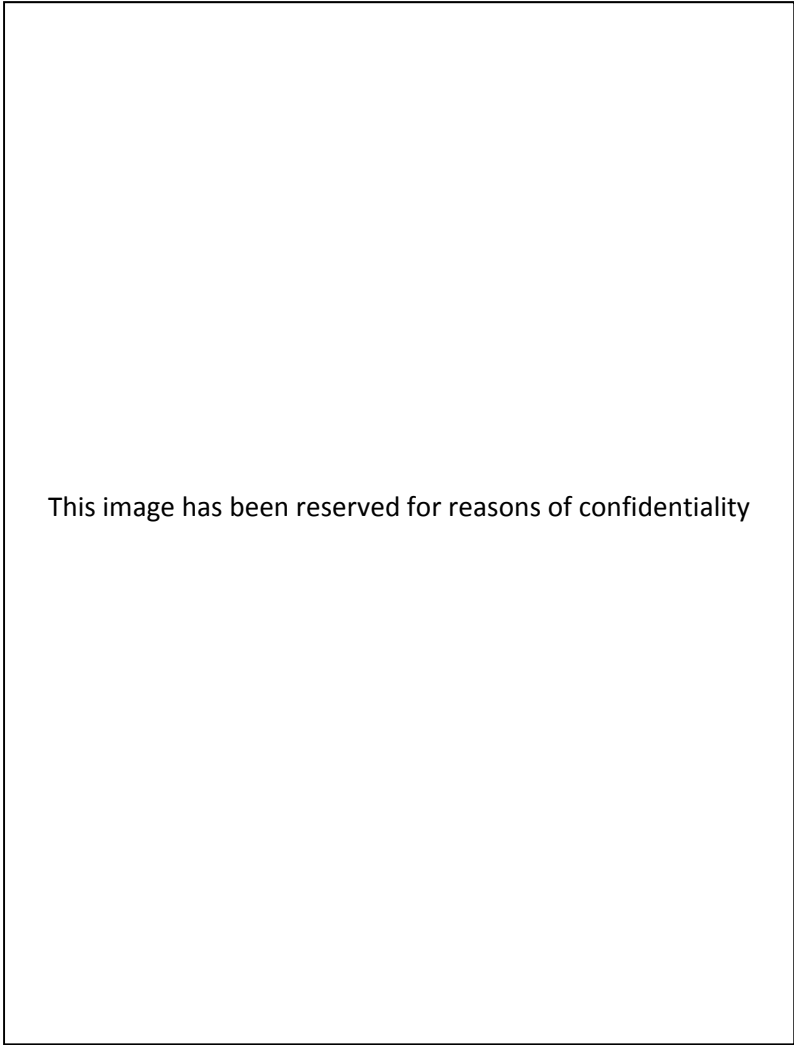
During the second interview, Douglas became excited to tell me that he had been to new places in the hospice, and met new people. He described the effect this had on his perception of the hospice as a place. The hospice had become much more than a place for the dying for Douglas. Its meaning had been extended as he encountered new places and the people associated with those places:

“There’s much more going on. I mean today I’ve extended what I’m doing and know about the place by about 35%, which just gives you an idea of how poor I am at...finding out where I am. [...] I’ve been downstairs! [laughing] [...] I’ve met a new person! [...] I’ve gone down to see the lymphoma [lymphoedema] nurse. [...] And it simply means I’ve been to a fourth place in the building. And like I was saying last week, I’ve seen [elements] of coming and going. And people talk about “downstairs” and “upstairs” with sort of equal... [...] But it’s just the fact that the word “hospice” is associated with care, at the tail end of someone’s very painful life usually. Whereas it seems to be a much wider care basis amongst a wider group of people in a way, that would be a hospice. And in a way that’s relieving.” (Douglas: Day Care Patient - Photo-elicitation Interview)



This image has been reserved for reasons of confidentiality

Figure 7.8: Douglas, photo P9D. The corridor through day care (leading past the lift and stairs down to reception)



This image has been reserved for reasons of confidentiality

Figure 7.7: Douglas, photo P9G. The corridor from reception (leading past the lift and stairs to day care and on to the old CT room)

Douglas's venturing had led him to discover that there was more going on in the hospice than he had previously experienced and perceived. He had discovered new places and through the journey of his illness extended his sense of place. The most exciting part of this for Douglas was going downstairs and meeting a new person. In this context, it would seem that she is intrinsically a part of his place experience. His overall sense of relief was perhaps heightened by the fact that she was not immediately associated with his dying process but there to help manage his condition. He alluded to the mystery and anxiety created by the word "hospice" "upstairs" and "downstairs" and the fact that these places were associated with a painful end, whereas actually his venturing revealed that there were other places "downstairs" in which other kinds of care took place for people who were not necessarily in the last stages of life. For Douglas the discovery of these new places revealed new meanings to hospice and his sense of place changed. The relief resulting from this discovery I believe was because the less such places were associated with dying the further away from death he felt.

## **Crossing Thresholds And The Limits To Venturing**

### The boundaries to venturing

In the earlier chapter "Drifting", I described Jim's initial fear of meeting one of the in-patients, and how he had then subsequently met one while in the smoking room. This encounter changed his perceptions of the hospice and what it was like to be an in-patient. I sensed that this demystified for Jim how other patients made sense of what was happening to them and how they coped with dying:

"I thought this man's not ripping his bed sheets at night, you know in terror, and all the rest of it wondering when he's going to go, he's got other things to think about. And I thought he's just like me, he's living his life like me and...this is what I'm beginning to learn, this is what I'm starting to understand and this is what's made me think like what's happening with me own circle of friends like, you know. Them that have decided to blank me and drink elsewhere, because they think I'm going to be...you know... "Help me! Help me! Somebody help me!" But I don't feel like that. If they want to talk about it,

fine. If they don't want to talk about it, that's fine as well. . I've got a laid back attitude at the moment with it, like you know. I'm not saying, I'm going to be as glib and as brave as all this when my time's coming up. I don't know how I'm going to face it. But right now, this place has helped me to take it on, and live with it. And I'm getting better at it, each week I come like, you know, so...that's what I'm grateful for to this place, yeah?" (Jim: Day Care Patient - 1st Interview)

The change in Jim's perception of what it was like to be an in-patient was evident and he described a process of learning. His sense of place had changed as each week he stated that visiting the day care unit helped him to live with what was happening to him. Thus what had happened in one place helped him to understand what was happening in other places, as with his friends finding it hard to talk to him. Learning how to be with others who were dying helped Jim to understand the reasons his own friends had difficulty talking to him. Despite this progress, in the second interview with Jim he revealed that despite his learning he still could not bring himself to go near the in-patient ward. His exploration revealed that he had found his own limits and boundaries through his venturing at the hospice:

"I know it's probably not true, but I just get the feeling I'm restricted when I come in [...] Now, I'm not saying it's right, it's just the way I feel. There are limits to where I can go. I can't turn to the right, for some unknown reason, I've never asked why I can't go down this corridor. I see lasses going down to have their hair done, so I think well it can't be that off limits, can it really like if ladies are going down to have their hair done. But I don't know what's down there, but it's me own fault because I've never asked. I've just built me own story in me own head." (Jim: Day Care Patient - Photo-elicitation Interview)

Jim talked about feeling restricted as though there were limits to where he could go and yet he had imposed the limits upon himself as his fear had created boundaries beyond which he would not go. He stated that he had "just built me own story in me head". Psychologically he had created places he feared to go for what they might have revealed. He could have asked what was down the corridor but didn't for fear of confirmation of the answer he had already created. When I asked Jim if he therefore put limits on himself he replied:



“Yeah, yeah, if you will really. Well because...you're in a sensitive place Drew. There's people here dying [...] Like I say I can make things off limits, and even now I feel that way. I don't ask anybody what's down there, because I already know the answer up here [pointing to his head]. I've already made the answer up.” (Jim: Day Care Patient - Photo-elicitation Interview)

Jim described creating psychological limits or boundaries around “sensitive” places. As he stated he imagined that there were people dying in those places. His refusal to ask about the nature of those places highlighted his fear of crossing the final threshold, in terms of his dying. He already had a sense of those places, though he had not seen them; he had imagined what they would be like in a vicarious manner creating a psychological landscape of fear.

Jim therefore defined the limits of his venturing at the hospice based on his fear of confronting his own death. He firmly placed himself in day care, the place of the living, not wishing to venture “downstairs” to the in-patient wards, the place of the dying:

“To me this place is sensitive. Even though I find it relaxing and I come here for the day, but I have the limit. I just come here for the day care, enjoy the company, see the doctor, bit of time for me and relaxation and everything. But I do not want to go downstairs and see these people who are... [note he does not say ‘dying’] I hope they never come to me and say would you like to come and have a word with such a body or...would you consider doing...to a man who's got like a week to live. I don't know how I'd cope with it Drew, do you know what I mean? So it's difficult for me to say but I find that terribly sensitive, I don't know how I'd cope with it.” (Jim: Day Care Patient - Photo-elicitation Interview)

He called the hospice “a sensitive place” and this is appropriate for the OED definition of “sensitive” suggests not only an appreciation of other's feelings but something kept secret or undisclosed to avoid endangering security. Jim stated that although he enjoyed the benefits of day care (his security) he made some places such as downstairs off limits because he feared jeopardising that security. In particular, he feared going “downstairs” and meeting other patients who were dying, saying that he would not know how to cope

and I felt that was the case because he did not yet know how he would cope with his own death. Death represented an unknown place for Jim, the final threshold. He expected to find evidence of it behind the closed doors and corridors he feared to walk down. So there were limits to the hospice itself, albeit self imposed, that stopped Jim from venturing any further, both in his exploration of the hospice as a place, and in his own illness in terms of confronting his own demise.

### Upstairs Downstairs – the Living and Dying places

Like Jim, Douglas recognised that there were places in the hospice that he had not yet been to though he gave different reasons for not venturing into these places:

“And there are just loads of corridors going to places that I don't know what of. Some of them are important to me some of them are not. And I tend to be the sort of guy, where I'll go to places that are important to me, and the others I will not bother about until they need to be bothered about.” (Douglas: Day Care Patient - Photo-elicitation Interview)

Douglas explained that he only went to places that were important for him, but other places he did not have to bother about until he needed to go to them. One of these places was “downstairs” The in-patient wards were often referred to as “downstairs”; a euphemism for everything that patients feared about their own journey towards death. I feel it represented an end-place or a point of no return to the day care patients, as they seemed to avoid it. Bernadette (Day Care Sister) suggested that patients thought of downstairs as “where we go to die.”

Rather than go to the in-patient wards Douglas even took photographs of the staircase (see figure 7.9) at the end of the day care unit that joined the upper floor (administrative offices) and the ground floor (the in-patient wards). This photograph symbolised two places he had not yet ventured into:

This image has been reserved for reasons of confidentiality

Figure 7.9: Douglas, photo P9C. The staircase from day care (leading up to the administration offices and down to the in-patients wards)

"One of the things that is ... unclear, is that a treatment for me here is along that level. Now within that level, whilst it is level, there are times of in and out of dark and light, which to me epitomises, or personifies my existence, up and down. But on one level [day care]. Whereas here, there are places that you go off to. Until we took these photographs. I hadn't been up stairs, or downstairs. Other than to come in the doors and over there and up. Whereas here we are reaffirming that concept that there are other areas. There's only one photograph of that, and it's simply showing that.., it exists. Because I haven't been there, I haven't been downstairs to where all the hospital care cases lie [ ... ] When we were out taking the photographs, we saw ... heard all the kafuffle of an ambulance arriving and a patient being delivered [.1 And another I think it was last week when I saw a patient being delivered by ... actually on a bed ... the whole basket case. [ ... ] The whole point of this photograph was just that there is things going on upstairs and things going on downstairs, and there's a lot more going on than I'm aware of [ ... ] I don't think to be honest it's going to do me much good to find out." (Douglas: Day Care Patient - Photo-elicitation Interview)

He described his place at the hospice as on a level, where he could go up and down, in and out of darkness and light. The photograph clearly shows areas of darkness leading upstairs and downstairs, whereas the level in the middle is well lit. I felt that his use of the words “light” and “darkness” were both objective and metaphorical. When he said it “personifies my existence”, I felt he meant in the sense of fluctuations in his health. The staircase also represented the places that he had not yet ventured to; upstairs or downstairs, and these represented places he knew existed but did not care to explore as he felt it would do him no good to find out. Describing the commotion of patients arriving suggests he feared what such places would reveal. He described seeing one patient on a bed as “the whole basket case” as though he saw no hope for that patient. Like Jim, he felt that such places were the limit of his venturing at the hospice.

Such places represent a threshold for the day care patients in the sense that they have imbued them with negative meaning and constructed psychological landscapes of fear. There is a reluctance to cross over the threshold into these places, and though the patients have some knowledge of what occurs within such places, they are still relative outsiders to these places. These places remain in the domain of the unknown:

“Overall I would say that there’s the concept that there’s a lot more happening than is apparent. Because there are more levels than I thought, and of those levels more is going on in them than I thought. When I first came here, I thought no, hospice has been put out of my mind. But it was there when I was told about it. As I understood it, the change was from hospice and palliative care, to more open style care. The reality is that while the change has happened, they haven’t left their history behind. So that element of care still exists and still in use.” (Douglas: Day Care Patient - Photo-elicitation Interview)

Douglas talked of the concept that there was a lot more going on at the hospice than was apparent. He was effectively describing a sense that although he was comfortable and relaxed when visiting the day care unit, he knew that there were other places which he had not yet explored for fear of what they would reveal, in which the things he feared still happened. He understood day care as having “a more open style of care”, one in which he was comfortable, in which living not dying was the focus of care. Yet,

he stated that other places within the hospice resounded with his old perceptions of hospice as a place for the dying. He described this as “their history” and an element of care that still existed. He associated unknown places in the hospice with a sense of anxiety and an overall impending fear of dying. To Jim and Douglas, their historical perceptions of hospice as an end place resurfaced, regardless of what they already knew to the contrary - that people often just came to stay in the in-patient wards for respite, or to get their medication under control. Downstairs was still a place for the dying and therefore out of bounds, symbolising the final threshold for them.

## **Conclusion**

In this chapter, I have identified that there was a process of venturing among the patients as they sought to explore their disease and tried to position themselves within the space of their illness through discovery and learning. Different places within the hospice had different effects on how the patient ventured and indeed if they wished to venture into those places. The hospice was sometimes seen as confined and ill suited to helping patients to open up and talk. The garden facilitated venturing through physical landscapes that were characterised by an openness and expansiveness and through psychological landscapes characterised by an openness and expansiveness of thought. This created a sense of moving forward, in relationships with others but also in relationship to the illness. This sense of exploring, learning, discovering and moving forward further strengthened the image of the patient being on a journey. The garden also represented somewhere to venture away from the hospice, in the sense that it provided a place apart from the hospice, or a common ground not associated with illness or medical care, but part of a shared domestic culture with which all could associate.

The hospice itself provided patients with a place in which there were opportunities to make achievements and to venture out of their own home, and the patients valued this in the sense that it helped them to “get out and about” and to live their life more fully. In the sense of journeying, there was sense of equipping the patient with the right skills and providing the right support in order to venture out and Douglas referred to this as “making a new start” and a “vastly more interesting way forward”.

Complementary therapies provided one such opportunity for exploration. Often a new experience to patients, it opened up a “whole new world” as one patient described it, and there was a keenness to explore this world more fully and to try other therapies. The physical location of the old complementary therapy room also allowed for a venturing in the sense that it provided patients with somewhere other to go at the hospice apart from day care and as such created a movement through places. This movement for both staff and patients was valued as a time-space routine that deepened the sense of place.

The process of venturing also revealed new places that altered the sense of place for the patients such as Douglas. The discovery of new places that were not associated with dying changed the meaning of his overall sense of place. And yet, patients also found the limits of their willingness to venture to places they felt were associated with dying. Patients imposed limits upon themselves for fear of what unknown places would reveal. Despite not having experienced these places directly, they perceived them as being associated with dying and therefore refused to venture into them. This acknowledgement of their own limits demarcated places for living and places for dying and revealed their fear and anxiety and their unwillingness to cross the final threshold.

## CHAPTER 8

### DISCUSSION AND CONCLUSIONS

“Home is the foundation of our identity as individuals and as members of a community, the dwelling-place of being. Home is not just the house you happen to live in, it is not something that can be anywhere, that can be exchanged, but an irreplaceable centre of significance [...] It is the point of departure from which we orient ourselves and take possession of the world”  
(Relph 1976 p.39-40)

Within the findings chapters, I presented three broad themes, which stand as a triad of existential modes of being. These are namely drifting, sheltering and venturing. Each of these modes may occur in combination with another mode simultaneously and reflect the participants’ perceptions and experiences of, and actions within, the spaces and places of hospice day care. Having laid out the broad definitions of the three terms, I move on to reflexively show the resonances these terms from my research have with my own experiences of undertaking the study and writing the thesis. From there, I consider the original aims of the study and how these have been fulfilled. I use an explanatory framework based in humanistic and existential geography to consider the three existential modes of being further in the concept of “finding home”. I demonstrate how in drifting there is both “unhomelikeness” and “homelessness”, showing the link between these concepts. In particular, patient experiences of threshold anxiety are shown to augment unhomelikeness, which leads into a discussion of how complementary therapies are used in relation to the three existential modes, with an emphasis on how CT creates a particular therapeutic landscape. I then use the notions of “home” and “homelikeness” to show how, through sheltering and venturing, patients came to find a sense of home, both within themselves and within the hospice as a place, bringing together a phenomenology of illness and a phenomenology of space, place and home.

## **The discovery of three existential modes of being**

From the findings, three existential modes of being were discovered which characterised the patients' experience of hospice day care; namely drifting, sheltering and venturing. In short, *drifting* was characterised by uncertainty; anxiety; disorientation and the unhomelike. In *sheltering*, patients found certainty and trust in the care they received and comfort in the homelike and familiar. Lastly, *venturing* was experienced whenever patients deliberately went beyond their sheltering, to explore the unknown.

These three modes of being, discovered through my interpretation of the data, come together within the patients' experience of being in the hospice. By using a larger explanatory framework they can be considered further in the concept of "finding home". As seen in the literature review, the values and the premise (and promise) of hospice care is that it should create a homely, rather than a clinical/medical, hierarchical and alien environment. Its premise is one of continuity between the patient's home and the notion of an ideal home (Cooper-Marcus 1999; Godkin 1980; Verderber & Refuerzo 2006).

Patients, staff and therapists used the words 'home' and 'homely', but a sense of home is more complexly presented here, as finding a home within the self and finding home symbolically, rather than just a superficial or literal aesthetic sense of home. Notions of home are evident in the psychological, social, symbolic, physical and natural landscapes associated with the hospice day care unit. Gesler's (1992) concept of therapeutic landscapes will be alluded to, to further illustrate how patients experienced these three modes within each of the various landscapes.

The theoretical framework I will use as a basis for this discussion focuses on theories of *space*, *place* and *home* which are central to the humanistic/existential geography of Relph (1976), Tuan (1977) Buttimer (1980) and Seamon (1979;1980;2009), as introduced in the literature review. I will also draw on Svenaeus's (Svenaeus 2001;Svenaeus 2009) phenomenology of medicine and his notion of health and illness as *homelikeness* and *unhomelikeness*, which was first introduced in the literature



review. I will use core concepts from humanistic/existential geography, these being sense of place, rootedness, insideness and outsideness, showing how these are linked to homelikeness in their resonance. As this is an emergent thesis I will weave in the notions of homelikeness within the discussion chapter after first presenting it here in relation to the experiences of the patients.

Note: It is wise to point out here and to avoid later confusion that when I refer to the “homely” and “un-homely” I am referring to symbolic or physical aesthetic characteristics of the wider environment, beyond the self. When I refer to “homelikeness” and “unhomelikeness”, I am referring to a state of being in relation to the self. My assertion throughout this chapter is that there is a relationship between the two sets of terms.

### **A view through the lens of my experience**

I am aware, as I have been throughout the study, that I will interpret all I have experienced during this research through the lens of my own experiences and perceptions. My being-in-the-world is not just being in *the* world, but in *my* world, the world as constantly interpreted by me, though I am aware it is also the world of others and not entirely my world.

In my search for an essence within the phenomena presented, I found three modes of existential being. Three modes of existence within the data, that far from applying only to the participants also had parallels with my own experiences.

I have drifted at many stages over the past three years whilst conducting this research. I experienced uncertainty with my choice of methods and methodology. I have been lost within the data, and I have been lost within my personal life, experiencing the ending of a relationship that left me feeling uncertain about many things.

I have also sheltered, within the support, love and encouragement shown by others; I sheltered at stages of accomplishment, such as finishing a chapter, unwilling yet to venture into the unknown domains of the next chapter, happy to pause for a while. I

sheltered within the ideas that emerged from the data, finding safety in their perceived solidity. And I sheltered in the positive feedback I received from those academics whose knowledge and wisdom I sought and who offered encouragement and praise, advising me to venture even further. In particular, my e-mail correspondence with the existential and humanistic geographer David Seamon offered a great sense of sheltering in this respect. I have included, with his permission, his responses to my findings (See Appendix 5).

And in my venturing, I began this project. I ventured out of the security of my home in Alice Springs, Australia, back to the uncertainty of England to explore the unknown and unfamiliar. I ventured into new places, searching to find a home to inhabit. Most of all, I ventured into new landscapes of knowledge, exploring new ways of thinking and new ways of seeing the world. I feel now I have come to a place of certainty, returning to a sense of sheltering for a moment.

In some respects, the findings and synthesis reflect my own journey and the difficulties I experienced trying to analyse the data and write the thesis. Just when I thought the data had finished speaking to me, it started again and the merry-go-round of the hermeneutic circle continued. And in the sense of the hermeneutic merry-go-round I start my final chapter by taking the reader back to the beginning of the study - to the original aims, to consider in what way these have been fulfilled and how the focus shifted through drifting/sheltering and venturing within the data.

### **Returning to the beginning**

The study set out to explore the experiences, perceptions and meanings attributed to the use and provision of complementary therapies at the hospice.

The aims were to:

- provide a qualitative account of complementary therapy use within a hospice setting and to seek to understand how complementary therapy is perceived and utilised by patients and staff within a hospice.

- begin an exploration of the geography of care within the hospice and the nature of patient experiences of CT within this environment.
- critically examine the dimensions, places and spaces within the patient/therapist interaction, and using the conceptual framework of therapeutic landscapes, identifying the contribution of complementary therapy towards the care provided within a hospice setting.

Although the aims have been fulfilled in different ways, the focus of the study changed as I followed the data and the findings that arose from them. This is in keeping with the emergent nature of the phenomenological approach.

Within the emergent data, the focus of the study started to shift towards the participants' experiences and perceptions of the spaces and places of hospice day care. During data analysis, elements of space and place became increasingly evident. I began to see a movement between three broad themes, primarily in the stories of the patients. This led to my proposal of three existential modes of being that characterised patient relationships with the spaces and places of the hospice and their lifeworld.

The participants' (patients, therapists and staff) narratives revealed that complementary therapy was perceived by them as so integrated within the landscape of care, so "part and parcel" of day care provision, that it did not stand out as anything more or less extraordinary than other modes of care provided. Rather it complemented other modes of care that shared therapeutic intentions to meet the needs of the patients. CT also created a particular therapeutic landscape, which contributed to the wider landscape of care within the hospice preventing drifting and enabling patients to shelter and venture within this landscape. Potentially CT helped patients to become more 'at home' within themselves.

## Notions of Home

In discussing notions of home, it is important here to illustrate how patients experienced place within the hospice. Their sense of place, as conveyed from the findings, is put into the context of others' notions of place experience. Patients experienced feelings of uncertainty and anxiety due to their illness and its consequences. Essentially, they were no longer at home within themselves or within the world, but drifting. This was due in part to their illness and exacerbated by events such as entering into the unfamiliar place of the hospice. It is possible to explain this phenomenon using Svenaeus's (2001) notions of *homelikeness* and *unhomelikeness*, which illuminate how illness affects our being-in-the-world, and hence I suggest our experiences of place. These notions were first introduced in the literature review, but it is worth reviewing their meanings here. Svenaeus (2001 p94) asserts that health can be understood as *homelikeness*: "a being at home that keeps the not being at home in the world from becoming apparent". It is a taken-for-granted state that we fail to notice, as our basic attunement to the world is one of engagement in activities that matter to us, and therefore have meaning for us. In illness, this attunement may become disrupted, and there is a basic change in the meaning-structure of the world, as our ability to inhabit it becomes impaired in illness, and the self as we lose control over our body thus becoming alienated from it. This results in a disorientedness and alienation from the world and the self, experienced as *unhomelikeness*.

Jager's (1985) description of alienation as the failure of inhabitation and embodiment, as discussed in the literature review, offers further understanding in the analysis of the patients' experiences of drifting, sheltering and venturing. Jager's focus was essentially on inhabiting the world, whilst Svenaeus's focus was essentially on inhabiting the self. Drawing together these two notions provides a way to further analyse the experiences of the participants.

Using Svenaeus's concept it is possible to see how the experiences of patients led to feelings of unhomelikeness. The findings suggest that the hospice environment provided possibilities for finding homelikeness – a coming to inhabit self and world, which was evident in patients' experiences of complementary therapies and the themes of sheltering and venturing. This leads to the assertion that with a loss of homelikeness

within the self, day care provided the possibility of rediscovering homelikeness both in the world and in the self, through various elements of the hospice environment in which patients drifted, sheltered and ventured.

### **Drifting and the loss of home**

In the study, the patients sought to find meaning in their experience of illness, lost and disorientated as they were in a suddenly unfamiliar lifeworld. The everyday taken-for-grantedness of their lifeworld had been disrupted. Outside hospice day care, patients experienced breakdowns in social relationships. Friends and relatives started to treat them differently. Arthur felt he was treated like a “leper” and Andrea (DCP) felt “smothered” by her family. Essentially, they were losing their “usual rhythm” with the world, leading to a sense of unhomelikeness in Svenaeus’s terms or a failure of inhabitation in Jager’s terms. Essentially, they were no longer at home within themselves, or in the world, but drifting.

Unhomelikeness brings with it an awareness of actions and tasks that are no longer unselfconsciously carried out with ease, such as Jim’s desires to go sightseeing or book a holiday. Realistically he knew he could no longer do these things, and that he would end up “stuck in the house and full of pain”. In essence, the patients no longer *inhabited* the world as they did before the disease, but became alienated from a sense of self and from their taken for granted life world. This loss of a sense of being at home in the world was evident in the alienation that patients described. Jim described feelings of alienation, as his attunement to his social world became disrupted:

“People are scared of me now. They don’t come near me because they don’t know what to talk about” (Jim: Day Care Patient - 1st interview)

Jim’s social world changed as he became terminally ill. His friends ceased to talk to him. Arthur discovered this same sense of alienation. His friends, being present in the same room, treated him as though he was no longer there:

“You know they're all talking around me. [...] It's like the old poor lepers isn't it? [laughing] [...] You know, 'oh he's a leper, throw him on an island somewhere'” (Arthur: Day Care Patient - 1st interview)

Arthur's visit to his local public bar where talking with friends was part of his taken-for-granted lifeworld became very different when friends found out he was ill. Rather than being 'at home' in the bar, he found himself on a metaphorical island, cast out of the world he knew before, drifting in a state of unhomelikeness.

Relph's (1976) powerful quote at the beginning of this chapter suggests that home is fundamental to our identity as human beings, a centre of such significance without which we lose our orientation to a sense of self and world. If this is the case then, once patients had lost a sense of homelikeness, they had lost their orientation to the world - their bearing - and so drifted in uncertainty. This was evident in the uncertainty that patients felt about their disease, their future and entering into an unknown place such as the hospice. Jim described feelings of being “left up in the air” in regards to his cancer. To be in the air is to have no solid ground under our feet. He talked about never getting to know his condition in terms of what stage he was at, or whether he was improving or deteriorating. He was describing a detachment from solid ground, as though he had no anchoring in any kind of certainty or knowledge. This concurs with Frank's (1995 p.1) description of illness as the loss of a “destination and map” that had previously guided the life of the ill person.

Jim's developing sense of place at the hospice was evident in his comments at the time of the first interview. He suggested that he was “finding his feet” and that “so far” it had “dispelled the fear and the dread”. He was describing a changing sense of place. Initially he was afraid of entering the hospice. In terms of a sense of place, he was feeling what Relph would describe as existential outsidersness:

“...An awareness of meanings withheld and an inability to participate in those meanings [...] A selfconscious and reflective uninvovement, an alienation from people and places, homelessness, a sense of unreality of the world, and of not belonging.” (1976 p.51)

As his fear and reluctance lessened, feelings of outsidership were gradually replaced by a growing insidership, as he became comfortable, attached and at home within the hospice, understanding its positive significances for him.

I propose that illness may be described as a metaphorical space in itself, in which the patients found themselves lost and uncertain, adding to their sense of drifting. Jim's realisation that there was no general pattern to his disease and that everyone "was taken differently" left him no level of certainty about his future, no sense of order, no definite path or map to follow. Jim had lost his bearing or reference point, and there was a strong sense of wanting to know. This is what first convinced Jim to try day care, so that he could find out about his disease and gain some knowledge of where he was with it, to find a reference point in the space of his illness.

Relph (1976 p.1) suggests: "To be human is to have and to know your place", and Jim did not know his place in terms of *where* he was with his disease. Even the hospice could not fulfil his need for information. His only reservation about the hospice was that the doctors could not tell him enough about his illness and his constantly fluctuating health. He said he never knew what "stage" he was at; and there are further spatial suggestions in his words such as "making improvements" and "going any worse", "back to fed up with myself and stuck in the house". Jim's descriptions indicate progress, direction, and movement or lack thereof if progression is to be seen as moving forwards, and getting worse is to be seen as moving backwards, or being 'stuck' in a place. Being "stuck in the house" reflects Relph's quote at the beginning of the section - home is not just the house one lives in. It is also a centre of significance from which we orient ourselves. Any sense of being at home within the self is for Jim, compromised by disorientation and uncertainty. Jim was essentially drifting in what could be seen as chaos, a space with no order and nowhere to anchor himself with any certainty. I would suggest that his illness could be seen as a chaotic space that he must navigate. Relph (1976 p.43) asserts that places are the basic elements in the ordering of our experiences of the world, citing Max Scheler who writes:

"To find one's place in the world, the world must be a cosmos. In a chaos there is no place."

Drifting is then associated with a chaotic space that has no order and therefore no certainty for those within it. As we drift, we are anxious to find an anchoring point in meaning from which to orient ourselves. Bachelard (1964) suggests that home is “our corner of the world [...] it is our first universe, a real cosmos in every sense of the word.” (1964 p.4) In drifting, there is no sense of home or cosmos. Our corner of the world is no longer ours but opened wide to uncertainty and possibility. As a result, we suffer an increase in existential anxiety as our situatedness-in-the-world becomes less clear and we become less ontologically secure (Giddens 1990). Existential anxieties concern the questions related to the parameters of our very existence in the world; questions about time, space, continuity and self (Giddens 1991). Questions like: who am I? Why am I here? What will happen to me? How long do I have left? Ontological security refers to “the confidence that most human beings have in the continuity of their self-identity and in the constancy of the surrounding social and material environments of action” (Giddens 1990 p.92). Furthermore, ontological security ties in with the phenomenological notion of a practical consciousness that brackets the chaos that exists on the other side of the taken for granted world. This natural attitude “brackets out questions about ourselves, others and the object-world which have to be taken for granted in order to keep on with everyday activity” (Giddens 1991 p.37). This corresponds with Svenaeus’s (2001) idea of a homelikeness in health that keeps at bay the basic unhomelikeness of being in a world that is mine (the taken for granted) but not entirely mine (the chaotic other). Thus in drifting, we also experience ontological insecurity, which gives rise to existential anxieties, leading to a basic homelessness or unhomelikeness.

Within drifting, there is also venturing in terms of a search for meaning - essential to finding homelikeness within the self - and a search for a sheltering environment or homelike place. Thus, these three existential modes may occur simultaneously within one another. I used the same quotes from patients a number of times throughout the findings chapters as one quote often indicated that more than one of the modes were experienced simultaneously, such as Jim’s comments about being “left up in the air” in regards to his illness. In his drifting, he saw the hospice as an opportunity to explore his illness and so ventured in this way effectively seeking shelter.



If searching for meaning implies movement within the metaphorical space of illness, we can consider Tuan's (1977) assertion that pauses in movement are often where we find place. If we consider this in terms of Jim's search for knowing (meaning), then it is easier to understand that Jim was constantly drifting backwards and forwards within the metaphorical space of his illness, yet never *knowing* this space, never pausing enough to get an idea of what stage (place) he was at. If he could find significance and meaning in his illness he would come to a place more easily organised and navigated - a cosmos rather than a chaos, which would lead to a more homelike state in Svenaeus' terms. Tuan further asserts that "space is transformed into place as it acquires definition and meaning" (1977 p.136). Knowledge about his illness would create definition and meaning, giving Jim a place within his illness, the "stage" he spoke of, increasing his level of certainty.

The hospice is then also to be seen as a place of knowledge. Places are to be understood as "centres of meaning, or focuses of intention and purpose" according to Relph (1976 p.22). For Jim, the hospice was his focus of intention and purpose, a centre of meaning, somewhere he could discover "where" he was with his illness in terms of what "stage" or place he was at. The literal place of the hospice helped him to find his inner place within the space of his illness. In providing a sense of certainty, the hospice then also provided a sheltering place for Jim. Patients found shelter at the hospice in a number of ways, but first they had to cross the threshold into the hospice. As I mentioned earlier in this section, one of the most evident examples of patients drifting was during their entry into the hospice. Here they experienced feelings of anxiety and "unhomelikeness".

### **Crossing the hospice threshold**

Patients described feelings of anxiety when first entering into the hospice. During this state of drifting, there existed a continuum of experience, from Jim's strong sense of foreboding and fearful apprehension, to Douglas's (DCP) milder apprehensiveness, whilst others, like Carl (DCP), felt a positive anticipation. To most patients, the hospice was a strange and unfamiliar place, and though some had previous positive experiences of it, there was an underlying theme of anxiety about crossing its threshold.

The patients' preconceptions of what hospice and day care entailed created an anxiety similar to that which most people have experienced in other places such as a new school, a new workplace or entering a hospital. The point between familiar and unfamiliar places may be termed a 'threshold'. The physical manifestation of a threshold is "the strip of wood or stone forming the bottom of a doorway which is crossed when entering a house or a room" (Oxford English Dictionary 2006). Lang (1985 p.206) posits that the threshold is both uniting and separating - and with the acceptance of the threshold, "we install a radical discontinuity in human existence". The threshold then is the boundary between two different worlds. In the case of the patients, the threshold is a division between the familiarity of the known world and the unfamiliarity of the hospice. For some it is also a threshold between the living and the dying, as patients often feared that the hospice was their end place:

"Cause you thought...ninety nine percent of the people thought, like bloody hell, I thought I'd come here to die!" (Arthur: Day Care Patient - 1st interview)

In his phenomenology of transition Lang explores the existential meaning of doors and thresholds. Of doors, Lang suggests "...across their thresholds passes our fate. Through doors we move from one world to another..." (Lang 1985 p.205). This certainly resonates with the patients' words. As the central feature of the door, the threshold brings to fore the taken-for-grantedness of inhabitation by revealing a discontinuity between the outside and inside, the familiar and unfamiliar. At thresholds, an unhomelikeness threatens to reveal itself, as we become truly aware of our taken for granted situated-ness within the world:

"By honouring the threshold, I accept an essential limit in existence, marking a division in the homogenous space, establishing an outside and inside, installing a difference. As a radical discontinuity and a place of transition, the door is also a reminder to me of my final threshold – death's door. By accepting the threshold as an undeniable limit in life, I welcome the tragic dimension of existence. At a doorway there is an intensification of life; I become truly aware of shifts and turns in life, of openings and closing, of beginnings and ends. Here I live my transitions concretely." (Lang 1985 p.207-208)

The passage above helps to make sense of the experiences of the day-care patients who came to recognise the hospice as the final threshold. Patients acknowledged the *essential limit* and *the tragic dimension of existence* and voiced an acceptance and resignation to the *undeniable limit in life*:

“I never thought I would ever, you know...become part of it. But there you are, that's life isn't it?” (Derek: Day Care Patient - Photo-elicitation Interview)

Derek (DCP) regularly gave donations to support the hospice from the outside, and yet he was now inside, more a part of it. The resignation in Derek's words is clear as he accepted he had crossed a threshold to become part of the place.

Lang (ibid) also spoke of an ‘intensification of life’. The aim of day care was to help patients to live a fuller and better quality life. They felt they had made achievements, they found a supportive social group and community. Douglas suggested they had the opportunity to “play”. As patients entered into the day care unit they became more aware of the ‘shifts and turns’ as the direction of their life changed with their illness, as their health status changed, as they became part of the day care community. The hospice for many also represented a positive opportunity to learn about their own disease, to try new things, and to meet others in the same situation. These are the ‘openings’ and the ‘beginnings’ of new insights, relationships and experiences and they are part of both sheltering and venturing. Yet, they were also aware of ‘closings’ and ‘endings’, as they were witness to the dying of others from the day care community, a reminder of their own finiteness. In the hospice, patients certainly lived their transitions concretely as Lang suggests.

As stated earlier, patients' narratives revealed various levels of anxiety resulting from the prospect of facing one's death and their perception of the hospice as a place of ultimate transition, as an ‘end place’. Anxiety as Tuan describes it is:

“...a diffuse sense of dread and presupposes an ability to anticipate. It commonly occurs when an animal [human being] is in a strange and disorienting milieu, separated from the supportive objects and figures of its home ground.” (1980 p.5)

Becoming separated from supportive objects and figures of home ground is essentially what happened to some patients. They experienced illness as a disorienting milieu in which they drifted away from a homelike familiarity with the world. The physical landscape of the day care unit and other areas of the hospice were constructed to include supportive objects, forming a representation of a homelike place in an attempt to reduce such anxiety. However, what became evident in the patients' narratives was a sense of *threshold anxiety* – a foreboding and uncertainty at crossing the threshold to the hospice in the first instance.

This experience is recognised in the German language as '*Schwellenangst*', a compound of '*schwelle*', which means 'threshold or barrier, sill, sleeper, or step' such as that forming the bottom of a doorway; and '*angst*' meaning 'fear' or 'anxiety'. So, it is the fear or anxiety of entering an unknown or unfamiliar place, which I will refer to from now on as *threshold anxiety*.

The unhomelikeness experienced in illness is in a sense augmented by the unhomelikeness (the uncanny or *unheimlich*) felt in threshold anxiety – the perception being that the hospice will be anything but homelike and quite the opposite. Jim's anxiety was particularly evident, as he recalled having constructed a dark and disturbing place:

"What I feared most was erm...it was one of those grab places, they get you, they take you in and er...and you never come out of these places... ..I always expected long corridors and dark passages... ..and I just found the whole thing you know, in my mind very disturbing." (Jim: Day Care Patient - 1st interview)

Jim's negative perceptions of the hospice quickly changed as his sense of place changed. Arthur thought he was coming to the hospice to die, but was "astonished" by what he found. Their anxiety is in contrast to others who had previous experience of the hospice, such as Percy (DCP) who had an overall positive view as his brother had died in a hospice; and Carl who had worked at the hospice previously and knew people who worked there.

## **Complementary therapies as a way of finding home**

In discussing the place of complementary therapies within hospice day care, it is possible to ask the question, where does CT fit into drifting, sheltering, venturing and the notion of homelikeness? Firstly, it is evident in the findings that many aspects of the hospice reduced a sense of drifting, leading to a sense of sheltering, and complementary therapies were perceived by therapists and staff as a particular “way in” to the hospice. It was seen as something that would reduce the patients’ threshold anxiety, enabling them to enter into the hospice, then to shelter and venture. As can be seen in the findings, CT was deliberately offered as something to help combat threshold anxiety and the perception that hospice was ultimately an ‘end place’. As Jackie stated:

“So, it’s quite a good way of getting them over the threshold to the hospice without feeling as soon as they’re associated with it they’re going to drop dead because that’s what a lot of people think.” (Jackie: Contract Therapist - Photo-elicitation Interview)

CTs helped to stop the patients from drifting in the sense that they were immediately available to the patients, there was no waiting around for an appointment, creating a sense of easiness and accessibility. CT changed the patients’ sense of place, encouraging feelings of safety, comfort and relaxation rather than anxiety, though it was noted by one of the therapists that this relaxation was sometimes gradual, as those who had not experienced any CT before became accustomed to it. This potentially represents a paradox, as some patients had never tried CT before, yet it was used to help reduce their anxiety about entering a new place. I feel that it worked because CT was introduced as something potentially pleasurable and relaxing, as something unlike medicalised interventions, and its intention was different. It was not intended in any way as a cure for cancer, but to invoke feelings of well-being. This intention was recognised by patients like Jeffrey:

“I felt as if she [the therapist] was trying to make me feel well and strong, that sort of thing.” (Jeffrey: Day Care Patient - 1st interview)

Douglas spoke of a “feeling of good will”, while Arthur recognised that the intention was not curative:

It’s not that she’s cured me. But, she’s doing something that relieved a bit of pain. [...] Well it was great.” (Arthur: Day Care Patient - 1st interview)

Feelings of good will, support and healing intentions add to the feeling of being sheltered in a therapeutic place.

The physical environment of the CT room was constructed to represent a less clinical and more “homely” environment that would aid relaxation. The ‘tools of the trade’ such as the treatment couch and the trolley of oils would be out of place in a homelike setting, but the therapy room was still considered to be *more* “homely” in comparison to the physiotherapy room, which was described as “harsh” “medical” and “technical”. A more homely environment added to the sense of a place in which patients could shelter, being at-ease with the therapist, feeling relaxed, cared for, comfortable and safe.

The change from drifting to sheltering was evident in patients’ changing sense of place. Arthur described the hospice as “heaven”. His first experience of CT left him with the impression that he had walked into an “unknown world” where everything “opened up from head to toe”. In this context, I feel the “unknown world” was one of positive possibility in which Arthur had the chance to venture into new experiences and ways of being cared for, one in which he stated he could “get a little more life” out of himself. He expressed an immediate “confidence” in the place, which helped to make him feel more ontologically secure. Confidence in his surroundings and the actions that took place within them signified a halt to drifting and the beginnings of sheltering, in the sense that once threshold anxiety subsided, uncertain spaces started to become sheltering places. As Bachelard (1964) noted, wherever human beings find the slightest shelter, notions of home begin to emerge.

Arthur’s comment about a world where everything opens up from head to toe is important, as it indicates that CT helped patients to reconnect with their body, and in a sense to venture within the internal space of their body. The effects of aromatherapy

massage and reflexology led to a sense of embodiment within the experience of being cared for. With embodiment, there is a return to the body, from which patients felt alienated. This was evident in the data as Jackie (Contract Therapist) spoke of relaxing patients and reminding them of how their body felt to be relaxed and ‘normal’ when they were healthy, different to the state of anxiety and tension they experienced in illness. Douglas described massage as someone “talking” to him “through their hands”, what I would describe as a ‘physical conversation’ which indicates an embodied sense of being cared for. Jim, spoke of acquiring ownership of his feet again after he had felt as though they were no longer a part of his body. His description of the effects of reflexology indicate a sense of regaining bodily wholeness:

“I could feel the heat coming back, the warmth of the blood. I could feel all the tension coming out like you know and oh! [...] Oh it was so...it were lovely...I’m bloody near dancing coming out of there like because I can feel everything in my feet, lovely, it’s great!” (Jim: Day Care Patient - Photo-elicitation Interview)

Cathy (Staff Nurse) spoke of patients being “blown apart by the diagnosis”, regaining a sense of themselves through CT. The effects of massage and reflexology seemed to reconnect the patients with their physical bodies leading to an enhanced sense of embodiment.

If we return to Svenaeus’s theory of homelikeness and compare it Jager’s theory of alienation and inhabitation, we can see that complementary therapies provided the patients with a move towards homelikeness. As stated by Jager (1985) earlier, “A fully inhabited world is also at the same time a fully embodied world. Alienation – a painful discordant embodiment – is itself a loss of access to the flesh of nature [...] Alienation is ultimately the failure of inhabitation and embodiment.” Jager was talking about inhabiting the world as in the “house or a city” (ibid p.218) whereas Svenaeus (2001) was essentially talking about alienation as the failure to inhabit one’s own self. Despite Jager’s acknowledgement that the body is connected to the world, through the embodiment of the objects within the world, he does not propose that there is also an inhabitation of the self as Svenaeus does. Svenaeus (2001) provides a link, through his theory of homelikeness. Using both Svenaeus and Jager’s notions it is possible then to

see, that complementary therapies helped patients to reconnect with their own body, thus finding a sense of inhabitation and embodiment that moves them closer to a sense of homelikeness, helping them to feel at-home both within themselves and within the world.

Complementary therapies also provided a shelter for the patients in the sense that they created feelings of being safe and in control. CT fostered a sense of trust between the patients and therapists, which potentially heightened feelings of ontological security providing what Giddens (1991) refers to as a *protective cocoon*. Complementary therapy strengthens the protective cocoon against feelings of ontological insecurity and existential anxieties, those elements that give rise to unhomelikeness. I would suggest that while this concept works well, the relationships between patients and other members of staff in day care, strengthened feelings of trust and ontological security.

CT was one of many modes of care offered as a choice to patients. Providing a choice creates autonomy for patients. It was a way for patients to take part in their own care, “a vastly more interesting way forward” as Douglas described. Human agency plays a critical role in the creation of what Relph (1976) called “authentic places” (Williams 1998). Human agency, in combination with feelings of intimacy, trust, security and good-will between the therapists and patients created what Gesler (1992 p.738) termed “networks of interpersonal concern”. These interpersonal networks are found in caring “authentic” places such as “therapy rooms”, as opposed to inauthentic (uncaring) places, which invoke feelings of “spatial separateness and isolation”. The combination of human agency and an authentic place experience, together with a homely physical environment, contributes to the development of what Gesler (1992) termed a ‘therapeutic landscape’. Complementary therapy in this sense adds to the creation of a holistic landscape of care, and further strengthens feelings of psychological rootedness, ontological security and “homelikeness”.

### **Blurring the boundaries of therapies**

The data suggests that CT was integrated as “part and parcel” of the day care service. The fact that it did not stand out as anything more or less extraordinary than other



elements of care such as hairdressing, or nursing care, shows that it complemented and was aligned with these elements of the care package, demonstrating its integrated fit into a holistic landscape of care. The fact that patients, staff and some therapists considered CT to be much wider than its traditional definitions, even including hairdressing as a CT, showed how the context of the hospice affected how CT was perceived when juxtaposed with other elements of the day care “package of care”.

This effect was also evident within the hairdressing service. The context of the hospice and the actions and relationships between hairdresser and patients within the salon space, was different to that of a high street salon, yet encouraged feelings of normality and everydayness, leading to a sense of sheltering. The hairdressing experience within the hospice had a more therapeutic quality in the opinions of the hairdresser and the staff. The maintenance and re-creation of a more positive self-image for patients influenced this perception. The hairdresser herself even considered that she might be more aligned with complementary therapies. However, this does not mean that hairdressing can be classed as a CT, but that it shares a focus on meeting the holistic needs of the patients through its therapeutic intent, complementing rather than constituting a formal complementary therapy.

### **Coming to Shelter**

There is an open dialectical relationship between our imagination and reality as we see it. Referring back to Bachelard’s quote at the beginning of chapter 6, Bachelard alludes to a relationship that compels us to conjure *home* as an ideal. One of the criticisms levelled at the use of the word ‘home’, is that not all home places are ideal - homes may be the site of struggle or violence, disharmony, and domestic anxiety (Blunt & Dowling 2006). But it is out of a marriage between imagination and yearning that an ideal notion of home is born out. It is this ideal notion of home that is created at the hospice.

I suggested earlier that the patients’ experiences of the world outside the hospice could be characterised by the uncanny or the unhomelike, and that hospice day care offered a place that helped them to reorient themselves towards a sense of homelikeness. Tuan

(1977) asserts that the home becomes even more sheltering in times of sickness and vulnerability, and that our lasting affection for home is in part due to the nurturing and intimate experiences we associate with it. The hospice offers an alternative homelike place where patients can shelter in the certainty of the intimate and nurturing care provided. It offers the essence of the notion of home and a re-orientation towards homelikeness. This was evident within the concept of sheltering.

Sheltering was part of the lived experience of patients. Patients became certain of being cared for. This was achieved through supportive relationships that built trust between the patient and the staff and therapists. The patients' trust in the care provided at the hospice strengthens the notion of day care as a sheltering place. Trust is vital to feelings of ontological security. As I stated in the findings, if we are never certain of when or how we will receive care, we cannot shelter within its integrity, as its structure is compromised by an uncertainty that weakens its essential nature.

Patients perceived the staff as "going out of their way" to care for them, and they perceived that nothing was too much trouble for the staff. A good example of the certainty of care was given by Percy, who stated that his needs (such as a glass of water) were never trivialised. If it were not possible to meet his needs at that particular moment, he was given a point in time when they would be met. Giving a patient a time when something would be done creates for them a "fixation in the spaces of the being's stability – a being who does not want to melt away..." (Bachelard 1964 p.8). This creates a stronger sense of ontological security. By creating a bearing or location in temporal space, it provides something that is certain for the patient to hold onto, so they are not left drifting. Additionally it strengthens the network of interpersonal concern (Gesler 1992). Thus, it adds to an authentic place experience and provides a shelter from uncertainty.

Patients' relationships with the staff, and the place itself, were also characterised by what Jim referred to as 'closeness'. Jim said he was "closer to this place" than he was with other places associated with care and his disease, because he found he could relate with the staff in an "easy" manner. Relationships between patients and staff/therapists were characterised by easiness. Patients could talk to the staff and therapists at depth about their illness, or about other things, without the pressure of time. The feeling of *at-*

*easeness* is one of the five fundamental aspects of the experience of *at-homeness* (Seamon 1979). Seamon describes at-homeness as:

“...the taken-for-granted situation of being comfortable and familiar with the world in which one lives his or her day-to-day life. Observations on home point to five underlying themes which mark out the experiential character of at-homeness – rootedness, appropriation, regeneration, at-easeness and warmth.” (Seamon 1979 p.78)

Rootedness is found within various elements of patients’ sheltering experiences. This was evident in the way that patients, staff and therapists related to each other. There was a familiarity amongst the patients and staff, of ‘being known’ that helped patients to feel comfortable and at home. Douglas describes this feeling of being known and how it created a sense of homeliness for him:

“Because you were aware of people knowing what you...who you were and what was wrong because you’d explained, and so on. So there was a real sense of...I suppose a sense of coming to a home, rather than to a house. [...] It seems appropriate. Because it’s err...the same feeling I’d have going into my own home.” (Douglas: Day Care Patient - 1st interview)

Douglas seemed to know that a house is not necessarily a home. Feelings of familiarity create intimacy and warmth. Calling a patient (or anyone) by their first name is also a gesture of familiarity and intimacy. For Percy this gave him a “big kick” and “the right sort of support”. Intimacy is from the Latin *intimus* meaning “inmost” (Oxford English Dictionary). Using a person’s first name to address them is at once an act of familiarity, but also a calling into belonging, an invocation of existence *within* this time and place. It also suggests that the named is *inside* the confidence and care of another. Huebener (2007) suggests it creates an explicit connection between people, place and history:

“Naming is a vocalizing of belonging, an incorporating of the named into one’s life story, a making explicit of a particular connection: whether this connection is with another person, a nonhuman aspect of one’s surroundings, or the past.” (Huebener 2007 p.618)

As such, using someone's name in such a way has permutations through social, physical, symbolic, temporal and psychological landscapes. Using someone's name is a powerful way of calling them into place. It creates a sense of rootedness, confirming that one is known within a place, belonging in the *here* and *now*. In combination with the caring attitude of staff, it also created a sense of familiarity, at-easeness, and warmth. Seamon (1979 p.84) describes *warmth* as "an atmosphere of friendliness, concern and support that a successful home generates". Feelings of rootedness and warmth were also felt within the sense of community within the hospice. Douglas stated that despite being "a rather odd group of people" there was a normality to the life they led, strengthened by the sense of being part of a community of people who shared the same situation. Carl referred to day care as like a "club", and Bill talked of "friendship" and "comradeship" while Jeffrey suggested "brotherhood". Whereas outside patients experienced alienation from others, day care provided a community for patients where there was a possibility of acceptance and a reconnecting with people. It provided a way of coping. Patients like Jim who lived alone, found value in learning how to reconnect with people. He suggested that: "loneliness is no cure for nowt". Those living alone found comfort in the closeness of people, and the community created feelings of warmth, characterised by friendliness, support, concern, and feelings of security, contributing to feelings of at-homeness. Community also created feelings of rootedness, which are vital to the realisation of at-homeness. In describing rootedness, Relph (1976 p.38) asserts that:

"To have roots in a place is to have a secure point from which to look out on the world, a firm grasp of one's own position in the order of things..."

Day care provided a secure point from which patients could look out on the world (to venture). Their sense of rootedness was evident in the notion of the community in which they sheltered and in which they were known. A symbol of rootedness, the 'butterfly monument' photographed by Lucy (therapist), was a shelter for memories - an abiding place that spoke of not just community, camaraderie, continuity and permanence, but of a care for and rootedness within place.

Rootedness is also about caring for place, and the places to which we find ourselves attached literally become what Relph calls "fields of care". These involve more than a

passing concern for place, but a “real responsibility and respect for that place both for itself and for what it is to yourself and others” (Relph 1976 p.38). This was evident in the concern that staff and patients had for day care. Susan (staff nurse) related how patients were upset that during developments at the hospice, the Day Care unit had not been refurbished. She spoke of a need to maintain the physical appearance of Day Care and there was disappointment amongst patients and staff as it had been neglected. Derek also expressed concern over the developments, that things could “go out of control”, somehow effecting the essential nature of day care. He wanted to *spare* day care from unnecessary change and exploitation. This ties in with notions of rootedness as a kind of “sparing” – “a willingness to leave places alone and not to change them casually or arbitrarily, and not to exploit them” (Relph 1976 p.39). There is also a disruption to appropriation (Seamon 1979). Appropriation involves a sense of possession and control over places and forms a part of the experience of at-homeness. Seamon suggests that “appropriation is disturbed when the home is infringed upon in some way” (1979 p.80). The work within day care seemed to have brought to light a sense of appropriation amongst the staff and patients and therefore adds to the sense of at-homeness.

### **A home from home**

As we have seen, from drifting, patients came to shelter in various ways that became evident in their place experiences; through a certainty of care, a sense of rootedness and at-homeness, and feelings of ontological security, redolent of that found in ideal notions of home. The hospice is essentially constructed in a physical sense as a “home from home”. Bernadette chose the location for day care out of what seemed a strong attachment to place:

“I know that you can make a place look homely, and the atmosphere will still be there because I think that’s the overall atmosphere of the hospice, but I just felt that this up here was special. And the patients felt the same as well.”  
(Bernadette: Day care sister - 2nd interview)

Bernadette describes a sense of rootedness and attachment to place. Her sense of place was evident in her feeling that the location of day care was “special”. She encouraged patients to view day care as an extension of their own homes. This concurs with Godkin (1980 p.82), who suggested the creation of a homelike environment in a palliative care setting emphasised a continuity in life that was “reflected in and symbolised by the construction of a physical setting which incorporates items which are familiar to patients.” Relph asserts that in the creation of an ‘authentic place’ there is both a selfconscious and un-selfconscious design process:

“The self-conscious and authentic sense of place is associated with a design process that is goal oriented and may involve finding innovative solutions to problems; it is founded on a complete conception of man and his relationship to the gods and nature, and on the possibilities of expressing this in particular settings. The result is usually places which possess both internal harmony and which fit their context.” (Relph 1976 p.67)

Bernadette in her caring (rootedness) for place consciously made the environment homely, without altering unnecessarily the spirit of the place, its “special-ness”. As discussed in previous chapters, the hospice was originally a private residence, and evidence of this was visible in the interior of day care and the “old part” of the hospice. Bernadette tried not to alter this context, or its essence, whilst still trying to achieve an environment that suited the needs of terminally ill patients and the staff who cared for them. Physical and symbolic objects such as the mismatched furniture, footstools, fresh flowers on the balcony, created a sense of homeliness, adding to the spirit of the place. Bernadette also acknowledged that homes are full of risk and she had tried to capture this by introducing coffee tables that were potentially trip hazards but which added to a feeling of authenticity. The mismatched furniture created a less institutional, more informal homely space. The kitchen and the living room were “domestic” and “ordinary”, generating what Douglas referred to as “very positive vibes”. These positive vibes can be equated with a positive sense of place. Douglas’s comments on the living room were particularly poignant in terms of Seamon’s (1979) notion of at-homeness:

“The key thing is, is that most of us have got houses, or lived in houses, or know people who’ve got houses, in which their living room is identical [to this one]. That to me has a warmth. A comforting feel of home about it. And it’s clean, it’s tidy, it’s neat. It’s a place where you can go and sit and enjoy the atmosphere.” (Douglas: Day Care Patient - Photo-elicitation Interview)

Comfort, warmth, and an enjoyable atmosphere create feelings of at-homeness for Douglas. Added to this is the sense of safety that patients felt at the hospice. As Jim described, the hospice was somewhere he could relax in the knowledge that he was secure:

“It’s pleasant it’s relaxing and you feel safe. And that to me is the most important thing. [...] That...you do feel safe you know, you feel like you can talk about owt. You feel like you’re amongst friends.” (Jim: Day Care Patient - Photo-elicitation Interview)

The natural landscape of the gardens also contributed to a feeling of being in a home from home. It provided a shelter from the “hustle and bustle” of Carl’s home life, a place, and a time to be alone, to “chill out and relax”. Feelings of at-homeness were deepened by the time-space routines (Seamon 1979; 1980) that strengthened Carl’s sense of rootedness.

### **Venturing – points of departure**

Homelike places provide a centre from which we move out and venture into the world. As Relph states, home is “the point of departure from which we orient ourselves and take possession of the world” (Relph 1976 p.40). The hospice offered various points of departure and opportunities for the patients to orient themselves, to find their bearings and to re-engage with their life.

Day care was the point of departure, for many patients to venture out into the world. For some it was a place in which they had a sense of living their life. In venturing, they found opportunities to reach beyond their sheltering and homelike place, to a world

from which some felt alienated. Day care facilitated a re-attunement to the world, a re-establishing of some level of homelikeness. This was accomplished by providing a place in which patients felt at-home, safe, secure, comfortable and cared for; a place in which they found a sense of belonging and community; a place in which they were considered normal. This was evident in their experiences of sheltering. Sheltering implies pause, and in pause we find place, whereas venturing implies movement, and with movement, there is a basic transcendence of the present condition (Tuan 1977). Not only did the hospice represent a pause on the patients' illness journey, where they could rest and be nurtured, it also offered patients opportunities to venture forward to transcend their current state of unhomelikeness, by moving towards something more meaningful. If illness is described by Svenaeus as the experience of meaninglessness (incomprehensibility), then venturing offered the opportunity to find meaning. Simply having time to explore one's disease was one of the most valued opportunities, and in such exploration there is the promise of finding meaningfulness and therefore a homelikeness and re-attunement to the world.

Any movement then becomes a transcendence of the previous state, implying progress. Douglas described the opportunities that day care offered - such as complementary therapies and painting - as "a vastly more interesting way forward" which, facilitated by a supportive and encouraging network of people, enabled him to see beyond his sphere of illness. He was learning new skills and new ways of thinking and new ways of taking part in his own care, enabling him to adapt and cope with his illness, to live his life and not the disease as he stated.

The natural landscape and open spaces of the garden was also a place of venturing. Gardens are part of a shared domestic culture and so familiar to most, creating a sense of being at-ease, a common ground on which to relax. It also represented a place apart from the hospice, and therefore less associated with illness. It was essentially an escape from the confines of a building, which to some patients could seem oppressive when they needed to talk. When talking about a patient who was suffering with particular anxieties Cathy (staff nurse) said it felt like the walls were closing in, and there was "no space and no development". Yet when she took the patient into the open spaces of the garden he began to "open up" and talk. In venturing into the garden, the natural landscape facilitated a venturing in thought:



“Spaciousness is closely associated with the sense of being free. Freedom implies space; it means having the power and enough room in which to act [...] Fundamental is the ability to transcend the present condition, and this transcendence is most simply manifest as the elementary power to move.”  
(Tuan 1977 p.52)

The open spaces of the garden imply a freedom and the possibility of movement and thus a transcending of the present condition. Cathy also spoke of how patients formed an attachment to the places in which they first began to talk, often returning there when the need arose again. This shows how places become significant centres of meaning, often unselfconsciously, showing a deep sense of place (Relph 1976).

Venturing into the garden after dinner was part of Carl’s time-space routine. The routine deepened his sense of place and rootedness, and therefore his experience of sheltering, while he enjoyed the garden because it allowed him to “get back to nature”, to return to something restorative. Thus, the garden was both a place of venturing and sheltering for Carl. As a place of contemplation, the peace of the garden allowed Derek to venture physically away from the hospice and psychologically in terms of his thinking. He contemplated his past, present and future as he searched for meaning in his life and for a sense of homelikeness.

The social landscape of day care also offered chances to venture and to find meaning and value. Jim learned how to be with other people again. He felt loneliness in his own home, describing himself as sitting alone and worrying about the future. In venturing, he discovered that day care was somewhere he felt a sense of achievement as he learned new ways of being. He spoke of coming everyday if he could, and missing it when he could not, indicating a sense of rootedness and attachment to the place (Relph 1976).

In providing opportunities to venture, day care helped to make the patients’ world bigger. Julie (palliative care specialist) described the patients’ worlds as getting smaller as they became ill and stopped doing what they previously took for granted, for fear that their health would prevent them in some way, or suffer as a result. The everyday taken-for-grantedness of their lifeworld had become disrupted. They experienced an

alienation from, and a shrinking of their lifeworld. Julie's aim was to help patients to see beyond the hospice, to engage with the world again, in a way that would enable them to live a fuller life. The opportunities available in day-care such as complementary therapies, painting, craft, hairdressing, all represented an expansion of their world. They offered opportunities to venture in the hospice, but could also be found outside the hospice when they were ready to venture further.

### **Sheltering and venturing: dialectic experiences in hospice**

Venturing and sheltering represent a dialectical experience. In sheltering, we have seen venturing and vice versa. One incorporates elements of the other, as they must. One cannot shelter forever without moving out of place. Patients found shelter in the hospice, yet ventured in different ways within the sheltering environment. Carl's time-space routine of visiting the garden after lunch was a venturing out of the hospice into the garden, but also sheltering in the sense that it was restorative and helped him to digest his food and to feel at-home getting "back to nature". Venturing implies reaching, but it is always reaching out from a significant place. Dialectical relationships are seen throughout phenomenological perspectives of place; an inside that is separate from outside, dwelling and journey, movement and rest, home and reach, centre and horizon - Relph (1976), Buttimer (1980) and Seamon (1985) all suggest that human existence is experienced through dialectical relationships and these are fundamental to notions of home:

"Like breathing in and out, most life forms need a home and horizons of reach outward from that home." (Buttimer 1980 p.170)

If we do not venture then the home stagnates. It is moving out and returning that keeps the notion of home alive. In venturing within the physical places of the hospice, Douglas described a journey: he perceived that places within the hospice were associated with certain elements of care, describing the corridors as "places to go, where you get another crack at getting you involved in an organic process of taking care of yourself". This implies a sense of venturing, where the patients have the opportunity to be involved in their own care. He was essentially reaching to extend his

horizons, to find something new that held the possibility of improving his condition and possibly, reinforcing his sense of hospice day care as a sheltering place. In his venturing, he discovered new places and new people. He also found that in reaching beyond his homelike place, his perception of the hospice changed in a positive way; “Downstairs” was usually associated with dying, despite patients knowing this was not always the case. He also discovered that downstairs included positive places associated with the treatment of his illness. He extended his horizon by venturing, and his perception of hospice as ultimately an ‘end place’, was re-placed by a more positive sense of place.

However there were limits to the patients’ venturing. To venture into some places risked a disruption of ontological security and a return to drifting. In refusing to venture into some places within the hospice, patients were essentially protecting themselves from the incomprehensibleness (meaninglessness) that they associated with dying. Douglas knew that the back stairs from day care led down to the in-patient wards. He photographed the staircase leading from day care to the in-patient wards, to show symbolically what he did not want to venture into physically. As he said “I don’t think to be honest it’s going to do me much good to find out.” Downstairs for Douglas still represented a place for the dying. Jim also imposed limits upon himself. He still experienced anxiety when approaching corridors to unknown places, fearing that they led to the in-patient wards. In his mind, he had created boundaries beyond which he would not physically go for fear of what they might have revealed. Patients defined their own limits to their venturing, beyond which the unhomelike threatened their sense of homelikeness. Not all of the places within the hospice created a sense of home. I feel that the homelike place of day care was situated on the boundary of a place that for the patients represented the least homelike place.

If there exists a dialectic of sheltering and venturing in which we are constantly moving between the two, then what does drifting represent? Drifting represents the loss of shelter, unhomelikeness, disorientation, existential outsidership, the uncanny, uprootedness and a basic alienation from the world. Drifting is the uncertainty experienced in anxiety, but even in this state, there is a yearning to find shelter and meaning, and these are found through venturing. This yearning is a basic intention to dwell in the world, a yearning to inhabit, to find a home. The hospice day care unit

provided patients with a homelike place, from which to find a sense of homelikeness. Essentially the patients' experience is one of finding a sense of home.

### **Conclusion – Finding a sense of home**

In writing this thesis, I have used the three existentials of drifting, sheltering and venturing to draw together a phenomenology of illness and a phenomenology of space, place and home. Finding a sense of home is key to the synthesis of these two phenomenologies. I agree with Svenaeus, that illness can be seen as unhomelikeness, in the sense that in its occurrence we experience a loss of meaning and alienation from the self. However, I think that homelike places help us to become re-attuned with homelikeness within the self. If unhomelikeness is equated with illness and a sense of drifting, then homelikeness is equated with a feeling of at-homeness and sheltering. Venturing further strengthens the notion of home as a significant anchor or point of orientation with the world.

From the experiences and perceptions of patients, staff and therapists, it has been possible to see that a combination of physical, social, psychological and symbolic elements, visible through drifting, sheltering and venturing, has helped patients to find a sense of home, both within the self and within the hospice. The homely elements of the hospice as a place, helped to mediate the patients' fear and anxiety, increasing feelings of ontological security and homelikeness within the self, while decreasing existential anxiety and unhomelikeness. This illuminates the hospice day care as place where the patients' experience was essentially one of finding a sense of home, both within the self and within the hospice.

The use of complementary therapies in day care contributed to the alleviation of feelings of drifting, creating a more positive sense of place. They created feelings of sheltering for the patients, taking them back to their body, and in a sense returning them to a sense of homelikeness within the self. Furthermore, they enabled patients to venture into new ways of caring for themselves, providing "a way forward" in terms of living with terminal illness. By creating a particular therapeutic landscape,

complementary therapies also strengthened the overall holistic landscape of care of the hospice.

### **Limitations of the study**

Within any study there are limitations, and during the different phases of the project, as my skills, knowledge and experience developed, I recognised them. Also, in discussing the project with my supervisory team and those with whom I had corresponded, other limitations were identified. I will now discuss them here.

One limitation as mentioned by Seamon in his correspondence (See Appendix 5) was that there was a uniformly positive account of the hospice, and this may be because those who did not 'take' to the hospice, and did not return, were not interviewed. Few of the patients revealed any negative perceptions of the hospice, with the exception of the seating arrangements in the day care room and fears surrounding in-patient places. However, the lack of negative findings in this study is also in line with the findings of other studies involving complementary therapies in palliative care settings (Gambles, Crooke, & Wilkinson 2002) and I suggest that because patients freely opted for complementary therapies the study is biased in favour of these. Furthermore, patients who did not return to the hospice after their first visit, possibly did not because as Seamon mentioned, it was a function of their individuality rather than anything fundamentally wrong with the hospice. Rasmussen and Edvardsson (2007) paraphrase Florence Nightingale, who asserted that the art of nursing is to provide an environment that creates possibilities for healing, but the healing must come from within the person. "Thus we can provide the possibilities - but never entirely secure the outcome" (ibid p.129). This suggests that though this hospice environment may provide possibilities for healing, it may not suit everyone's needs or preferences.

In terms of the sample characteristics for those who took part in the study, there were more male patient participants than female. The study may have been a more attractive proposition for male patients as it gave them something to 'work' on. Also, all the nurses in day care were female. There was only one other male volunteer besides myself that I ever saw in day care. In a preponderance of female patients and staff,

working on something with a male researcher may have been more appealing to the male patients. They may have felt more comfortable talking to me about their experiences than to a female.

In light of the difficulty in attracting patients to a palliative care research project, and in recognition of time constraints, it was pertinent to accept whoever met the inclusion criteria regardless of age, sex or any other demographic factors. Future studies might include a more balanced perspective by recruiting more female patients, though I do not feel this detracted in any way from this study.

Also to ensure anonymity, few demographic details of the participants were collected. However, it was not my intention to study these demographics as my focus was on people's experiences and perceptions of CT and the hospice environment, and demographics would not have added to a phenomenological perspective.

Despite recruiting all patients who met the inclusion criteria regardless of demographics, time constraints and the nature of palliative care research meant that I did not manage to recruit my anticipated target minimum of 12 patients. Although I recruited 12 patients, five patients died during the course of data collection. One lady died before she had taken part in her first interview. Out of 12 patients, five dropped out after their first interview, due to either a deterioration in health or because they could not cope with the study. Five patients managed to finish the study, completing both interviews. In light of this study, and in future studies I would not employ so many data collection methods. I feel that the data from the photo-elicitation interviews would be enough in future projects, representing a more manageable task for patients, and a smaller time frame for completion.

The hardest part of the recruitment process was achieving consent from the patients as close to their first admission as possible. Although the day care sister tried her best to identify suitable "well patients" interested in the study, I began to accept that due to sickness, prior engagements or other events some of the patients had been attending day care for a number of weeks before they were given an information pack, and the six week period between the first and last interview with patients would almost always be longer than six weeks. I was also overly cautious when ensuring I was not pressuring or

coercing patient participants into taking part in the study. I have learned that patients are often more resilient than I had at first thought. In Chapter 3, I mentioned that I had become a little more astute in the recruitment process, and I feel that in the future I would not be so overly cautious about approaching patients.

I also feel that, the questions I asked participants concerning both complementary therapies and space and place experiences could perhaps have been more direct and focused. I was careful not to ask leading questions but feel that I may have asked/framed more informed questions in hindsight.

Many of these limitations have been due to my own cautious and careful approach to this research. They have resulted from my limited experience as a researcher, my concern for those taking part in the research - in particular the patients - and as a result of the methodology and methods used. Whatever the limitations of this research, these limitations have served to broaden my own knowledge, skills and experience as a researcher.

### **Contributions to knowledge**

This project has made a number of contributions to knowledge in the areas of complementary therapies, humanistic/existential geography and palliative care.

I have shown that the use and provision of complementary therapies within the hospice was affected by context and place. Complementary therapies were used in a particular way within the hospice setting. In this study I attended to how complementary therapies were used by staff to generate a more positive sense of place, and specifically as a way of helping patients to mediate threshold anxiety (*schwellerangst*).

My phenomenological approach revealed some essential characteristics of the meaning-structure of the lives of terminally ill day care patients within this setting. This adds to an understanding of *how* terminally ill people experience the hospice as a place, and *why* they experience it as they do. Such an understanding could contribute to a more humanistic approach to developing hospice environments, with a deeper

understanding of the social, psychological, physical and symbolic landscapes that constitute a holistic care environment.

Also, through a phenomenological approach I have identified three existential modes of being that have illuminated the experiences of hospice as a place for patients, staff and therapists. These three existential modes make a contribution to the theory and conceptual development of the field of humanistic geography and have value, in that they could be applied as a broad interpretive framework to explore the lived experiences of place and how we understand human experiences of being-in-the-world in specific contexts and settings, and at various stages of the life course, such as during health and illness and approaching death. This framework may be used to explore other hospices and healthcare settings (see later section on implications for practice and recommendations) and wider settings such as the experiences of children growing up with a disability.

Drifting, Sheltering and Venturing also make a contribution to the theoretical development of the concept of home as both a place and as a way of being-in-the-world that is affected during (terminal) illness. These modes may help to illuminate a more complex understanding of how particular settings are experienced and possibly how they may be improved or developed in such a way as to optimise the physical, social, psychological, symbolic and spiritual environments, working towards an optimal therapeutic environment.

This study also complicates what Peace and Holland (2001) set out as the difference between “a home” and “at home” and whether a ‘homely’ environment is achievable as an ideal in care settings.

The concept of *Schwellenangst* and the fear and anxiety experienced by individuals crossing the hospice threshold, makes explicit the lived experiences of patients as they make the transition across the physical threshold of the hospice and the symbolic threshold of moving into a ‘dying place’. The experience of the uncanny is also made visible here as patients faced disorientating reality of their own death, which can in itself lead to a feeling of un-homelikeness (as the German word for ‘uncanny’ -



unheimlich or 'un-homelike' - implies). The notions of *schwollenangst* and the uncanny have not to my knowledge been drawn together like this previously.

The notion of therapeutic landscapes is also complicated and extended by this study, as previous notions of therapeutic landscapes have not recognised that within such landscapes there may be boundaries to what is therapeutic, and such landscapes may sit, juxtaposed against less therapeutic landscapes, such as the patients' experienced in their proximity to the in-patient wards. Therapeutic landscapes may be seen as bounded places, and the notion of what is and what is not therapeutic is essentially subjective and based on the experiences of those who live their existence within such places. For the in-patients the in-patient ward may be therapeutic, yet for day-care patients (such as Douglas) who had not yet reached that stage in their illness, the in-patient ward represented a non-therapeutic landscape of fear.

In using notions of home to illuminate an understanding of a setting that has been created to represent a homelike place, I have begun to fill a gap that exists between human geographic research and palliative care settings. This research has contributed to an understanding of how terminally ill patients experience space and place. In addition it has begun to address the lack of research on patient, staff and therapists' experiences and perceptions of day care provision. Hospice day care settings have not previously been the focus of place related studies, and so this study contributes to an understanding of how this environment is perceived, experienced and affects the patients who use it, and the people who care for them, and vice versa.

This research is also original in the manner in which I have used the data collection methods. The use of participant driven photo-elicitation methods has not previously been used to study a hospice day care environment and has potential for future use, as patients found this both enjoyable and productive, and allowed them to take a greater part in the research process. I feel that this encouraged feelings of autonomy and productiveness, particularly for the male patients in the study.

These contributions to knowledge and the findings of the study also have implications for health care and research practice. These recommendations will be discussed in the next section.

## **Implications for practice and recommendations**

As previously noted in the literature review, hospices as places have not been the focus of humanistic geographic enquiry. In the interests of a better understanding of palliative care and how it can best be provided, I suggest that there is further research into palliative care hospice settings, in order to broaden the perspective on patient and health care staff experiences of such environments. This would potentially lead to a greater understanding and sensitivity to the needs of patients and staff, and the quality of care provided in such settings.

Through the explication of the lived experiences of those attending and working in hospice day care, this study allows one to consider and integrate the lifeworld perspective of patients within a particular palliative care environment. A greater understanding of the lifeworld of the patients in hospice settings allows for more consideration into the importance of the meanings attributed to the physical built and natural, symbolic, psychosocial and spiritual landscapes that constitute the hospice as a place. This potentially has architectural design implications for future development within palliative care settings, but also within wider health care settings (such as hospitals) that may benefit from similar consideration. Within this study there was obvious concern amongst the patients and staff that plans to develop the hospice may impact on the patients' experience, especially in terms of them sheltering within a sense of safety and security. I would recommend a review of plans to open up the hairdressing salon to the public, as I feel it may have a detrimental effect and I would further recommend a survey of patient and staff opinions on plans to build a cafeteria for general public use.

The concept of threshold anxiety could also be explored further within wider healthcare settings. I feel it is important for thresholds not to lead into something so alien to the patient that they feel "uprooted", but for there to be a continuity across thresholds so that a positive sense of place may be quickly established, being closer to that which is familiar to a homelike setting - welcoming, supportive and secure. The use of complementary therapies as a way of promoting a more positive sense of place and place experience should also be explored further.

Hospice should not simply be seen as a philosophy of care 'rather' than a place in itself as Salisbury (1999) and others (Raudonis & Acton 1997; Skobel, Cullom, & Showalter 1997) suggest, but as a holistic entity that is informed by both a philosophy of care and a philosophy of place, brought together in the physical, symbolic, natural, psychosocial and spiritual landscapes of the hospice setting. This study, I suggest shows how 'place' can be informed by a philosophy that is fundamental to the essence of the place itself.

The use of complementary therapies within hospice and hospice day care services, despite being commonly and widely available, have been little studied in terms of how they are integrated within the landscape of care. Complementary therapies have been seen to provide a way for patients to venture within the internal landscape of the body, potentially leading to a re-attunement towards a state of wholeness. Further attention should be focused on these aspects as hospice remains one of the largest providers of CT to UK cancer patients and rather than remaining static, the full potential of this service should be explored and developed further through a more thorough and multi-dimensional analysis of provision within this context.

Finally, the three existential modes of being that were developed from the findings of this study, can be further investigated and used as a conceptual guide to frame questions about place experiences within other healthcare environments. These modes also be used to further explore the concept of home and homelike settings, health care settings and possibly settings outside of health care, such as national parks, inner city communities, and other micro and macro geographies of health, illness and well-being.

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## **Appendix 1: Electronic mail correspondence with Gavin Andrews**

Original message sent to Gavin Andrews on 16/10/2008 at 04:41pm

Dear Sir,

I am a PhD student in my final year of an exploratory study of complementary therapy use and provision in a hospice setting, using the therapeutic landscapes concept as a framework. My initial degree was in the field of complementary and alternative medicine, and after taking up a PhD studentship with a remit to study CAM in cancer care I was set upon the path of therapeutic landscapes after a comment made by a therapist in the hospice - her room was often used as a "safe place to chat". This single comment snowballed into a geographical study.

I have read your literature on the geographical perspectives of CAM with avid interest along with others in the field such as Wilbert Gesler and Robin Kearns and Alison Williams. I agreed wholeheartedly with calls for a greater exploration of 'place' and how it affects CAM and vice versa (Andrews, Wiles & Miller 2004) and my attention was drawn to the authors' suggestions of physical and psychological settings such as GP's surgeries, hospitals, palliative care wards, private CAM clinics, therapists' own homes, consumers' homes and workplaces. However I saw no mention of hospices, yet as the largest provider of complementary therapies to cancer patients in the UK (Macmillan Cancer Relief UK 2002), they represent an important area for research. I make the distinction here that I am talking of hospice as a physical setting, rather than 'hospice at home'. I have not yet come across any geographical studies of hospice as a setting in itself.

I wished to ask your opinion on the lack of mention of hospices as places of healthcare from a geographical perspective, and if perhaps you could see any reason as to why they have been overlooked, particularly in lieu of their status as a major provider of complementary therapy? I am concerned that there are reasons I have not yet considered.

I would greatly appreciate your opinion and advice.

Yours sincerely

Andrew Moore

PhD Candidate  
Department of Nursing  
Complementary and Alternative Medicine Unit  
University of Central Lancashire  
United Kingdom

Response from Gavin Andrews <andrews@mcmaster.ca> on 18/10/09 at 12:06am

Hi Andrew,

You are right, very few geographical studies have considered hospice settings (but see Brown 2003 a,b,c Chiotti and Joseph 1995, Beth 2007 and Roush and Cox 2000). Its probably due to the limited size of medical/health geography as a subdiscipline. Only 200-300 professional academics worldwide to cover all health and healthcare! My advice – go ahead and fill the gap

best

Gavin

## Appendix 2: Memo to hospice departments from Head of Care

Head of Care

Memo

**To:** All departments within the hospice  
**From:** [Head of Care]  
**CC:** Drew Moore, [Senior Day Care Sister]  
**Date:** 04/06/2010  
**Re:** Research project

---

Dear Colleague

I am writing to inform you that over the next few months a postgraduate student, Drew Moore, will be undertaking his PhD research project at [the hospice]. The project title is:

***"An exploration of complementary therapy in a hospice: perceptions of spaces, places and therapeutic landscapes"***

This will explore the perceptions of patients, therapists and stakeholders in to the environments in which healthcare and complementary therapies are carried out. It is hoped the research findings will contribute to the evidence base of health geography and complementary medicine.

The project will, in part, be achieved by the subjects taking photographs of areas they feel are particularly therapeutic and those which create negative feelings. Participants will not take photographs of individuals without their agreement. The project has received approval from the Research and Ethics Committee.

[The hospice] is very pleased to be involved in this project.

Please don't be surprised if you see a group of people out and about taking photographs. Should you have any questions or concerns, please contact either [Senior Day Care Sister] or myself.

Regards

Memo

**To:** Registered nurses – in-patient unit  
Registered nurses and nursing assistants – day care  
Complementary therapists  
**From:** [Head of Care]  
**CC:** Drew Moore, [Senior Day Care Sister]  
**Date:** 04/06/2010  
**Re:** Research

---

Dear

I am writing to inform you that over the next few months a postgraduate student, Drew Moore, will be undertaking his PhD research project at [the hospice]. The project title is:

***"An exploration of complementary therapy in a hospice: perceptions of spaces, places and therapeutic landscapes"***

Drew is hoping to recruit five medical / nursing staff and five complementary therapists to be interviewed about the topic and will be sending out invitations over the next few weeks. Meanwhile, expressions of interest are welcome and ought to be addressed to Drew C/O Day Care.

[The hospice] is pleased to support this study.

Regards

### Appendix 3: Letter to Head of Care and Day Care Sister suggesting a gardening activity

To: [Head of Care]

CC: [Senior Day Care Sister]

Date: 22<sup>nd</sup> October 2008

Dear [Head of Care],

Further to our discussion last Friday, I've been thinking more about gardening as an activity for hospice patients. I think that this could be one answer to the problem of providing activities suitable for the male day care patients, though of course I think you'll agree that it shouldn't be exclusive to either male or day care patients. However, it may provide something that the male patients find more appealing in terms of a social, physical, and creative endeavour.

The activity could potentially provide physical, spiritual and emotional benefits for patients. An ever growing evidence base of published medical and scientific studies shows that environmental design and exposure to nature can reduce anxiety, lower blood pressure, lessen pain, decrease recovery periods and shorten hospital stays and has a positive association with better health (Ulrich, 1984; Rubin and Owens, 1998; Hartig *et al* 2003; Maas *et al* 2006). Many more studies recommend the healing and therapeutic benefits of nature (Gesler and Kearns 2002; Gesler 1992, 2003; Milligan *et al* 2004; Morita *et al* 2007) and it is obvious that through the ages the benefits of nature and natural settings have long been known. As I'm sure you will know, in light of the changes occurring at [the hospice], there has been growing attention to the importance of healthcare setting and design, particularly in relation to psychological benefits to healthcare outcomes. Research has shown that poorly designed or psychologically inappropriate physical environments have a detrimental affect. As awareness of the effects of the built and natural environments on health has increased, gradually healthcare settings that specialize in the care (rather than cure) of their patients such as hospices have "embraced the importance of a garden along with a homelike interior" (Cooper Marcus and Barnes, 1999 p.2)

[The hospice] gardens are almost certainly grander and more opulent than most of the patient's personal gardens, and while many patients may not have access to gardens of their own, to take part in tending the hospice garden could, potentially provide new experiences, or re-kindle a favourite activity that may have been forgotten as physical health has declined. Being involved in gardens as grand as [the hospice] could possibly, as Gerlach-Spriggs *et al* suggest, "provide experiences that are part of a shared domestic culture, but also something richer than most of us experience on a daily basis" (1998 p.94). It is in a way bringing an activity associated with home into another setting, aiding in the process of continuing a homelike environment. There is also an inescapable symbolism inherent in the activity of gardening, which is aligned with the hospice spirit of caring, cultivating new growth and acceptance of natural cycles. Gardening, like hospice care, is in itself about "nurturing the living, growing, and dying and to teaching the acceptance of the life cycle." (Gerlach-Spriggs, Kaufmann and Warner, 1998 p.91)

Most people who “garden” would most likely describe the activity as therapeutic on a number of different levels, allowing people in the act of cultivation to physically and psychologically meld with the earth in a haven removed from more public spaces. It has the potential to create an outside space in which patients can enjoy more fresh air and the freedom of space, while giving patients a sense of purpose. Milligan *et al* (2004 p.1783) suggest that, “Such activity involves a unique personal engagement with nature that derives from the sights, sounds and smells generated within the garden environment.”

Milligan *et al*’s (2004) study of older persons and communal gardening activity on allotments in the North of England, attempts to build on evidence that shows gardens and gardening activity as offering a “key site of comfort and a vital opportunity for an individual’s emotional, physical and spiritual renewal.” (p.1781). The authors illustrate how older people gain a sense of achievement, satisfaction and aesthetic pleasure from gardening and although the physical shortcomings of the ageing process may require additional support, the act of communal gardening creates inclusionary spaces in which older people benefit from gardening activity in a mutually supportive environment. Such an environment may help to contribute to the development of social networks to combat social isolation (Milligan *et al* 2004). This I feel would be no less applicable to terminally ill patients who by all accounts experience the same feelings of social isolation. The authors maintain that such activities enhance the quality of life and emotional well-being of older people. I do not see why this could not be the same for the patients of [the hospice].

There is additionally the potential for a vegetable/herb/fruit garden. Patients could plant and grow their own produce. I’m aware that many patients may not live to see their efforts come to fruition, but if the literature is correct, the very act of gardening - mixing with the earth, experiencing nature through, vision, smell and touch - is enough to produce a therapeutic and enlivening effect. The focus would not be in seeing the “end product”, but in taking part in a therapeutic activity. Patients in a community garden would have no strict ownership of produce, and so there would always be something to harvest, to grow or maintain as the efforts of everyone assures growth all year round. I also assume that other patients would make sure to tend to all of the garden rather than having their own “patch”. Produce from the garden could be used in the hospice kitchens, helping to keep down costs by providing “home-grown” healthy produce. Similarly, patients could take produce home, giving them a sense of pride, providing for their family, giving something back to those who care for them. The act of growing fruit or vegetables could also give the patient a chance to assert a much needed sense of control over his or her life (Healy 1986).

I am positive that these ideas are not impossible. The gardens of Trinity Hospice in Clapham, London contain raised beds of edible vegetables – marrows and tomatoes, whilst flowers, leaves and vegetable matter from the garden are used in an arts and crafts programme for paper making (Cooper Marcus 1999). Of course such an activity has many potential pitfalls, including finance and organisation, staffing and supervision. How would patients be supervised? Which patients would be physically able enough to take part? What are the risks? Such things as the physical strains and stresses of gardening are better determined by an occupational therapist, but they could be lessened by raising flower beds, and there are various gardening aids widely available. Seeds and plants could be donated by local horticultural societies, or patients,

staff and volunteers. As the weather and seasons change, gardeners may have to retreat indoors, and provision of a potting shed/greenhouse would ensure that activities could continue all year round. These sheds are relatively cheap and can be easily improved in terms of insulation.

I believe this could be a great opportunity for increasing the quality of life of patients. The opportunities are endless in fact. It is not unfeasible that in the future, a kind of "Hospice in Bloom" celebration could potentially spread the activity to other hospices in the area and indeed further a field.

I hope you'll give these ideas some thought. As I said I would be happy to help in any way I can. I've included some papers that I think may be of interest and a list of references.

Kind Regards

Drew Moore

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**Appendix 4: Table of participation in data collection methods (note specific dates have not been used as this could breach anonymity of participants)**

<u>Participants</u>	<u>Time of in-depth interview</u>	<u>Time period of photo-elicitation interview</u>	<u>Number and timing of completed postcards</u>	<u>Time period of participant observation</u>
<i>Staff</i>				
S1 Thomas (palliative care specialist)	N/A	Early Autumn 2007	6 over 6 weeks (late Summer – early Autumn 2007)	N/A
S2 Penelope (auxiliary nurse)	N/A	Early Autumn 2007	5 over 6 weeks (late Summer to early Autumn 2007)	N/A
S3 Susan (staff nurse)	N/A	Mid Autumn 2007	6 over 6 weeks (late Summer to mid Autumn 2007)	N/A
S4 Cathy (staff nurse)	N/A	Early Autumn 2007	N/A	N/A
S5 Julie (palliative care specialist)	N/A	Late Spring 2008		N/A
S6 Bernadette (day care sister)	N/A	Late Spring 2008	6 over 6 weeks mid Spring to Early Summer 2008	N/A
<i>Therapists</i>				
T1 Lucy (contract)	N/A	Early Autumn 2007	6 over 6 weeks late Summer to Early Autumn 2007	
T2 Jackie (contract)	N/A	Mid Autumn 2007	6 over 6 weeks late Summer to mid Autumn	Mid Winter 2008 Mid Summer 2008 Late Summer 2008 x2
T3 Harriet (volunteer)	N/A	Mid Autumn 2007	6 over 6 weeks mid to late Autumn 2007	
T4 Jane (volunteer)	N/A	Mid Winter 2008	N/A	

T5 Melanie (volunteer)	N/A	Early Summer 2008	1 in mid Spring 2008)
T6 Sheila (hairdresser)	N/A	Mid Autumn 2008	N/A

*Patients*

P1 Ethel	Late Autumn 2007			
P2 Andrea	Late Autumn 2007			
P3 Bill	Late Autumn 2007	Mid Winter 2008		Mid Winter 2008
P4 Derek	Late Winter 2008	Early Spring 2008		
P5 June				
P6 Terry	Late Winter 2008			
P7 Jim	Early Spring 2008	Early Summer 2008		Late Summer 2008
P8 Percy	Early Spring 2008		2 over 2 weeks Early Spring 2008	
P9 Douglas	Early Spring 2008	Late Spring x2 2008		Mid Summer 2008
P10 Jeffrey	Early Spring 2008			
P11 Arthur	Early Spring 2008			
P12 Carl	Late Spring 2008	Late Summer 2008		Late Summer 2008

☐ Indicates the participant either withdrew due to failing health of died.

☐ Indicates that the participant did not attempt to carry out the activity as it required too much effort in the circumstances.

## **Appendix 5: Core services available across the whole hospice.**

- A specialist Lymphoedema service
- Family support and bereavement services
- Chaplaincy service assisting patients of all backgrounds, cultures and spiritual and secular beliefs
- Physiotherapy service
- Complementary therapy services, which includes aromatherapy, massage and reflexology
- Beauty therapies and hairdressing
- Creative arts and diversional therapies
- Occupational therapy
- Breathlessness services led by a physiotherapist
- Referral to counselling services
- Transport services for day care
- Education and training support for doctors, nurses and healthcare professionals.

## **Appendix 6: Electronic mail correspondence with David Seamon**

Original Message sent to David Seamon on 09/07/09 at 10:44am

Subject: space and place research in hospice

Dear David,

I am a PhD research student from England and I wrote to you some months ago concerning my phenomenological study at a hospice. You asked me to keep you posted and I am very happy to write to you as I have now discovered that which I was looking for within my study. If you remember, I was looking at how patients, staff and complementary therapists experienced a palliative care hospice as a place in itself, and how the provision of complementary therapy affected and was affected by this place. What I discovered was that complementary therapy was so integrated within the landscape of care it hardly stood out as anything more or less extraordinary than the rest of the care provided. It was truly embedded within the landscape, and yet this is cause for concern in some respects as it's potential was not fully realised at the hospice. However, it is the illumination of three modes of existential being that emerged that most excites me. I have identified what I suggest are three existential modes of being which patients experienced at various times in various places within the hospice. These I have called Drifting, Sheltering and Venturing and I will allude to them through this letter.

The papers that you kindly sent to me I read and read again. I left them alone for a period whilst concentrating on my data analysis and the writing of my findings chapters. Now I am at the stage of my discussion and waiting for the pool of findings to clear so that I can glean some kind of coherent reflection. yesterday I read the paper you presented at the annual meeting of the IAEP in Pittsburgh, October 19th , 2008 entitled "Homes and Inhabitation in Two Works by American Writer Louis Bromfield: Some 20th Century Implications". Your words and those of others you quoted suddenly revealed much more than I had seen before, and I would like to tell you what I have found within my own study, which has become clearer, stronger and perhaps more solid as a result of those words.

Hospices are often constructed as homelike places. They reclaim Death as a continuation of the life cycle and not some absolute negative event to be sequestered to the fringes of society, as it is often purported to be so in hospitals. Hospices are therefore constructed as homelike in order to create a sense of continuity of place, from the patient's home to another place that has an essence of familiarity, warmth and easiness. The hospice in the study is a particularly homelike place. Dating back to the 17th century it was once a grand residence with opulent gardens and it's original homelike interior remains in a number of places melding with the more modern developments. This is particularly evident in the day care unit, which was the main focus of the study.

In your paper you spoke of "the uncanny", how Bromfield's (1951) character Ferris suddenly realises that "his life is devoid of substantive accomplishment" (your words). Bromfield describes his character as searching to concretize the pattern and significance of his own existence. This could as easily describe the periods of drifting that the patients experienced. Following a diagnosis of terminal illness, there was doubt and

fear, and a searching for meaning within dying. They had lost their sense of direction, moving back and forth between points of uncertainty. Frank (1995 p.1) suggests:

“serious illness is a loss of the ‘destination and map’ that had previously guided the ill person’s life...”

I found this to be so amongst the patients. They seemed to be lost in the space of their own illness, uncertain and afraid. There was often a sense of becoming worthless, especially when friends and even family ceased to treat them as they had before. There was evidence of existential anxiety and a feeling of everything being "up in the air" as one patient phrased it, never knowing what stage he was at in terms of his illness.

In the narratives of the day care patients, they spoke about entering into the hospice for the first time. Patients experienced various levels of insideness. Some patients knew of the hospice through friends and relatives who had resided and died there; some knew others who worked there and others had heard ‘tales’ of dying and subsequently expressed fear of such places. Despite this continuum of experience in most there was at least some sense of anxiety at entering this relatively unknown place. They described a ‘coming to know’, a crossing of thresholds as they entered into the unknown place (place being both the physical landscape of the hospice, the psychological landscape in terms of what specialist palliative care entailed, and the spiritual landscape in terms of their finding meaning in their life as ‘dying people’). Once they had crossed this threshold they experienced a growing insideness. They formed deep and intimate relationships with staff, therapists and other patients, finding a sense of sheltering within both the community and the care provided. They also found a location - a point of anchoring within the space of their own illness, as they came to understand it more, as they gained knowledge about their illness through talking to the specialist doctors and consultants. They experienced a state of drifting that was characterised by loss of meaning, uncertainty, anxiety, lack of motivation towards any particular direction, and a loss of self and a sense of isolation. From this state of drifting, they moved towards a state of sheltering characterised by an anchoring in certainty, feelings of safety and comfort, supportive relationships, and a homelike environment.

You stated in your article that when the taken-for-grantedness of Ferris’s home life suddenly fell into question it set him on his quest. Like the patients in the study, they too found themselves in a situation in which their taken-for-grantedness of not just their home life but also their complete life (work life, social life) fell into question, setting them on their own quest. They were seeking to find a more authentic way of inhabiting their world, finding community and relationships, warmth and comfort, easiness and peace, those essences of at-homeness. In your paper you referred to Bernd Jager’s (1985) words:

“A house...when properly inhabited, not merely remains something seen; it itself becomes a source of vision and light according to which we see.... To enter and finally come to inhabit a house...means to come to assume a certain stance, to surrender to a certain style of acting upon and of experiencing the surrounding world...” (pp.218-219)

Patients and staff came to inhabit the hospice and it became “a source of vision and light” (Jager 1985) A member of staff photographed a painting by a deceased patient who had depicted the hospice building with multicoloured lights shining out of the

windows, as if they were rays of hope and love and courage and ebullient humanity. This painting surfaced in my thoughts the moment I read Bernd Jager's quote. It is true that the lady who painted that picture did not want to be a patient at the hospice and she resisted taking part in anything, or interacting with anyone until she came to inhabit the art room. She found steadily that after entering and finally coming to dwell within this place, it had a profound effect upon her.

The hospice provided patients with the means to help patients sustain their selfhood. Patients felt a sense of autonomy and control; they had opportunities to make achievements and to venture out into psychological landscapes, physical landscapes and spiritual landscapes. They experienced the world thereafter differently, a result of dwelling within that place and they came to "assume a certain stance" (Jager 1985). As one patient put it, he was 'living life and not the disease'.

I felt that patients had "finally come to inhabit" (Jager 1985) the day care unit when they spoke of the hospice as a 'home from home'. Some even wished aloud that they could live there, such was the sense of rootedness and dwelling, whilst others demonstrated a caring for the place. This was evident in their concern over new developments at the hospice and in their protective attitudes to the staff who cared for them.

The hospice then provided what Lawton (2000) calls "an alternate reality" and a "safe haven", what the patients called 'a home from home', a familiar place of certainty and "supportive ambience" (your words). This supportive place once properly inhabited provided a sheltering experience for the patients similar I feel to that which Ferris experienced:

"Here, with plenty of time to be alone and write, Ferris is able to complete his life story, out of which arises 'a kind of satisfaction...a kind of purification and the realisation of purpose, without which my life would have remained incomplete and even confused and meaningless' (327)"

I realise I am taking bold steps in suggesting that this is exactly the experience of patients within the hospice, but I merely suggest it is the essence of this statement that is evident in the data. Patients found a place that provided a sense of sheltering, which in turn allowed them to venture forth, to complete their incompletes, to learn new skills and ways of coping and adapting, and to find a sense of satisfaction and meaning. This was their venturing .

It is having plenty of "time to be alone and write" that enables Ferris to complete his life story. I feel he perhaps sheltered in his solitude and ventured on paper, whereas the patients ventured in other ways. The hospice provided them with opportunities to explore their diseases, to "play" as one patient phrased it, learning new skills such as painting and crafts. They had the opportunity "to make a new start", and to engage in new experiences of being cared for such as complementary therapies – a patient referred to these opportunities as "a vastly more interesting way forward". Patients also took time alone to venture in psychological, physical and spiritual landscapes. This was evident in the natural space of the gardens where one patient in particular related how he thought about his position in life, his past, present and future in light of his illness:

“You think about the position you’re in and what’s happened to you and what’s happening in your life. And I think I tend to be, if I’m out, I contemplate more on what’s actually happening in your life you know, and what’s going to happen.” (Day-care patient)

The day care sister felt that the greatest gift was time:

“Time. I think that’s the biggest thing of all that we can offer the patients, is time; Time for them to...to explore their own disease and where they are with it.” (Day Care Sister)

She is talking about giving them temporal space to explore the spaces of their own illness and to find a bearing from which they can find meaning and direction, a point of anchoring if you will. The hospice provides a place in which to shelter whilst patients venture in thought, moving forwards or backwards in their psychological landscapes. This enabled them to work towards completing their life story as Bromfield stated, and I feel they transcended their drifting state, by sheltering within the home place and venturing forth to find completeness and meaning.

Finally, in asking the question “What are inhabitation and home to become in the 21st Century?” you suggest that one conceptual need is to “rephrase the nature of house and home in ways that incorporate its more typical lived qualities but also provide a place for those qualities less typical, sometimes hidden opposites...” Your words are very close to what I have found at the hospice. The hospice day care is constructed as a home, with its “intimacy of similarities” in its domestic ambience and familial relationships, to the homes of others, and yet it recognises and is open to difference. It is not every home. The staff and patients share the metaphor of family whilst simultaneously recognising that these are “non-traditional relationships and linkages”. And lastly there are senses of “anchoring and permanence” within the narratives of patients and staff. There is anchoring in the shelter of a place that provides a sense of certainty, of care and love and warmth. For the staff a sense of permanence is found within the memorials of patients that make up the symbolic landscape. There is permanence in the continuity of life cycles within the nature of the gardens and in the claiming of physical places within the hospice as in ‘this is my room, this is my desk’. And yet, in all of this, perhaps more than in other places, there is a “ready acceptance of both supportive and undermining change in and connectedness to the world beyond” (your words).

I have not expanded so much on the modes of drifting, sheltering and venturing in this letter as I found too much within your article which resounded with my own findings and I wanted to see what your thoughts on these were. I think that hospices are incredibly interesting places, little studied in a geographical sense and enormously important in terms of what they could teach us about healthcare establishments as places and the experiences of people those who frequent them in terms of health and illness. And truthfully, simply writing this letter helps me to focus on the discussion chapter that I am trying to write. I hope to finish my thesis at the end of August. Once I have written this chapter (hopefully within the next two weeks), I will try to write and keep you updated. I thank you again for your interest and wisdom.

Kind regards



Andrew Moore

PhD Research Student  
School of Nursing and Caring Sciences  
University of Central Lancashire  
Preston, PR1 2HE

Response from David Seamon <triad@k-state.edu> on 12/07/2009 at 02:28

Andrew,

Your email is most interesting, and I am glad some of the materials I sent you have been useful, including the Bromfield piece.

Your interpretation seems insightful to me and arising out of your various means of documentation. I like the themes of drifting, sheltering, and venturing; what you say suggests you have the lived evidence to argue satisfactorily that these themes arise from your lifeworld investigation.

I can imagine how the disorientation of one's facing his death would lead to a kind of "uncanny," though I would never have thought of it in this way had you not been focusing on the hospice situation.

One possibility I would suggest is to keep in mind variations from these broad themes (and also examples that call into question your conclusions--e.g., the picture you paint of the hospice you study is uniformly positive; I would imagine there must be some residents who, for whatever reason, don't really "take" to the place, though perhaps this might be more a function of their particular individuality than to the place or the situation).

What I like best about your interpretation is that it is fresh and novel, pointing to themes that one might not imagine just through analytic consideration of the situation. I hope the last chapter comes together and am glad your writing me has been helpful.

I am travelling right now so aren't able to print out and study your email. So my response is somewhat shorter than it might be otherwise. I hope you will consider sending us some sections from the dissertation to publish in EAP.

Continue to keep me posted. I like your approach and discoveries!

David Seamon

p.s. I'm going to try to attach a revised version of the Bromfield piece, which I've tried to orient a bit more toward Bachelard. This version will be published in an edited collection entitled PHENOMENOLOGY 2009, edited by Lester Embree and published by Zeta Press in Bucharest (of all places!). I'll get you the final copy once it is published.

DS

## **Appendix 7: Invitation Letter to Patient (Version 2. 07/06/2007)**

[Researcher's name and address]

Tel: [Telephone number]

[Date]

Dear Sir / Madam

As a day-care patient at [hospice] you are being invited to take part in a research project, funded by the Department of Nursing at the University of Central Lancashire. The title of the study is:

"An exploration of complementary therapy in a hospice: Perceptions of spaces, places and therapeutic landscapes".

This is a doctoral study forming part of an academic qualification for the researcher Mr. Andrew Moore. Please find enclosed information sheets detailing the study. Please take your time to read them and decide if you would like to be involved. I will be available at the hospice next week to discuss the project with you. If you are interested you will be given a consent form and a further 48 hours to decide whether you would like to take part. Your time is greatly appreciated.

Yours Sincerely,

Andrew Moore

Postgraduate Research Student, University of Central Lancashire.

## **Appendix 8: Invitation Letter to Staff (Version 1. 23/04/2007)**

[Researcher's name and address]

Tel: [Telephone number]

[Date]

Dear Sir / Madam

As a member of the healthcare team working at [hospice] you are being invited to take part in a research project, funded by the Department of Nursing at the University of Central Lancashire. The title of the study is:

“An exploration of complementary therapy in a hospice: Perceptions of spaces, places and therapeutic landscapes”.

This is a doctoral study forming part of an academic qualification for the researcher Mr. Andrew Moore. Please find enclosed information sheets detailing the study. Please take your time to read them and decide if you would like to be involved. Your time is greatly appreciated.

Yours Sincerely,

Andrew Moore

Postgraduate Research Student, University of Central Lancashire.

**Appendix 9: Invitation to Complementary Therapist (Version 1.  
23/04/2007)**

[Researcher's name and address]

Tel: [Telephone number]

[Date]

Dear Sir / Madam

As a Complementary Therapist working at [hospice] you are being invited to take part in a research project, funded by the Department of Nursing at the University of Central Lancashire. The title of the study is:

“An exploration of complementary therapy in a hospice: Perceptions of spaces, places and therapeutic landscapes”.

This is a doctoral study forming part of an academic qualification for the researcher Mr. Andrew Moore. Please find enclosed information sheets detailing the study. Please take your time to read them and decide if you would like to be involved. Your time is greatly appreciated.

Yours Sincerely,

Andrew Moore

Postgraduate Research Student, University of Central Lancashire.

## **Day-Care Patient Information Sheet**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it involves. Please take some time to read the following carefully. Talk to others about the study if you like.

- **Part 1 tells you the purpose of this study and what you will be asked to do if you wish to take part.**
- **Part 2 gives you more detailed information about how the study is conducted.**

If anything is not clear then please ask me if you would like more information. It's important that you take time to decide whether or not you wish to take part.

### **Part 1**

#### **What is the purpose of the study?**

The purpose of this study is to explore the experiences of day-care patients who use complementary therapy in the hospice. I would like to explore how you feel about complementary therapy and its use within the hospice and what experiences you can share with me about your therapy. I'd also like to explore how you feel about the place in which you receive care.

This study aims to increase the evidence base about complementary therapy and deepen the understanding of hospice care.

The study also seeks to investigate the place (environment) in which care takes place and its effect on our health and well-being.

#### **Why have I been chosen?**

You've been chosen because you're a day-care patient receiving complementary therapy at the hospice day-care unit. It's hoped that around 12-18 day-care patients will be involved with the study.

#### **Do I have to take part?**

No, you do not have to take part. It's up to you to decide whether or not to take part. If you do, you will be asked to sign a consent form. Even if you decide to take part you are always free to withdraw at any time without giving a reason. A decision to withdraw from the study or a decision not to take part will not affect the standard of care you receive in any way.

**What will happen to me if I take part?**

There are **four** things that you will be asked if you would like to do. You don't have to take part in all of them; all you need to do is let me know which ones you would like to take part in. The things that you could take part in are:

**Interviews (x2):** You will be given the opportunity to take part in two interviews; one before you start a programme of complementary therapies and one afterwards. The interviews will last approximately 40 minutes but if you want to carry on talking for longer or take a break and resume later that is OK. Remember that you can end the interview at any point and you don't have to give me a reason.

With your consent your interview will be audio taped and I will transcribe (write up) the interview within one or two days of the interview taking place. I will anonymise the transcription (written copy) of the interview. I will maintain all the information that you share with me in your interview in strict confidence. Nothing that is said within the interview will be repeated to anyone else at the hospice. You are free to ask if the recording can be paused, stopped, replayed or edited at any time. You may also review the transcript if you wish.

The first interview would take place hopefully before or just after you have started your course of complementary therapies. I would like to ask you about your experiences of complementary therapies and your feeling about the hospice as a place.

The second interview would take place approximately six weeks later when you have finished your course of complementary therapies. For the second interview you will be invited to take photographs of the places and spaces that you find particularly therapeutic or which you feel have a more negative feeling, within the hospice setting and outside this setting. We can then talk about these photographs in the second interview. Of course, if you are taking photographs you will need to be particularly considerate of other people, as they may not wish to be recorded in a photograph. A disposable camera will be provided. The researcher will then take the photos to a reputable lab for development. You may have copies of the photos if you wish but I will need to keep the originals as research data.

You are also free to bring in photographs that you have taken previously. The interview will also focus on questions about your thoughts and experiences of complementary therapies after your course of treatments, your relationships with patients and staff and your perceptions of the hospice as a place.

**Postcard Diaries:** You will also have the opportunity to fill in 6 blank postcards, one per week, to record your feelings and reflections about the hospice and your complementary therapy. Reflections can take the form of words, drawings, pictures, photographs, poems, and collages, which you have either written/created by yourself or which you have found from existing material.

**Participant Observation:** I would also like to observe a complementary therapy session. I am particularly interested in how this room is used and how that differs from other spaces within the hospice. I would not be taking part in any way other than taking notes with your consent.

**What are the possible disadvantages and risks of taking part?**

You may find sharing some of your experiences a little distressing but you will not specifically be asked to reveal distressing events.

**What are the benefits of taking part?**

There are no direct benefits for you if you decide to take part but we hope that the information from the study will contribute to further understanding the hospice service and complementary therapies.

**What happens when the research stops?**

Your time at the hospice will continue as normal and your care will not be affected. One of the risks that we take very seriously and which we manage very carefully is to do with maintaining confidentiality and anonymity. In order to make sure that all the information you share with me is kept safely and securely. I follow the guidance of the University Code of Research Conduct; all data will be kept within a secure research room in a locked filing cabinet to which only I and my academic supervisors have access.

**What if there is a problem?**

Any complaints about the way you have been treated or any possible harm you might have suffered in this study will be addressed. Detailed information on this is given in Part 2.

**Will my taking part in the study be kept confidential?**

In order to make sure that all the information you share with me is kept safely and securely, I follow the guidance of the University Code of Research Conduct; all the data and information about your participation in this study will be kept confidential.

**If you have any more questions or are unsure about any part of this information please contact me:**

**Contact Details:**

[Researcher's name, work address and work telephone number]

## **Part 2**

### **What will happen if I don't want to carry on with the study?**

If you don't want to carry on with the study then that is fine and it will not affect you in any way. If you have already provided the study with information we can either destroy this or we can keep it in the study. This decision is completely up to you.

### **What if there is a problem?**

**Complaints:** If you have a problem with any part of this study, you should ask to speak to me and I will do my best to answer your questions.

Drew Moore – [work number]

If you remain unhappy and wish to complain formally, you can do this by contacting [name] (Junior Day-care sister) at the hospice or by contacting my Director of Studies:

Dr. Kay Byatt – [work number]

or the Head of the Nursing Department at the University of Central Lancashire:

Dr. Bernard Gibbon – [work number]

**Harm:** In the event that something does go wrong and you are harmed during the research study there are no special arrangements for compensation. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action for compensation, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

**Unprofessional Conduct:** If I find evidence of any unprofessional conduct I will have to report this in accordance with the hospice guidelines and procedures. Similarly if I observe any unprofessional conduct I will have to report this to my Director of Studies and my clinical supervisor at the hospice.

### **Will my taking part in this study be kept confidential?**

In accordance with the University Code of Research Conduct the data will be stored securely at the University of Central Lancashire for 10 years. This data will only be made accessible to other researchers with your informed consent. After this time the data will be destroyed.

### **What will happen to the results of the research study?**

Reporting and publishing the results of research is very important. It is intended that the results will be published in academic journals and shown at conferences. The results could also be made available to the participants who took part in the study; in a report for the hospice; a feedback seminar and workshop and possibly other papers during the study and thesis. No-one who takes part in the study will be identifiable in any report or publication unless they have consented to release such information.

### **Who is organising and funding the research?**

The research is being supported by a postgraduate student bursary by the Department of Nursing, Faculty of Health, University of Central Lancashire.



**Who has reviewed the study?**

This study has been reviewed by a doctoral supervision team:

**Prof. Bernie Carter - Professor of Children's Nursing**

**Dr. Kay Byatt - Principal Lecturer / Divisional Leader of Complementary Medicine**

**Dr. Anne Hunt – Post-Doctoral Research Fellow- Children's Palliative Care**

and by a reviewer external to the Department of Nursing as part of the Governance procedures within the University. In addition it has been reviewed by the Faculty of Health Ethics Committee at the University of Central Lancashire and by the NHS Research Ethics Committee. The study has also been reviewed and approved by the hospice.

**If after considering the research you wish to be involved, you will be given a consent form to sign. You will keep one copy and the researcher will keep one copy.**

**I would like to thank you for considering taking part in this research and for reading the information sheet.**

**If you have any questions please do not hesitate to contact me.**

## **Appendix 11: Healthcare Staff Information Sheet (Version 2.07/06/2007)**

### **Healthcare Staff Information Sheet**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take some time to read the following carefully. Talk to others about the study if you like.

- **Part 1 tells you the purpose of this study and what you will be asked to do if you wish to take part.**
- **Part 2 gives you more detailed information about how the study is conducted.**

If anything is not clear then please ask me if you would like more information. It is important that you take time to decide whether or not you wish to take part.

#### **Part 1**

##### **What is the purpose of the study?**

The purpose of this study is to explore the experiences and perceptions of patients, complementary therapists and healthcare staff concerning the use of complementary therapies in a hospice setting. I would like to explore how you feel about complementary therapy and its use within the hospice and what experiences you can share with me.

The study also seeks to investigate the place (environment) in which care takes place and its effect on our health and well-being.

This study has the potential to increase the evidence base about complementary therapy and its use within hospice care.

##### **Why have I been chosen?**

You have been chosen because you are one of the people who provide care to patients attending the hospice.

##### **Do I have to take part?**

No, you do not have to take part. It's up to you to decide whether or not to take part. If you do you will be given this information sheet to keep and you will be asked to sign a consent form. Even if you decide to take part you are free to withdraw at any time without giving a reason. A decision to withdraw from the study or a decision not to take part, will not affect you or your work at the hospice in anyway.

##### **What will happen to me if I take part?**

There are **two** things that you will be invited to do. You don't have to take part in all of them; all you need to do is let me know which ones you would like to take part in. The things that you could take part in are:

- Photo Elicitation Interview (An interview in which photographs are used to inform discussion)
- Postcard diary

**Photo Elicitation Interview:** You will be invited to take photographs of the places and spaces within the hospice setting and outside this setting that you find particularly therapeutic or which you feel have a more negative feeling. Of course, if you are taking photographs you will need to be particularly considerate of other people, as they may not wish to be recorded in a photograph. A disposable camera will be provided. The researcher will then take the photos to a reputable lab for development. You may have copies of the photos if you wish but I will need to keep the originals as research data.

We can then talk about these photographs in an interview using them to inform a discussion. You are also free to bring in photographs that you have taken previously. The interview will also focus on questions about your thoughts and experiences of working at the hospice, your relationships with patients and other staff and your perceptions of complementary therapies.

The interview should last approximately 40 minutes but if you want to carry on talking for longer or to take a break that is OK. Remember that you can end the interview at any point and you don't have to give me a reason.

With your consent your interview will be audiotaped and I will transcribe (write up) the interview within one or two days of the interview taking place. I will anonymise the transcription (written copy) of the interview. I will maintain all the information that you share with me and the photographs used in your interview in strict confidence. Nothing that is said within the interview will be repeated to any other patients or staff. The photographs will not be seen by anyone else other than the research team and yourself. You are free to ask if the recording can be paused, stopped, replayed or edited at any time. You may also review the transcript if you wish.

**Postcard Diary:** You will also have the opportunity to fill in 6 blank postcards, one per week, to record your feelings and reflections about the hospice and your work. Reflections can take the form of words, drawings, pictures, photographs, poems, and collages, which you have either written/created by yourself or which you have found from existing material. You are free to fill in these postcards however you wish. At the end of each week I would like you to place the postcards in a confidential and secure 'bin' in the foyer of the hospice.

### **What are the possible disadvantages and risks of taking part?**

You may find sharing some of your experiences a little distressing but you will not specifically be asked to reveal distressing events.

### **What are the benefits of taking part?**

There are no direct benefits for you if you decide to take part but we hope that the information from the study will contribute to better understanding of the hospice service and complementary therapies.

**What happens when the research stops?**

Your role at the hospice will continue as normal. One of the risks that we take very seriously and which we manage very carefully is to do with maintaining confidentiality and anonymity. In order to make sure that all the information you share with me is kept safely and securely, I follow the guidance of the University Code of Research Conduct; all data will be kept within a secure research room in a locked filing cabinet to which only I and my academic supervisors have access.

**What if there is a problem?**

Any complaints about the way you have been treated or any possible harm you might have suffered in this study will be addressed. Detailed information on this is given in Part 2.

**Will my taking part in the study be kept confidential?**

Yes. All the information about your participation in this study will be kept confidential. The details are included in Part 2.

**Contact Details:**

Researcher's name, work address and work telephone number]

## **Part 2**

### **What will happen if I don't want to carry on with the study?**

If you don't want to carry on with the study then that is fine and it will not affect you in any way. If you have already provided the study with information we can either destroy this or we can keep it in the study. This decision is completely up to you.

### **What if there is a problem?**

**Complaints:** If you have a problem with any part of this study, you should ask to speak to me and I will do my best to answer your questions.

Drew Moore – [work number]

If you remain unhappy and wish to complain formally, you can do this by contacting your line manager at the hospice or by contacting my Director of Studies:

Dr. Kay Byatt – [work number]

or the Head of the Nursing Department at the university:

Dr. Bernard Gibbon – [work number]

**Harm:** In the event that something does go wrong and you are harmed during the research study there are no special arrangements for compensation. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action for compensation, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

**Unprofessional Conduct:** If I find evidence of any unprofessional conduct I will have to report this in accordance with the hospice guidelines and procedures. Similarly if I observe any unprofessional conduct I will have to report this to my Director of Studies and my clinical supervisor at the hospice.

### **Will my taking part in this study be kept confidential?**

In accordance with the University Code of Research Conduct the data will be stored securely at the University of Central Lancashire for 10 years. This data will only be made accessible to other researchers with your informed consent. After this time the data will be destroyed.

### **What will happen to the results of the research study?**

Reporting and publishing the results of research is very important. It is intended that the results will be published in academic journals and shown at conferences. The results could also be made available to the participants who took part in the study; in a report for the hospice; a feedback seminar and workshop and possibly other papers during the study and thesis. No-one who takes part in the study will be identifiable in any report or publication unless they have consented to release such information.

### **Who is organising and funding the research?**

The research is being supported by a postgraduate student bursary by the Department of Nursing, Faculty of Health, University of Central Lancashire.

**Who has reviewed the study?**

This study has been reviewed by a doctoral supervision team:

**Prof. Bernie Carter - Professor of Children's Nursing**

**Dr. Kay Byatt - Principal Lecturer / Divisional Leader of Complementary Medicine**

**Dr. Anne Hunt – Post-Doctoral Research Fellow- Children's Palliative Care**

and by a reviewer external to the Department of Nursing as part of the Governance procedures within the University. In addition it has been reviewed by the Faculty of Health Ethics Committee at the University of Central Lancashire and by the NHS Research Ethics Committee. The study has also been reviewed and approved by the hospice.

**If after considering the research you wish to be involved, you will be given a consent form to sign. You will keep one copy and the researcher will keep one copy.**

**I would like to thank you for considering taking part in this research and for reading the information sheet.**

**If you have any questions please do not hesitate to contact me.**

## **Complementary Therapist Information Sheet**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take some time to read the following carefully. Talk to others about the study if you like.

- **Part 1 tells you the purpose of this study and what you will be asked to do if you wish to take part.**
- **Part 2 gives you more detailed information about how the study is conducted.**

If anything is not clear then please ask me if you would like more information. It is important that you take time to decide whether or not you wish to take part.

### **Part 1**

#### **What is the purpose of the study?**

The purpose of this study is to explore the experiences and perceptions of patients, complementary therapists and healthcare staff concerning the use of complementary therapies in a hospice setting. I would like to explore how you feel about complementary therapy and its use within the hospice and what experiences you can share with me.

The study also seeks to investigate the place (environment) in which care takes place and its effect on our health and well-being.

This study has the potential to increase the evidence base about complementary therapy and its use within hospice care.

#### **Why have I been chosen?**

You have been chosen because you are one of the people who provide care to patients attending the hospice.

#### **Do I have to take part?**

No, you do not have to take part. It's up to you to decide whether or not to take part. If you do you will be given this information sheet to keep and you will be asked to sign a consent form. Even if you decide to take part you are free to withdraw at any time without giving a reason. A decision to withdraw from the study or a decision not to take part, will not affect you or your work at the hospice in anyway.

#### **What will happen to me if I take part?**

There are **three** things that you will be invited to do. You don't have to take part in all of them; all you need to do is let me know which ones you would like to take part in. The things that you could take part in are:

- Photo Elicitation Interview (An interview in which photographs are used to inform discussion)
- Postcard diary
- Participant observation

**Photo Elicitation Interview:** You will be invited to take photographs of the places and spaces within the hospice setting and outside this setting that you find particularly therapeutic or which you feel have a more negative feeling. Of course, if you are taking photographs you will need to be particularly considerate of other people, as they may not wish to be recorded in a photograph. A disposable camera will be provided. The researcher will then take the photos to a reputable lab for development. You may have copies of the photos if you wish but I will need to keep the originals as research data.

We can then talk about these photographs in an interview using them to inform a discussion. You are also free to bring in photographs that you have taken previously. The interview will also focus on questions about your thoughts and experiences of working at the hospice, your relationships with patients and other staff and your perceptions of complementary therapies.

The interview should last approximately 40 minutes but if you want to carry on talking for longer or to take a break that is OK. Remember that you can end the interview at any point and you don't have to give me a reason.

With your consent your interview will be audiotaped and I will transcribe (write up) the interview within one or two days of the interview taking place. I will anonymise the transcription (written copy) of the interview. I will maintain all the information that you share with me and the photographs used in your interview in strict confidence. Nothing that is said within the interview will be repeated to any other patients or staff. The photographs will not be seen by anyone else other than the research team and yourself. You are free to ask if the recording can be paused, stopped, replayed or edited at any time. You may also review the transcript if you wish.

**Postcard Diary:** You will also have the opportunity to fill in 6 blank postcards, one per week, to record your feelings and reflections about the hospice and your work. Reflections can take the form of words, drawings, pictures, photographs, poems, and collages, which you have either written/created by yourself or which you have found from existing material. You are free to fill in these postcards however you wish. At the end of each week I would like you to place the postcards in a confidential and secure 'bin' in the foyer of the hospice.

**Participant Observation:** I would like to observe a complementary therapy session to see how the therapy room is used and how this differs from other spaces within the hospice. With your consent and that of the patient, I would like to take notes.

#### **What are the possible disadvantages and risks of taking part?**

You may find sharing some of your experiences a little distressing but you will not specifically be asked to reveal distressing events.



**What are the benefits of taking part?**

There are no direct benefits for you if you decide to take part but we hope that the information from the study will contribute to better understanding of the hospice service and complementary therapies.

**What happens when the research stops?**

Your role at the hospice will continue as normal. One of the risks that we take very seriously and which we manage very carefully is to do with maintaining confidentiality and anonymity. In order to make sure that all the information you share with me is kept safely and securely, I follow the guidance of the University Code of Research Conduct; all data will be kept within a secure research room in a locked filing cabinet to which only I and my academic supervisors have access.

**What if there is a problem?**

Any complaints about the way you have been treated or any possible harm you might have suffered in this study will be addressed. Detailed information on this is given in Part 2.

**Will my taking part in the study be kept confidential?**

Yes. All the information about your participation in this study will be kept confidential. The details are included in Part 2.

**Contact Details:**

[Researcher's name, work address and work telephone number]

## **Part 2**

### **What will happen if I don't want to carry on with the study?**

If you don't want to carry on with the study then that is fine and it will not affect you in any way. If you have already provided the study with information we can either destroy this or we can keep it in the study. This decision is completely up to you.

### **What if there is a problem?**

**Complaints:** If you have a problem with any part of this study, you should ask to speak to me and I will do my best to answer your questions.

Drew Moore – [number]

If you remain unhappy and wish to complain formally, you can do this by contacting your line manager at the hospice or by contacting my Director of Studies:

Dr. Kay Byatt – [number]

or the Head of the Nursing Department at the university:

Dr. Bernard Gibbon – [number]

**Harm:** In the event that something does go wrong and you are harmed during the research study there are no special arrangements for compensation. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action for compensation, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

**Unprofessional Conduct:** If I find evidence of any unprofessional conduct I will have to report this in accordance with the hospice guidelines and procedures. Similarly if I observe any unprofessional conduct I will have to report this to my Director of Studies and my clinical supervisor at the hospice.

### **Will my taking part in this study be kept confidential?**

In accordance with the University Code of Research Conduct the data will be stored securely at the University of Central Lancashire for 10 years. This data will only be made accessible to other researchers with your informed consent. After this time the data will be destroyed.

### **What will happen to the results of the research study?**

Reporting and publishing the results of research is very important. It is intended that the results will be published in academic journals and shown at conferences. The results could also be made available to the participants who took part in the study; in a report for the hospice; a feedback seminar and workshop and possibly other papers during the study and thesis. No-one who takes part in the study will be identifiable in any report or publication unless they have consented to release such information.

### **Who is organising and funding the research?**

The research is being supported by a postgraduate student bursary by the Department of Nursing, Faculty of Health, University of Central Lancashire.

### **Who has reviewed the study?**

This study has been reviewed by a doctoral supervision team:

**Prof. Bernie Carter - Professor of Children's Nursing**

**Dr. Kay Byatt - Principal Lecturer / Divisional Leader of Complementary Medicine**

**Dr. Anne Hunt – Post-Doctoral Research Fellow- Children's Palliative Care**

and by a reviewer external to the Department of Nursing as part of the Governance procedures within the University. In addition it has been reviewed by the Faculty of Health Ethics Committee at the University of Central Lancashire and by the NHS Research Ethics Committee. The study has also been reviewed and approved by the hospice.

**If after considering the research you wish to be involved, you will be given a consent form to sign. You will keep one copy and the researcher will keep one copy.**

**I would like to thank you for considering taking part in this research and for reading the information sheet.**

**If you have any questions please do not hesitate to contact me.**

## Appendix 13: Patient Consent Form (Version 2. 07/06/2007)

### CONSENT FORM – Day-care Patient

**Title of Project:** An exploration of complementary therapy in a hospice: Perceptions of spaces, places and therapeutic landscapes

**Name of Researcher:** Andrew Moore

**NOTE: Please initial the boxes if you are interested or in agreement**

I confirm that I have read and understood the information sheet dated.....  
(Version...) for the above study. I have had the opportunity to consider the  
information, ask questions and have had these answered satisfactorily.

☐

I understand that my participation is voluntary and that I am free to withdraw at any  
time, without giving any reason, without my medical care or legal rights being  
affected.

☐

I understand that I will take part in one or more interviews and that the interview will  
be recorded using audio equipment by the researcher.

☐

I agree that some direct quotes from interview material may be used in research  
publications, however these will be anonymised.

☐

I agree that any photographs or written material (postcards) will be kept as research  
data for 10 years, though copies will be made available to me.

☐

I agree that photographs may be used in subsequent research publications.

☐

I agree to take part in participant observation where the researcher will observe a  
complementary therapy session and take notes of his observations.

☐

I agree to fill in 6 postcard diaries, 1 per week for 6 weeks.

☐

\_\_\_\_\_  
Name of patient

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of patient's representative

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of independent witness

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

**Appendix 14: Staff Consent Form (Version 2. 07/06/2007)**

**CONSENT FORM – Healthcare Staff**

**Title of Project:** An exploration of complementary therapy in a hospice: Perceptions of spaces, places and therapeutic landscapes

**Name of Researcher:** Andrew Moore

**NOTE: Please initial the boxes if you are interested or in agreement**

I confirm that I have read and understood the information sheet dated.....  
(Version...) for the above study. I have had the opportunity to consider the  
information, ask questions and have had these answered satisfactorily.

☐

I understand that my participation is voluntary and that I am free to withdraw at any  
time, without giving any reason.

☐

I understand that I will take part in one interview and that the interview will be  
recorded using audio equipment by the researcher.

☐

I agree that some direct quotes from interview material may be used in research  
publications, however these will be anonymised.

☐

I agree that any photographs or written material (postcards) will be kept as research  
data for 10 years, though copies will be made available to me.

☐

I agree that photographs may be used in subsequent research publications.

☐

I agree to fill in 6 postcard diaries, 1 per week for 6 weeks.

☐

\_\_\_\_\_  
Name of participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of independent  
witness

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## Appendix 15: Complementary Therapist Consent Form (Version 2. 07/06/2007)

### CONSENT FORM – Complementary Therapist

**Title of Project:** An exploration of complementary therapy in a hospice: Perceptions of spaces, places and therapeutic landscapes

**Name of Researcher:** Andrew Moore

NOTE: Please initial the boxes if you are interested or in agreement

I confirm that I have read and understood the information sheet dated.....  
(Version...) for the above study. I have had the opportunity to consider the  
information, ask questions and have had these answered satisfactorily.

☐

I understand that my participation is voluntary and that I am free to withdraw at any  
time, without giving any reason.

☐

I understand that I will take part in one or more interviews and that the interview will  
be recorded using audio equipment by the researcher.

☐

I agree that some direct quotes from interview material may be used in research  
publications, however these will be anonymised.

☐

I agree that any photographs or written material (postcards) will be kept as research  
data for 10 years, though copies will be made available to me.

☐

I agree that photographs may be used in subsequent research publications.

☐

I agree to take part in participant observation where the researcher will observe a  
complementary therapy session and take notes of his observations.

☐

I agree to fill in 6 postcard diaries, 1 per week for 6 weeks.

☐

\_\_\_\_\_  
Name of participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of independent witness

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

**Focused Interview Schedule**

**(First Interview - Patients)**

**Can you describe for me your experiences as a day-care patient at the hospice?**

How do you feel about visiting [hospice name]?

Is there anything in particular that you really value or dislike about [hospice name]?

What is a typical day like at [hospice name]...can you describe it to me?

Can you describe your relationship with the staff for me?

Can you describe your relationship with the other patients?

What are your experiences of patient care at [hospice name]?

How do you feel about complementary therapies...what do you know about them?

Have you had complementary therapies before?

How do you see complementary therapy's role at [hospice name]?

How do you think complementary therapies [might] benefit you?

How do you think the staff feel about complementary therapies?

**Finally, how do you feel about [hospice name] as a place?**

Thank you very much

## **Probes**

Can you describe for me a time when that has happened?

Could you say something more about that?

Can you say anything else about that?

Have you experienced it yourself?

What was it like?

What happened?

Go on...

How do you mean?

Why do you think that was?

Can you describe that for me?

What did you think about at the time?

Have your feelings changed at all?

In what way?

Can you tell me more about...?

How does that make you feel?

## **Structural Questions**

I'd like to introduce a new topic...

Can I bring you back to...?

## **Paraphrasing**

So you're saying that...?

Am I right in saying that...?

Am I correct in thinking you feel...?

## **Silence**



## **Appendix 17: Patient Interview Schedule 2 (Version 1. 23/04/2007)**

### **Focused Photo-Elicitation Interview Schedule**

#### **(Second Interview - Patients)**

##### **Part 1. Focused Interview**

**Can you describe for me your experiences as a day-care patient at the hospice?**

Have your feelings about visiting [hospice name] changed?

Is there anything in particular that you really value about [hospice name]?

What is a typical day like at the [hospice name]...can you describe it to me?

Can you describe your relationship with the staff for me?

Can you describe your relationship with the other patients?

What are your experiences of patient care at [hospice name]?

How do you feel about complementary therapies now...have your views changed?

How do you see complementary therapy's role at [hospice name]?

Have complementary therapy's been of benefit you?

Can you describe your relationship with the complementary therapist?

How do you think the staff feel about complementary therapies?

**How do you feel about [hospice name] as a place now?**

(Would you like to take a break or have a cup of tea and we can continue later?)

##### **Part 2. Photo-Elicitation**

I'd like now to discuss the photographs that you've taken...

Can you describe to me how you feel when you look at this photo?

What do you think about when you look at this photo?

How do you feel when you're in that place?

What meaning does that place have for you?

What does the photo represent to you?

What is it about that place that you find...therapeutic / dislike?

What's your favourite photo out of all that you have here?

**Finally, as a place what would you say [hospice name] means to you?**

Thank you very much

## **Probing questions**

Can you describe for me a time when that has happened?

Could you say something more about that?

Can you say anything else about that?

Have you experienced it yourself?

What was it like?

What happened?

Go on...

How do you mean?

Why do you think that was?

Can you describe that for me?

What did you think about at the time?

Have your feelings changed at all?

In what way?

Can you tell me more about...?

How does that make you feel?

## **Structural Questions**

I'd like to introduce a new topic...

Can I bring you back to...?

## **Paraphrasing**

So you're saying that...?

Am I right in saying that...?

Am I correct in thinking you feel...?

## **Silence**

## **Appendix 18: Healthcare Staff Interview Schedule (Version 1. 23/04/2007)**

### **Focused Photo-Elicitation Interview Schedule**

#### **(Healthcare Staff)**

##### **Part 1. Focused Interview**

Can you describe for me your experiences of working at the hospice?

What do you do here at the hospice...can you describe your role for me?

How do you feel about working at the hospice?

What is a typical day like at the hospice? Can you describe it to me?

Can you describe your relationship with the patients for me?

How do you feel about complementary therapies...what do you know about them?

How do you see the role of complementary therapies at the hospice?

In what way do you think complementary therapies contribute towards patient care?

Can you describe your relationship with the complementary therapists?

How do you think the patient's feel about complementary therapies?

How do you think complementary therapy benefits the patients?

What is it about this particular setting that you value / dislike?

##### **Part 2. Photo-Elicitation**

I'd like now to discuss the photographs that you've taken...

Can you describe to me how you feel when you look at this photo?

What do you think about when you look at this photo?

How do you feel when you're in that place?

What meaning does that place have for you?

How does that place make you feel?

What does the photo represent to you?

What is it about that place that you find...therapeutic / dislike?

What's your favourite photo out of all that you have here?

**Finally, as a place what would you say [hospice name] means to you?**

Thank you very much

### **Probes**

Can you describe for me a time when that has happened?

Could you say something more about that?

Can you say anything else about that?

Have you experienced it yourself?

What was it like?

What happened?

Go on...

How do you mean?

Why do you think that was?

Can you describe that for me?

What did you think about at the time?

Have your feelings changed at all?

In what way?

Can you tell me more about...?

How does that make you feel?

### **Structural Questions**

I'd like to introduce a new topic...

Can I bring you back to...?

### **Paraphrasing**

So you're saying that...?

Am I right in saying that...?

Am I correct in thinking you feel...?

### **Silence**

**Appendix 19: Complementary Therapist Interview Schedule (Version 1. 23/04/2007)**

**Focused Photo-Elicitation Interview Schedule**  
**(Complementary Therapists)**

**Part 1. Focused Interview**

Can you describe for me your experiences of working at the hospice?

What do you do here at the hospice...can you describe your role for me?

How do you feel about working at the hospice?

What is a typical day like at the hospice? Can you describe it to me?

Can you describe your relationship with the patients for me?

How do you see complementary therapy's role at the hospice?

How do you see complementary therapy's role in patient care?

In what way do you think complementary therapies contribute towards patient care?

Can you describe for me your relationship with other medical staff?

Can you describe for me your relationship with the other therapists?

How do you think the patient's feel about complementary therapies?

How do you think complementary therapy benefits the patients?

What is it about this particular setting that you value / dislike?

**Part 2. Photo-Elicitation**

I'd like now to discuss the photographs that you've taken...

Can you describe to me how you feel when you look at this photo?

What do you think about when you look at this photo?

How do you feel when you're in that place?

What meaning does that place have for you?

How does that place make you feel?

What does the photo represent to you?

What is it about that place that you find...therapeutic / dislike?  
What's your favourite photo out of all that you have here?

**Finally, as a place what would you say [hospice name] means to you?**

Thank you very much



## **Probes**

Can you describe for me a time when that has happened?

Could you say something more about that?

Can you say anything else about that?

Have you experienced it yourself?

What was it like?

What happened?

Go on...

How do you mean?

Why do you think that was?

Can you describe that for me?

What did you think about at the time?

Have your feelings changed at all?

In what way?

Can you tell me more about...?

How does that make you feel?

## **Structural Questions**

I'd like to introduce a new topic...

Can I bring you back to...?

## **Paraphrasing**

So you're saying that...?

Am I right in saying that...?

Am I correct in thinking you feel...?

## **Silence**