EXPLORING FAMILY CARER INVOLVEMENT IN FORENSIC MENTAL HEALTH SERVICES

University of Central Lancashire

Support in Mind Scotland

Forensic Mental Health Services
Managed Care Network

Exploring Family Carer Involvement in Forensic Mental Health Services

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ACKNOWLEDGEMENTS

EXECUTIVE SUMMARY

Background

Scottish policy and law underline the importance of supporting family carers and using their knowledge and experience to increase the effectiveness of mental health care and treatment. In particular, the Mental Health (Care & Treatment) (Scotland) Act 2003 (MHCT Act), and *Caring Together,* Carers Strategy for Scotland (Scottish Government, 2010), emphasise involvement and participation of carers in mental health services. While there is a growing body of research about carers' experiences generally, the needs and experience of those who support individuals in forensic (secure) mental health services (forensic carers) have been neglected. Support in Mind Scotland (SiMS) and the Forensic Network thus commissioned this independent study to examine what they identified as 'significant gaps and inconsistencies', focusing in particular on the views and experiences of forensic carers.

Purpose of Study

The study aimed to provide evidence about:

- Existing support for family carers across forensic mental health services in Scotland
- Any gaps between what professionals say is provided and carers' experience
- The extent to which carers access available support in forensic mental health services
- What works well and what hinders carers from accessing this support

In addition to gathering information from carers about their experiences and views, the study has gathered information from forensic mental health services about existing support, as well as about access and uptake.

Methods

The study used a range of mainly qualitative methods, and an appreciative or capacities approach, in gathering information about the aims and objectives including:

1. A review of literature focusing on innovative and best practice;
2. A questionnaire survey auditing forensic mental health services' practice in supporting carers;
3. A questionnaire survey of forensic carers;
4. In-depth qualitative interviews with carers.

Samples

All forensic mental health services across Scotland were surveyed, achieving a response rate of 79%, with varying levels of response across different parts of Scotland and the State Hospital. Sixty six responses were received from family carers or friends to an online and paper questionnaire, and 19 individual carers were interviewed face-to-face.

Key Findings

Forensic mental health services' perspective

In summary, the survey of forensic mental health services' perspectives of carer support found:

- Most forensic mental health services report that they identify carers when a patient is admitted to the ward or service, or as soon as possible thereafter.
- Levels of patient/carer contact were thought to vary, although staff estimated that an average of 69% of patients were in contact with their relatives. This was mainly by telephone or when their relatives visited.
- Services reported wide-ranging levels of carer involvement in CPA meetings, with a reported average of 53% across forensic mental health services.
- Services reported providing at least one form of support to carers, even if only providing information leaflets.
- The most common form of support reported by services was a link with the named key worker or nurse for the relative. Carer support groups and behavioural family therapy were less frequently available.
- Carer support is promoted mainly through direct communication, but staff also highlighted that they provide information leaflets, posters, and write out to carers about the support available.
- The decision to provide support to carers was most strongly associated with specific service drivers, such as legislation and policies.
- Face-to face consultation with forensic carers about what support they wanted was mostly non-existent, and a fifth of services had no mechanism for monitoring or evaluating the support they offered to carers. There were exceptions such as the State Hospital's annual survey of carers.
- Staff in services estimated that an average of 43% of carers engaged with the support they provide, with variations ranging from zero to 100% carer engagement.
- Half of the services reported experiencing some difficulty in providing carer support, which included low or no involvement in carer support groups they had initiated.
- Staff believed that many forensic carers were not interested in engaging, or were not in contact with their relatives or friends, thus complicating attempts to engage with them.
- Low uptake therefore was primarily explained in terms of carers' choice or circumstance and/or the stigma associated with caring for a relative in forensic mental health services. Having to travel long distances to visit someone in these services was another main reason why they thought carers did not engage with the support provided.

Experience of being a forensic carer

The survey and interviews with carers resulted in the following key messages about the experience of being a forensic carer:

- The term 'carer' did not sit easily with this group; many rejected this label and preferred to call themselves 'supporter', 'visitor', or simply referred to the nature of their relationship with the person such as 'mother', 'brother', 'sister', etc.
- Some said health professionals did not consider them to be carers when their relative entered forensic mental health services.
- However, a distinct role and sets of circumstances emerged that suggests it is useful to collectively refer to people in this situation, e.g. as 'forensic carers'.
- The forensic caring role was difficult to define, but at its core involved practical and emotional support provided to relatives or friends across different secure settings. Forensic carers carried a significant emotional burden.
- There were important differences between the experiences of forensic carers who were relatives and those who were friends of the person. Caring as a friend rarely brought the same emotional turmoil that close relatives described, nor was it felt by friends as important for them to be kept informed about care and treatment issues.
- Many carers reported not being listened to when raising concerns about their relative's deteriorating mental health prior to admission to forensic services.
- Carers commented on tangible improvements within forensic services in recent years. Some, however, commented that there was still some way to go before the individual needs of their relative were met.
- Feeling stigmatised was highlighted as a challenge for forensic carers, some losing friends and becoming isolated in their own communities.
- The impact of being a forensic carer was profound, impacting on all aspects of people's lives including their physical and mental health. For some, being able to share the responsibility for care helps mitigate the stress felt.
- Forensic carers had extensive experience of the named person role. Fifteen out of 19 people interviewed and 63% of survey respondents were, or had been, a named person for their relative or friend.

Forensic carers' experience of support

The survey and interviews with carers resulted in the following key findings about forensic carers' experience of support:

- Just short of half of survey respondents rated the quality of support received from forensic mental health services as either good or very good. However, nearly a fifth felt this was poor or very poor.
- A third of survey respondents had found it either easy or very easy to access support when they needed it, in comparison with around a third who had found this difficult or very difficult.
- Only just over a half of survey respondents had received any form of advice, information or support when their relative was first admitted to forensic mental health services. There was evidence to suggest this could, in part at least, be attributed to historical rather than current experience.

- 70% of survey respondents were aware of a carer group, though fewer attended one.
- Carer support groups played an important role in supporting carers, although geographically-based groups felt less relevant to some carers supporting relatives in high or medium secure units located elsewhere in Scotland.
- Over half of survey respondents did not know about independent advocacy support for carers, and of those who did, the majority said they had never been offered it. Only around one in ten said they had used an independent advocate.
- Carers valued interactions with staff with good interpersonal skills, empathy and insightfulness and who made time to talk with them. The importance of face-to-face contact was emphasised: few forensic carers valued written information above the chance to talk, listen and question.
- Slightly less than two fifths of survey respondents had received information indicating their rights, such as to a carers' assessment. Even amongst these, some felt this information had been 'too little, too late'. Three fifths of respondents rated the information as either good or very good, but a fifth said it was either poor or very poor.
- Forensic carers wanted to be listened to and respected more by services, and to get the information they need. Where individual professionals were seen to communicate actively and positively with carers, this was hugely valued.
- Almost half of survey respondents had experienced challenges in travelling to and from forensic mental health services and 44% had been challenged by the lack of flexibility around visits.
- Forensic carers in this study reported feeling frustrated and blocked in their attempts to access information, from hospitals in particular, but also failing to get replies from agencies such as Mental Welfare Commission for Scotland. Issues surrounding confidentiality were also a barrier.
- The factors that can impact on the frequency and quality of visits include distance to and from forensic units and ease of travel; the environment and having a comfortable space for visiting and with some flexibility for visits; and, the level of privacy afforded for what can sometimes be quite fraught interactions.
- Carers felt that many of the places where visits took place were overly restrictive and unsatisfactory, even taking into account the need for certain levels of security.
- A key source of stress around visiting was not being consulted or kept informed about their relative. Having staff that were able to support the caring relationship made all the difference.

Conclusions

In considering the issue of carer support from the perspective of both services and carers, this study has attempted to explain the identified discrepancies in service delivery. Examples of good practice in the support of carers were noted throughout the study, and these included investment in information exchange, carer support or development workers, carer support groups and behavioural family therapy. However, a significant finding was that carer support is inconsistent across Scotland and within some units, and secondly that the reasons for low uptake of available support are understood differently by staff and carers. Staff identified carer choice as a main reason for this, whereas carers identified a number of access barriers.

From carers' perspective the most important change that can be made is for staff to perceive carers as important to engage with, with needs of their own, as effective allies in a triangle of care, and relate to them consistently in a welcoming and respectful manner. The increased emphasis in health and social care policy on the importance of supporting and involving carers needs to become widespread practice. The fact that carers can attest to the benefits of such an approach suggests that this is achievable in forensic settings without compromising confidentiality or risk management. While there is good practice, the most pressing issue would seem to be the need to increase the range and spread of support, and to address the current inconsistent and patchy provision of carer support.

This study has a number of limitations including that it adds little to the literature on the separation of forensic patients from their children (Chao and Kuti, 2009), or the experience of diverse forensic carers, especially those from BME groups. It has not specifically explored issues that may be specific to women who require forensic care or the needs of disabled people, but arguably these remain important areas for further research and practice development.

Recommendations

As a minimum, we underline the importance of the following general recommendations from the *Triangle of Care*:

1. Carers and the essential role they play are identified at first contact or as soon as possible thereafter.
2. Staff are 'carer aware' and trained in carer engagement strategies.
3. Policy and practice protocols regarding confidentiality and sharing information are in place.
4. Defined post(s) responsible for carers is/are in place.
5. A carer introduction to the service and staff is available, with a relevant range of information across the care pathway.
6. A range of carer support services is available.

To meet the specialist needs of forensic carers in Scotland, we further recommend:

- Acknowledging and sharing across the forensic estate information about existing good practice in fostering a culture of partnership with carers and supporting them to be a core part of forensic mental health services.
- Having designated staff within forensic mental health services who are responsible for advancing the carer agenda, driving the agenda forward and being a point of contact for new carers.
- Forensic mental health services providing a comprehensive and accessible information pack for carers, taking into account their diverse communication needs.
- Forensic mental health services considering what information, advice and support planning needs to be in place to alleviate uncertainties for carers associated with transitions.
- Forensic mental health services working to minimise the stigma forensic carers experience, and doing so in partnership with carers who have direct experience of this stigma.

- Involving carers in support planning and review processes including active encouragement and support to be involved in CPA reviews.
- Forensic mental health services holding regular carer events such as open days at secure units.
- All forensic mental health services organising and/or supporting a regular forensic carer support group serviced by the unit or in partnership with the voluntary sector or carers along the lines of existing successful forensic carer groups.

1   INTRODUCTION

Background

The importance of supporting informal carers and using their knowledge and experiences to increase the effectiveness of mental health care and treatment is implicit in Scottish law and policy: specifically in the Mental Health (Care & Treatment) (Scotland) Act 2003 (MHCT Act) and the national Carers Strategy for Scotland 2010-2015 *Caring Together* (Scottish Government, 2010). Recent UK-wide developments such as the *Triangle of Care,* carer peer support, implementation of a recovery agenda for informal carers (Worthington *et al*, 2013; Machin and Repper, 2013), and the Royal College of Psychiatrists' *Partners in Care* campaign, serve to further underline the importance of engaging mental health carers across the UK. That said, it is recognised that research is urgently needed to provide a more secure evidence base for developing carer-centred services generally (Samele *et al*, 2007). Particularly lacking is research that examines the perspectives and experiences of mental health carers, and especially that of family carers supporting people in forensic mental health services.

Evidence from early implementation of the MHCT Act, however, suggested that mental health carers were not always treated as 'partners in care' (Ridley, Hunter and Rosengard, 2010). Dissatisfaction among carers generally with levels of involvement with services and frustrated access to information is recognised in international literature (Mental Health Council of Australia and Carers Association of Australia, 2000; Marshall and Solomon, 2000; Scottish Intercollegiate Guidelines Network, 2013). In the Scottish context, the Moffatt Report (Kelly *et al*, 2010) pointed to shortcomings including low numbers of carers in receipt of carer assessments and appropriate information. Initiatives such as *Equal Partners in Care* (EPiC), a joint project between NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) focussing on workforce education and learning from sharing best practice, have subsequently sought to address some of these concerns.

Analysis of consultations during 2012 and two major forensic mental health services conferences held in 2010 and 2011 identified 'significant gaps and inconsistencies' in respect of forensic carers' experiences and levels of existing support reported by professionals (Forensic Network Advisory Board, 2012). While generally acknowledged that there have been improvements over the past decade, these recent consultations concluded that forensic carers in Scotland felt uninformed, traumatised, bewildered, and did not understand what was happening to their relative, or what they could do to help them or manage their own distress. Support in Mind Scotland and the Forensic Network commissioned this independent study to examine these discrepancies, focusing on the experiences and views of this neglected group of carers.

Terminology

Uncertainties surrounding the term 'carer' in policy and research were clear from the outset and have impacted on the study. In addition to carer, a range of other terms

are commonly in use including 'relative', 'unpaid carer', and 'informal carer' (Scottish Government, 2010, p16), and more recently, 'caregiver' was the term used by the Scottish Recovery Network (Chandler, Bradstreet and Hayward, 2013).

More general uncertainties around the role of carer have been documented elsewhere (HM Government, 2010). For the group of carers under consideration, there are specific difficulties posed by common definitions of carer that make assumptions about residency, including that a carer is someone who helps a person to 'remain at home' (EPiC), or legal definitions that require an amount of care or eligibility for local authority services (Scottish Government, 2007).

It is worth emphasising that the recent service specification for high secure forensic services in England acknowledges that family and friends are carers, and supports the principles underpinning the *Triangle of Care* by the National Mental Health Development Unit (NMHDU).

It is also not easy to define 'forensic mental health services' as service boundaries are not always clear. For example, intensive psychiatric care units (IPCU) have locked wards and may care for a mix of inpatients using forensic mental health services and general mental health services. Services participating in the study were identified as forensic mental health services by the Forensic Network in line with its definition:

> *Forensic mental health services assess and treat mentally disordered offenders and patients with major behavioural, mental health problems and learning disabilities, in a range of secure health facilities and the community, in police stations, courts and prisons.*

Forensic mental health services provide treatment and support to those assessed as at risk of offending, or who have offended as a consequence of a mental health problem, personality disorder or learning difficulties. It should be noted, however, that not all inpatients within forensic mental health services will have offended. Some will be cared for in a secure environment due to other risk factors, such as problem behaviours rather than purely on risk of offending.

Inpatient forensic services are delivered through a combination of low and medium secure hospitals and the high secure State Hospital. Community forensic mental health services are delivered through day centres and Community Mental Health Teams (CMHTs). However, some of those who are at risk of offending, or who have offended because of their mental health problems, will be supported and treated in general mental health services.

Our definition of a 'forensic carer' therefore was:

> *Someone of any age who provides unpaid support for a relative or friend who is using forensic mental health services, including those provided in low, medium and high secure and community settings.*

Because of the long term nature of involvement with these services and the stigma surrounding them, this identity may be retained after their relative or friend has left hospital.

Study Purpose

The study aimed to provide evidence about:

- The support for carers that exists across forensic mental health services in Scotland
- Any gap between what professionals say is provided and carers' experience
- The extent to which carers access available support in forensic mental health services
- What works well and what hinders carers from accessing this support

In addition to gathering information from carers about their experiences and views, the study has gathered information from forensic mental health services about existing support, as well as access and uptake. This study has only looked at forensic mental health services in Scotland and the relatives and friends that relate to people in these services. It does not include the experiences of carers who live in Scotland and provide support to people in forensic mental health services elsewhere in the UK. As there are no women's high secure facilities in Scotland, the voices of carers of women in high secure services are not included.

Research Design

This evaluation research has applied the approach of appreciative inquiry to gather information about current support and experiences, focusing particularly on detecting strengths and what works and why, and considering how this could be extended. The study used mixed methods, mainly qualitative, to explore experiences and views and to develop greater insight and understanding into the gaps and discrepancies reported in previous consultations with forensic carers. The design was refined in consultation with the project Working Group.

Methods

There were three main approaches to data collection/information gathering:

1. A review of literature focusing on innovative and best practice (see Appendix 1);
2. An audit of forensic mental health services reporting of their practice in supporting carers via an online questionnaire survey (see Chapter 2);
3. Gathering information from carers in the forensic system about their experiences and views via a questionnaire survey and in-depth qualitative interviews (see Chapters 3 and 4).

Literature review

A brief search of the published research and practice literature in the UK within the past 25 years (and to a more limited extent, international literature) was undertaken to identify contemporary thinking about best practice in supporting carers, and to draw together evidence on innovative and effective practice in forensic mental health services. This review is presented in Appendix 1 to this report.

Questionnaire survey of services

By way of auditing the levels and types of support provided to carers with relatives or friends in forensic mental health services, a questionnaire survey based on the most recent study in England and Wales (Canning *et al*, 2009) was conducted across all secure, medium and low secure units, and community services in Scotland. The survey consisted of 30 items including specific, multiple choice and open questions gathering both quantitative and qualitative information. The online questionnaire was administered via email to targeted forensic mental health services staff deemed to be knowledgeable about relevant practices; staff were identified initially by the Forensic Network and appropriate respondents, and then confirmed by each service. The questionnaire aimed to gather information about forensic mental health services/units; the extent of their involvement with, and support provided to carers; how and who provided support to carers; the benefits and challenges of supporting carers; and the perceived uptake and reasons why carers might not be accessing support.

Questionnaire survey of forensic carers

Forensic carers throughout Scotland were invited to complete a questionnaire survey either online or paper copy which they returned in a prepaid envelope. The questionnaire was designed in conjunction with carers on the Working Group, and drew upon key issues identified in the literature. Forensic carers were asked to give details about themselves (e.g. age, gender, ethnicity, etc.), and about the person they cared for, their experiences of forensic mental health services, the nature of carer support including independent carers advocacy that they were both aware of and/or had used, their experience of the person they cared for being transferred into or between forensic mental health services, the key challenges they had faced in this role, and for suggestions about how support to forensic carers could improve.

A total of 550 questionnaires were distributed on behalf of the researchers via a range of services and organisations: 400 of these were distributed through forensic mental health services across Scotland; 50 through Support in Mind Scotland; 50 via carers organisations and groups (including Tayside Forensic Voices, Lanarkshire Links, Charing Cross Carers Group and Edinburgh Carers Council); 20 via SACRO transport service; and 50 were given out at the annual Forensic Network Carers Conference. In addition, information about the study and an electronic version of the questionnaire were circulated via email to advocacy organisations providing carers advocacy, and other user and carer organisations including Voices of Experience (VOX). Organisations such as the Scottish Independent Advocacy Alliance (SIAA) and the Community Health Exchange (CHEX) ran items in their newsletters inviting carers to participate in the study. Also, Support in Mind Scotland circulated

information widely to carers, individuals and organisations on their databases. An internet link to the survey was given in the information sheet.

Interviews with carers

Carers who responded to the questionnaire survey were asked to indicate if they would like to be interviewed. Staff in medium, low and community forensic mental health services in the North and South East of Scotland invited forensic carers associated with their services to participate in interviews. Information about the interviews, along with the survey, was also circulated to forensic carers alongside the State Hospital Carers Newsletter. The interview topic guide, designed in collaboration with carers on the Working Group and in light of issues identified by forensic carers in previous consultations, adopted an appreciative approach to explore what worked well in addition to the challenges and barriers to carers or using support from forensic mental health services. The topic guide asked carers about their experience of being a forensic carer; about moves from prison or general psychiatric services to forensic mental health services and changes in level of secure services; about their experience of forensic mental health services' support to carers including carer support groups; and for their suggestions about improving carer support.

Analysis

Quantitative information gathered through closed, specific and multiple choice questions in the surveys was analysed using descriptive statistics. Most interviews with carers were digitally recorded and transcribed except for three where notes were taken with the consent of the interviewee. Qualitative data collected both by questionnaire and from interviews was analysed using standard qualitative data analysis methods, starting with coding and identifying key themes and patterns in the data (Coffey and Atkinson, 1996; Bazeley, 2013). Data were coded and NVivo 10 (a qualitative data analysis package) assisted in the systematic search and retrieval of data. The process of identifying themes was shaped by the research objectives, identified themes from the literature review and the team's interpretations. A broad interpretive framework, which included carers' perspective, was achieved through involvement of all research team members in developing the coding frame, coding transcripts and either writing up or commenting on the developing analysis. Further critical perspectives have been incorporated through consultation with the Working Group.

Ethical approval

Ethical approval for the study was given by the PSYSOC Ethics Committee at the University of Central Lancashire. Advice was also taken from NHS South East Scotland Ethics Board on behalf of NRES, who advised that NHS ethical approval was not required since the study was service evaluation. Research governance approvals were given from 10 Health Boards including the Research Committees at the State Hospital and Greater Glasgow & Clyde. Care has been taken not to identify individuals. Identifying features such as place and secure service have been changed or omitted in writing this report.

Study Limitations

In order to address limitations of survey methods, the questionnaire of forensic mental health services was based on a modified measure that had been tested previously with forensic mental health services elsewhere in the UK (Canning *et al*, 2009). The initial draft questionnaire was checked for validity with the Working Group and Forensic Network, and was slightly amended. The sample of forensic mental health services was identified through the Forensic Network and relevant contacts for each service were verified by the research team. This ensured the selection of the most relevant individual respondents. The study is a unique survey of forensic mental health services in Scotland.

While the questionnaire survey with forensic carers had some limitations, the method enabled us to reach a diverse range of carers across the country. The Working Group was consulted about the questions used and we piloted the survey with two carers who completed it online. As a result of the pilot, slight word changes were made to ambiguously worded questions. Participation in the study was reliant on information being circulated on our behalf by services for data protection reasons, and because the commissioners wanted the study to be promoted to all forensic carers and not only those who had participated in past consultations. The findings in Chapter 3 and 4 demonstrate that this was achieved.

Reaching forensic carers via another party in a limited timeframe was a major limitation that impacted on levels of participation in both the survey and interviews. A longer timeframe and better resourced study might have been able to develop a more localised and tailored approach to working with services to recruit carers. For instance, word of mouth between carers in existing trusting relationships helped us to contact additional interviewees and with more time this approach could have been extended. That there are generally low levels of carer engagement in some services currently meant that the pool of carers to invite for interview was small to begin with. To address this, we engaged with staff in a wider range of forensic services than initially planned for, including the State Hospital, to help recruit an interview sample. The study therefore adds to an area where there is limited knowledge in a specifically Scottish forensic context.

Report Structure

The next chapter presents findings from the survey of forensic mental health services and the support they provide for carers. This is followed by an exploration in Chapter 3 of the experience of being a forensic carer, and of journeys into and through forensic mental health services. Chapter 4 examines forensic carers' experience of support and their ideas about improving support to carers. Finally, in Chapter 5 we draw together the key themes across the data and discuss the implications for services and the development of a national carer strategy that takes account of forensic carers.

2   FORENSIC MENTAL HEALTH SERVICES' PERSPECTIVES

Introduction

Findings from the survey of staff in forensic mental health services are the main focus of this chapter. The survey aimed to gather information about how services engaged carers, the types of support provided, how they promoted such support, identified challenges and benefits of this provision, and understandings of differential levels of uptake amongst carers. Chapter 2 begins by describing the forensic mental health services that responded, and then discusses key findings about carer support from the service perspective.

Thirty three email contacts were identified across the whole forensic estate, covering high, medium and low secure and community forensic mental health services. Most were in the NHS sector, while two units were privately run. A questionnaire was sent to a named respondent (e.g. Lead Nurse, Senior Charge Nurse, Forensic Practitioner, Community Service Manager) to complete on behalf of each service/unit and a response rate of 79% (26 replies) was achieved. As Table 1 below shows, responses came from across the forensic estate but response rates varied by area, ranging from 33% (Grampian Health Board area) to a 100% response from others.

Table 1: Survey response rates by NHS health board.

Location	No. of Services Responded	No. of Services Contacted	Response Rate (%)
Tayside	4	4	100
Greater Glasgow & Clyde	3	3	100
Lanarkshire	2	2	100
Forth Valley	2	2	100
Independent sector	2	2	100
Highland*	1	1	100
Fife	4	5	80
Ayrshire & Arran	2	3	67
Lothian	2	3	67
State Hospital	2	4	50
Dumfries & Galloway	1	1	100
Grampian	1	3	33
Total	26	33	79

*Both Highland and Dumfries & Galloway responses were completed by one respondent on behalf of the whole forensic mental health service (two respondents in each were contacted originally).

Profile of Services

The size and scope of forensic mental health services varied greatly with the number of beds or patients within a service or unit averaging 53, and ranging from three to up to 72 inpatient beds across different units at different levels of security. Four hubs in the State Hospital provided 35 beds each (140 in total), whilst in medium secure units the number of beds ranged from 13 to 72 beds, and in low secure settings bed numbers varied from three to 50. Numbers of community forensic patients varied between teams and areas from 15 to 80 patients.

The majority of services/units (78%) were providing a service to people with mental illness. Those catering only for people with mental illness (42%) were in the majority, while a minority catered specifically for people with learning disabilities (19%). Both private units providing low secure inpatient services were catering for both people with mental illness and people with learning disabilities, as were eight other NHS units (38%). Designated wards for people diagnosed with personality disorders were only provided by the two private hospitals responding to the survey; there were none in any of the responding NHS units.

Involvement and Engagement of Carers

The vast majority of services (81%), including both private units, stated that they identify patients' relatives or carers at the time of admission to forensic mental health services or as soon as possible thereafter. A minority (15%), all in the NHS, stated that they identified the patients' carers prior to admission. One respondent stated that some carers made themselves known to the service prior to their relative being admitted.

Levels of contact

Overall, forensic mental health services judged that an average of 69% of patients were in contact with their relatives/carers. Despite wide variations in responses, it suggests that significant numbers of forensic carers could potentially benefit from some form of support but may not be accessing this currently. Estimates of the proportion of patients in contact with relatives range from as few as 20-39% to as many as 100% across different services/units (see Table 2 below). Further, those who identified low percentages of carers involved with their relative were typically responding on behalf of medium secure units, IPCUs and units in the independent sector.

Table 2: Service average estimates of patient/carer contact showing ranges (number and %) for comparison

Percentage Range	Total Sample N=26, (%)	Private Units N=2, (%)	NHS Units N=24, (%)
Average estimate	69%	55%	70%
Low (20-39%)	5 (19)	1 (50)	4 (17)
Medium (40-59%)	2 (8)	0	2 (8)
High (60-79%)	7 (27)	1 (50)	7 (29)
Very high (80-100%)	12 (46)	0	11 (46)

Method of contact between patients and carers

The vast majority of forensic mental health services staff thought that the most common method for patients to be in contact with their relatives/carers was by telephone, followed by visits. Sixty nine per cent of respondents highlighted contact via letter and through CPA and other meetings. Over half highlighted contact occurring when the person was on leave from hospital. Very few respondents believed patients and carers to be in contact via electronic communications such as email or Skype. A few identified contact occurring due to the person and his/her carer living in the same household, by way of text messages, participating in Behavioural Family Therapy (BFT), or attending carers support groups as ways of remaining in contact.

We also asked whether or not those carers who were in contact with their relatives were routinely invited to CPA meetings, and all but one independent hospital (96% of respondents) reported that this was the case. However, this did mean that corresponding estimates of carers actually involved in CPA meetings was similarly high. In fact, this could be as little as 10% to as high as 99% of carers involved in CPA meetings, with an average of around 53% believed to participate in such meetings. Both independent hospitals estimated that only a quarter of carers were involved in CPA reviews compared to 56% in NHS units. Interestingly, different low secure, rehabilitation wards and IPCU respondents were amongst both the low and high estimations, whilst most community forensic teams, including those working with people with learning disabilities, and private units tended towards low numbers of carers involved in CPA meetings.

Table 3: Services' average % estimate of carers involved in CPA meetings showing ranges (number and %) for comparison

Percentage Range	Total Sample N=26, (%)	Private Units N=2, (%)	NHS Units N=24, (%)
Average Estimate	53%	25%	56%
Low (0-39%)	9 (35)	2 (100)	7 (29)
Medium (40-59%)	7 (27)	0	7 (29)
High (60-79%)	2 (8)	0	2 (8)
Very high (80-100%)	8 (31)	0	8 (33)

Carer Support

Responses to the survey showed all services were providing at least one kind of support to forensic carers, though this might only be a link with the key worker or named nurse for the relative, and/or providing information leaflets. It did not imply that comprehensive packages of support were on offer to carers. The paragraphs below suggest the picture was rather patchy, with concentrations of good practice in a few areas and very little carer support in others.

Carer support ranged from low level support such as provision of general information leaflets, newsletters and websites to more intensive and proactive support and interventions through carers support groups, one-to-one support, and offering behavioural family therapy sessions. Forensic mental health services staff were reported to be facilitating and attending carer support groups, and to be taking a lead role in offering support and assessment to carers. Table 4 below illustrates the types of carer support being provided by forensic mental health services.

Table 4: Types of carer support available as reported by forensic mental health services

Types of Support	Total Sample N=26, (%)	Private Units N=2, (%)	NHS Units N=24, (%)
Key worker/named nurse contact	25 (97)	2 (100)	23 (96)
Information about mental illness	19 (73)	1 (50)	18 (75)
Information about medication	18 (69)	1 (50)	17 (71)
Service has information leaflet	18 (69)	2 (100)	16 (67)
Service runs carers group	15 (58)	1 (50)	14 (58)
Referral to external agencies	12 (46)	1 (50)	11 (46)
Independent carers' advocacy	10 (38)	0	10 (42)
Tailored web-based information	7 (27)	0	7 (29)
Financial support given	3 (12)	0	3 (13)
Dedicated telephone helpline	2 (8)	0	2 (8)
NHS carer support worker	2 (8)	0	2 (8)
Overnight accommodation	2 (8)	0	2 (8)
Visitor centre	2 (8)	0	2 (8)
Other	3 (12)	0	3 (13)

The majority of services (97%) said carers could receive support from a key worker or named nurse. Almost three quarters (73%) said they provided information on mental illness, and 69% that information was available for carers on medication, as well as there being information leaflets about forensic units. Fewer respondents (58%) identified their service as providing a carer support group, and just 39% identified independent advocacy for carers being available in their area.

We are unable to comment on the content and quality of information for carers as only three survey respondents forwarded materials to the research team, some of which was comprehensive, and others exceedingly brief. The State Hospital provides a comprehensive range of support and information, co-ordinated through a dedicated carers centre, with information widely available on its website and a regular newsletter for carers. Less frequently available were dedicated telephone helplines for carers, NHS carers support workers, overnight accommodation, and

visitor centres. A minority of respondents also highlighted provision of Behavioural Family Therapy, home visits from workers, and user and carer involvement activity.

Of the services offering a carer support group, these typically took place on a monthly basis. One community forensic mental health service reported hosting such a group for the last 15 years. This group was always attended by a senior psychiatrist and other staff, encouraged peer-to-peer support with carers choosing to exchange telephone numbers and produce their own newsletter and DVDs; the latter targeting both carers and staff education. Some services promoted carer support groups run by a voluntary sector organisation but were unsure of the level of forensic carer participation, or if the particular needs of forensic carers were met in groups offering more generic support to mental health carers. Some areas reported an absence of relevant forensic carer forums in the community. There appeared to be a general mismatch between forensic carers' needs relating to different levels of secure care with the focus and location of existing groups.

One respondent mentioned the National Forensic Carers Conference held every two years as an example of how carers as a group are supported. Different health and social care professionals in forensic mental health services, as well as carers and other external facilitators, were said to be responsible for supporting carers. However, most responding services (88%) identified nurses, followed by social workers (48%), then doctors (36%) as being responsible.

Carers with Specialist Needs

Support for diverse groups was limited to translation services, braille, signing services, pictorial aids and being 'respectful'. Almost half (48%) stated that their forensic health service did not cater for people with specialist needs, and most did not have separate support arrangements for carers with specialist needs. Only a fifth of respondents indicated that they provided specialist support for carers of patients with learning disabilities.

Over half of services (58%) reported catering for the needs of Black and Minority Ethnic (BME) carers, in the main through provision of translation services. Others remarked an equalities strategy was in place, and one respondent added they could access specialist BME support when needed.

The majority (65%) did not have specific provisions for carers with sensory impairments, including both private units. Those who did had information available in braille, induction loops, and access to BSL interpreters. Some respondents answered that they could access specialist provisions to meet these needs when required.

Few services had identified unmet needs or were planning to develop new support for carers. Conversely, other services reported plans to develop additional specialist services for carers, for new carer support services to be developed where there was nothing, or to further develop the family support work involving both patients and carers.

Promoting Carers Support

Survey respondents identified a variety of ways in which they understood carers were being made aware of the support available to them, with word of mouth and information leaflets believed to be the most effective methods of communication. All claimed that carers were made aware of support through direct communication from professionals in forensic mental health services. Notably, many said they promoted this to carers via information leaflets and that there were posters, or carers received letters informing them of availability of support. A few said they communicated by telephone, had DVDs for carers, or promoted support for carers at CPA review meetings.

Table 5: Methods forensic mental health services report they use to make carers aware of support

Method	Total Sample N=24, (%)	Private Units N=2, (%)	NHS Units N=22, (%)
Verbally by professionals	24 (100)	2 (100)	22 (100)
Information leaflets	21 (88)	2 (100)	19 (83)
Posters	15 (63)	1 (50)	14 (64)
Letters	13 (54)	2 (100)	11 (50)
Newsletters	6 (25)	0	6 (27)
Carers' assessments	4 (17)	0	4 (18)
Carer Support Worker	3 (13)	0	3 (14)
Email/internet	1 (4)	0	1 (5)
Other	3 (13)	1 (50)	2 (9)

Motivations and Benefits for Supporting Carers

A range of motivations were reported to have encouraged forensic mental health services to provide support to carers, including responding to demand from carers, implementing policy guidelines and known best practice, increasing understanding and improving relationships. This development was perceived to have a positive impact on inpatient services as well as a range of other benefits, demonstrating that at least in principle, many forensic mental health services staff understand the importance of involving carers:

> *"Carers play a very important role in the support of forensic clients. They provide valuable information on clients' mental health and can highlight concerns quickly to staff."*

For some, the decision to provide such support was primarily driven by the need to implement legal and best practice requirements. These might include: implementing the national carers strategy, nursing delivery plans or standards for schizophrenia care, risk management, inclusion, and overall minimum standards for secure services:

> "…we have legal responsibilities to work professionally with our carers as set out in the Mental Health Act."

Other respondents reported a value-based commitment to carer support, making the case that positive efforts in this regard are part of giving out a message about what the NHS stands for. This might be in tandem with instrumental motivations about the worth and impact of effective support for carers in terms of patient benefit and overall satisfaction.

Carer support was clearly well developed in some forensic mental health services, based on an understanding of the needs and views of forensic carers, and perhaps implying some level of collaboration. Only one service, however, commented that support initiatives had been developed organically in response to discussion with carers. There was little mention in the responses of any wider consultation exercises with either carers or service users.

Around two-thirds of services explicitly acknowledged the benefits of providing carer support. These included potential direct benefits to the person in forensic mental health services as well as to carers. Staff emphasised how supporting carers improved communications in the care team, including gaining information from family members about patient history, as well as enabling staff to give information and support reciprocally. This collaborative approach could be assumed to have indirect benefits for patients:

> "If carers have a better understanding of their relative's mental health they will hopefully understand care packages being provided and support them, ultimately impacting positively upon their relative's mental health stability."

> "Carers provide ongoing support for our patients. When a patient is first admitted the carers are extremely important in helping the clinical team develop an understanding of our patients' backgrounds and recent histories. At the same time chatting to and supporting carers allows us to alleviate their distress and anxieties."

Qualitative responses were replete with language indicative of perceived benefits to patients, carers and the service provision as a whole – with an emphasis on 'improved communication', collaborative 'exchange of information', reciprocal extension of 'understanding' of each other's perspectives, developing 'insights' into 'user perspectives and greater engagement with carers/patients'. There was a sense from some comments that provision of support to carers facilitated better engagement and 'buy-in' to packages of care. Similarly, carers were reported as well placed to provide advocacy for patients in CPAs and other meetings.

Difficulties in Providing Carer Support

Half the service respondents described experiencing difficulties in providing carer support. Both of the independent hospitals had had problems setting up or maintaining their levels of support. Slightly more NHS units (55%) had not, compared to those that had, experienced difficulties. Several services stated that difficulties arose because carers were not interested in engaging with forensic mental health services, or that the patients in their particular service tended to be estranged from, or not in ongoing contact with their relatives, thus complicating their attempts to engage with carers. One ward which supports patients both with and without a forensic history noted that:

> *"Current forensic carers were significantly less likely to accept support and engagement offered than their generic counterparts... only one patient's carers had ever attended a CPA review."*

There was nothing to suggest that the service had found out why take up was poor or used alternative means of engaging and supporting carers to attend review meetings. Even where services reported they had contacted eligible carers to invite them, for example, to join a support group, uptake could be so low that it did not justify the allocation of staff and resources. The reasons given for this lack of engagement were suggested to involve travel distances and suspicion of services. One respondent emphasised that there are opportunities for all staff to be more pro-active about contacting carers:

> *"There has been times recently with new consultants who do not contact relatives when patients are admitted so families may not know where their son is etc. and that is difficult for us as nurses to deal with as it could only be a 'your son is safe' phone call but also a lot of useful, essential information can be gathered re: someone's illness from such a call."*

One community service reported initial difficulties with staff commitment to the carers group because of a dislike of working evenings. To counter this, the group was staffed via a rota, but this perhaps diluted continuity of staff involvement. This problem was solved by a particular member of staff finding they enjoyed the work so much that they volunteered to staff the group permanently. This speaks of the potential for staff involvement in carer support to maximise job fulfilment, but might suggest some potential service vulnerability to staff illness or turnover. It also indicates that the service did not see carer involvement as part of its core work.

One fifth of services stated that they did not systematically monitor or evaluate the support offered to carers. While not systematic, the most commonly cited mechanism used was to 'obtain direct feedback from carers', followed by questionnaire surveys. The State Hospital conduct an annual survey of this kind.

The average percentage of carers reported to be using support across all types of forensic mental health services was 43%, with a range from zero engagement to 100%. Particularly high estimations came from one of the State Hospital hubs, who reported 100% involvement of carers through the Visitors Centre, and respondents

from low secure for learning disability services. Those estimating low uptake included all the medium secure units, one of the private units, an IPCU, a community forensic team and a day centre. Table 6 below shows that most respondents estimated uptake to be in the low to medium categories.

Table 6: Estimated percentages of carers who use support provided by forensic mental health services

Percentage Range	Total Sample N=21, (%)	Private Units N=2, (%)	NHS Units N=19, (%)
Average	43%	30%	45%
Low (0-39%)	8 (38)	1 (50)	7 (37)
Medium (40-59%)	8 (38)	1 (50)	7 (37)
High (60-79%)	2 (10)	0	2 (11)
Very high (80-100%)	3 (14)	0	3 (16)

Table 7 below shows that the main reasons why staff in forensic mental health services believed that carers did not take up the available support were predominantly about carers' own choices and circumstances, or with the stigma associated with caring for a relative in forensic mental health services. In this regard, the carer's choice was rated as the most likely reason by four out of five of respondents, followed next by geographical challenges, and, related to this, transport, and then stigma of the forensic label. Both independent hospitals cited geography and travel as the key reasons.

Table 7: Service perceptions for low levels of carer engagement with support

Reason	Total Sample N=22, (%)	Private Units N=2, (%)	NHS Units N=20, (%)
Carers' choice	18 (82)	1 (50)	17 (85)
Geographical	15 (68)	2 (100)	13 (65)
Transport	13 (59)	2 (100)	11 (55)
Stigma of forensic label	11 (50)	1 (50)	10 (50)
Financial difficulties	4 (18)	1 (50)	3 (15)
Language/cultural issues	2 (9)	0	2 (10)
Other	7 (32)	0	7 (35)

Most comments from the survey indicated that staff opinions about carers and their engagement were coloured by their views of carers not maintaining contact with their relatives, whereas the findings in the next two chapters show that many forensic carers clearly do stay in contact but experience a number of barriers to accessing support. Language or cultural differences were the least cited reasons as to why carers do not use available support. Almost a third of all service respondents gave 'other' reasons for carers not using the support provided. These included carers not having time, carers appreciating having less responsibility when their relative was in hospital, previous negative experiences, carers not believing their relative has a mental health problem, or the carer not having a relationship with the patient.

Although the majority (81%) of respondents reported having a confidentiality policy, just three forwarded these to the research team. Three respondents in NHS services did not know if the service had a confidentiality policy.

Key Findings

In summary, the survey of forensic mental health services' perspectives of carer support found:

- Most forensic mental health services report that they identify carers when a patient is admitted to the ward or service, or as soon as possible thereafter.
- Levels of patient/carer contact were thought to vary, although it was estimated that an average of 69% of patients were in contact with their relatives. This was mainly by telephone or when their relatives visited.
- Services reported wide-ranging of levels of carer engagement in CPA meetings – from as little as 10% to 99% - with an average across forensic mental health services of 53% carer involvement.
- Services reported providing at least one form of support to carers, although this might simply be providing general information leaflets.
- The most common form of support reported by services was a link with the named key worker or nurse for the relative. Carer support groups and behavioural family therapy were less frequently available.
- Carer support is promoted mainly through direct communication, but staff also highlighted that they provide information leaflets, posters, and write out to carers about the support available.
- The decision to provide support to carers was most strongly associated with specific service drivers, such as legislation and policies.
- Face-to face consultation with forensic carers about what support they wanted was mostly non-existent, and a fifth of services had no mechanism for monitoring or evaluating the support they offered to carers. There were exceptions such as the State Hospital's annual survey of carers.
- Staff in services estimated that an average of 43% of carers engaged with the support they provide, with variations ranging from zero to 100% carer engagement.
- Half of the services reported experiencing some difficulty in providing carer support, which included low or no involvement in carer support groups they had initiated.

- Staff thought that many carers were not interested in engaging or were not in contact with their relatives or friends, thus complicating services' attempts to engage with carers.
- Low uptake was therefore primarily explained in terms of carers' choices or circumstances and/or the stigma associated with caring for a relative in forensic services. Having to travel long distances to forensic mental health services was another main reason why they thought carers did not engage with the support provided.

3 EXPERIENCE OF BEING A FORENSIC CARER

Introduction

This chapter focuses on the findings on carers' perspectives on the support provided by forensic mental health services. It explores forensic carers' experience of and views on the journeys of their relatives into and through forensic mental health services and the impact on them, as well as carers' experience of being a 'forensic carer' and how this impacts. An overview of the carers who participated in the survey and interviews is given, showing participants in the study coming from diverse backgrounds and having experience of supporting relatives or friends in all types of forensic service, and from across the three Regions (North, South & East, West) and the State Hospital.

Carer Participants

Questionnaire survey respondents

Over a period of nearly six months, 66 carers replied to the questionnaire survey either online (21 respondents), or by post (45 respondents). Given that distribution of information about the study and paper copies of the questionnaire involved a number of routes, it is not possible to calculate a response rate with any certainty. However, previous estimates of the potential number of carers at around 500 would suggest a response from at least 10% of forensic carers across Scotland, which considering this a particularly 'hard to reach' group is a reasonable result. Although we would have liked to have reached more forensic carers, 10% was the minimum the commissioners had specified. The bulk of responses came from Tayside and the Greater Glasgow and Clyde areas, although as the table below shows the responses were spread across Scotland, with two from other parts of the UK.

Table 8: Number of forensic carer responses to the questionnaire by area

Area	Number of Responses
Greater Glasgow & Clyde (North Lanarkshire, Renfrewshire, Glasgow, East Dumbarton, Strathclyde, Argyll & Bute, Ayrshire, Inverclyde)	26
Tayside (Perth & Kinross, Angus, Dundee)	22
Dumfries & Galloway	2
Lothian (Edinburgh, Mid Lothian, West Lothian)	4
Central (Stirling, Falkirk)	3
Fife	3
Scottish Borders	1
Aberdeenshire	1
Highland	2
Other parts of UK	2
TOTAL	66

While questionnaire respondents tended to be female, were most likely to be mothers supporting a son in forensic mental health services and to have been caring for their relative more than 10 years, Table 9 below shows that the study captured a broad range of carer experiences and perspectives.

Table 9: Summary characteristics of carers responding to the questionnaire survey

Variable	Carer Respondents
Gender	Female – 62% Male – 38%
Age	25-54 yrs – 26 55-64 yrs – 19 65-74 yrs – 18 75 yrs + - 3
Ethnicity	All but one White/White Scottish
Disability	20% disabled (including mental health problems)
Type of carer	Parent carer – 54% Other relative – 17% Partners/spouse – 14% Sons or daughters 11% Friends – 5% Couple or family carer 55% Lone/single carer- 45%
Length of time caring	Less than 1 year – 5% 1-5 years – 29% 5-10 years – 11% Over 10 years – 55%

Those who responded also varied according to the circumstances of the person they were caring for, along with the current forensic health service the person was in (see Table 10 below). Most were caring for a male relative diagnosed with mental illness currently in various forensic mental health services. The largest proportion was currently in community forensic mental health services, followed by high secure and low secure services for mental illness. They had been in forensic mental health services for varying amounts of time, but a fifth had been in these services for over 15 years. The sample, therefore, included carers who were both new to forensic mental health services, as well as those with several years of experience of different secure settings.

Table 10: Summary of circumstances of person cared for

Variable	Person Cared For		
Diagnostic label	Mental illness – 75% Learning disability – 6% Personality disorder – 3% Combined - 13% Don't know – 2%		
Type of current forensic health service	High secure – Medium secure – Low secure – (mental illness) Low secure – (learning disability) Community service –	25% 19% 24% 3% 29%	
Length of time in forensic mental health services	Less than one year - 13% 1-3 years 24% 3-5 years 13% 5-10 years 16% 10-15 years 13% Over 15 years 20%		

Forensic carers interviewed

Thirteen forensic carers who had completed the questionnaire were interviewed, providing a further opportunity for these carers to share their experiences and perspectives in more depth. Six other people were recruited through various forensic mental health services. Altogether 19 individual carers (15 women and four men) from different parts of Scotland were interviewed, including people living in rural Aberdeenshire, Scottish Borders, Dumfries and Galloway as well as from the central belt of Scotland. One joint interview was undertaken that involved two carers relating to the same family member.

Most interviewees were over 50 years of age (14 interviewees), and half of these were aged between 60-76 years. Only one young person under 20 years (sibling carer) participated in the study. All those interviewed identified their ethnicity as white British or Scottish. On the whole, the carers interviewed were parent carers (12 interviewees), while others were partners, husbands or wives, or brothers or sisters of the person in forensic mental health services, and one interviewee was supporting a friend. Reflecting the predominance of men in forensic mental health services overall, it is not surprising that the majority of the people in forensic care that these carers were caring for were men (15 out of 18 individuals). They were currently placed in high secure (5 people); medium secure (5 people); low secure (3 people); community based services (3 people); independent sector low secure (one person); and general rehabilitation wards (one person).

Journeys Into and Through Forensic Mental Health Services

Accounts of their relative's journey into and through forensic mental health services became the key focus of many of the interviews. They clearly needed to share their

narratives, and for some, they were doing this for the first time. As one carer said 'it's absolutely amazing getting to chat to you and explain my side of the story.' Escalation of mental health problems, involvement with the criminal justice system, and behaviour resulting in appraisal that the person posed a serious risk to themselves or other people, were the key triggers precipitating entry to forensic mental health services. This might be admittance to high secure at the State Hospital or a move from an acute psychiatric ward to a low secure facility because of concerns over an individual's safety. Others were transferred to both high and low secure from prison, from general psychiatric care to low or community forensic mental health services, or combinations of moves between different levels of secure services. For one person, involvement with forensic mental health services followed on from a psychiatric assessment at the end of a short prison sentence:

> "At the end of a six month sentence they sent for a psychiatrist who came and within 10 minutes told them she felt he had hyper mania." (partner)

Parents and siblings identified troubles which, with hindsight, began in adolescence and with involvement of young people's, mental health and, in some cases, criminal justice services. One parent traced a journey that began when their relative was in her teens, resulting in admissions to a series of mental health and then forensic mental health services over a period of around 16 years. Another stated:

> "Looking back, his teenage years were kind of a bit turbulent and I think we thought he was being a teenager but perhaps looking back there was more to it than that. So he first became ill at university and he came home in the middle of second year, kind of crashed out and then he was more or less home for a year and a bit and that was a difficult time…" (mother)

Some forensic carers found out 'by accident' that their relative had been placed in secure services. Typically they reported feeling 'traumatised', 'uninformed', and 'left out'. As one stated, 'we were told he was being transferred to Carstairs and that was it'. Another, whose relative had become estranged said, 'I didn't know anything' until informed by the police that her relative was in medium secure care. While the knowledge that their relative had been placed in forensic mental health services invariably came as a 'shock', it brought relief to some carers who had been struggling to cope and were desperate for their relative to get some help – 'it felt wonderful to know he was safe, it took a lot of pressure off'.

Individual journeys into forensic mental health services were varied but some experiences proved common. For instance, the experience of raising concerns about the escalation of mental health problems, or of threatening behaviour, and not feeling listened to was commonplace. Concerns had been raised with GPs, the police and with mental health services, but carers were left feeling unsupported and their views unheard:

> "I was phoning his doctor a lot of times. I phoned the police and the police used to say until he does something we can't intervene' and the doctor would say `if you're worried about him phone the police' and this went on and on and he got worse…'" (mother)

This applied equally when their relative was well known to mental health services, and even where mental health professionals were regularly involved through community compulsory treatment orders:

> *"Leading up to the event, the incident, it was... it's been a terrible traumatic time because we had all been involved as a family trying to help him and basically every time we were phoning for help it just seemed to fall on deaf ears, it was you know `oh well we're dealing with it' or `you know he's known to the system' but they just didn't seem to take on our concerns at all, nobody seemed to you know appreciate the seriousness..."* (sister)

Service users themselves may also have told various agencies about their increasing mental distress and concerns about where this was leading, so that agencies may have had an opportunity to inform known carers and prevent the incident.

Experience of change in services

Survey respondents supported individuals who had a variety of histories in and through forensic mental health services: 38% had experienced a move from prison to forensic mental health services and 43% had experienced moves between mental health services including between secure settings. Interviewees spoke at length about transfers from hospital or prison to forensic mental health services or between levels of secure services. Moving to forensic mental health services from general adult psychiatry had, for some, resulted in improved care and treatment, and better consultation with carers:

> *"Nobody [in general psychiatric hospital] had thought to pick up the phone and check… the assumption was we were going to be there. With [name of secure unit] that doesn't happen, they're very careful, very careful and considerate and they know that we're doing the support so you know they check and they're also interested to know how visits have gone."* (mother)

Moving from hospital to the community could be experienced as extra pressure on carers as they anticipated that the burden of caring would fall to them. Supporting individuals under community forensic mental health services is an area fraught with difficulties, and carers will have differing needs to those supporting relatives in hospital. Survey respondents, as well as those we interviewed, who were supporting a relative in the community, were sometimes confused about whether the person was under community forensic or general community mental health services. Those with relatives who had moved through secure levels and into community forensic mental health services chose to focus on their experiences of higher levels of secure services. Changing between services meant carers having to forge relationships and communicate with new staff teams at every stage, which sometimes brought additional stress for them, although it might be beneficial:

> *"Sometimes you can look at that as a positive because people have different and new ideas and different approaches and there might be new people coming in that can have a fresh pair of eyes."* (mother)

There were extra responsibilities for carers at times of transition between services as this parent explains:

> *"We've had to support our son in jumping through hoops and meeting criteria in order to move from one stage to the next and always with it in the back of our mind that if we question things his stay in one level of security would become prolonged."* (father)

Interviews with forensic carers indicated that the experience of carers was not static. Carers are affected by changes in the health and the treatment of their relative and its impacts on them, as well as by organisational and personnel changes that impact on their communications with their relative and with professionals. Overall, there were indications of some improvements for forensic carers over time, as well as some disruptive and negative consequences.

Views on the quality of forensic mental health services

Forensic carers' perspectives on the nature and quality of forensic mental health care and treatment were variable. While secure environments were generally 'daunting', their descriptions of forensic mental health services highlighted positive features of these settings, including consistent and caring staff. Conversely, some were critical of what they perceived as inconsistent treatment that had a detrimental impact on their relatives:

> *"He's had lots of changes of treatment, so that's not been good. He's had five consultants in a year or so because they've all been on three month contracts…"* (mother)

A medium secure unit was felt by carers to be 'very modern in its approach' on account of its staff being 'empathetic and compassionate, just amazing'. A forensic rehabilitation ward was described as a 'good setup', supporting patients to prepare for moving into independent living situations. Support from a CPN in a forensic community team was described as 'absolutely terrific' in supporting an individual with his community treatment. Comments about positive relationships with staff occurred across all levels of secure services, although specific criticism was reserved for what some felt were more restrictive regimes in the high secure setting:

> *"They're locked up and… in my experience treatment is minimal other than drugs. They're extremely short staffed so you know they spend days sitting. It's no different from the psychiatric institutions of the Edwardians as far as I can see except for better security."* (mother)

However, it was the understanding of another carer whose relative had been in high secure for two years that he was 'in the best place, he's getting the correct treatment'. Some of the more negative experiences, especially of high secure, were located as historic rather than current experiences, and it was noted that there had

been tangible improvements in recent years. In particular, the more comprehensive range of forensic mental health services across Scotland meant the appropriateness of care and treatment had improved dramatically, and the modernisation of the built environment at the State Hospital was commented upon favourably:

> *"A lot of my experience is more sort of historical than contemporary because my experience when I first went to the State Hospital were of being treated like a number, no support, no explanations and that wouldn't be the case if you were going there today… A lot of my experiences have changed and the nature of the State Hospital's changed now, I mean in those days there were 300 and something patents, now it's 100 and something… it's a high secure State Hospital, whereas before it was having to take people who really should have been in medium secure or low secure but there weren't the facilities for them." (father)*

Nonetheless, some felt there was still some way to go before forensic mental health services, especially high secure care, catered for the individual needs of their relatives. This was especially the case where patients had learning disabilities and/or autistic spectrum condition (ASC). Positive change happened when their relative moved into ward regimes with staff operating 'less like security staff or prison guards'. A move to smaller wards at the State Hospital was also positively regarded. In relation to this, one carer commented, 'it's opened up the place', and 'it does work better'.

Carers were critical of 'punishingly high doses of medication' and drug treatments that seemed to do nothing other than sedate and control patients. Positive changes were noted when drug treatments were changed to suit the individual, so much so that one carer likened the difference when a new medication was tried to 'turning on the light'. In this case, the dramatic change in the person led clinicians to review the relevance of the prevailing level of security, and to consider a move to a medium secure facility. Moving from 'a level of intimidation' to openly being able to discuss clearly defined targets and aspirations for their relative, was how one interviewee contrasted past experience of high secure services at the State Hospital with a more recent experience of medium secure:

> *"You didn't feel 'oh if we say this or say that you'll be here for another two years' or whatever. It was just a much more positive experience at the [name of medium secure unit] and you felt much more positive about the whole place." (father)*

Being a 'Forensic Carer'

Being a carer for a relative or friend admitted to forensic mental health services presents its own specific challenges. The role of 'forensic carer' can bring with it some significant impacts on life-course, identity, psyche, welfare and well-being, as well as social relationships and financial impacts. Notwithstanding this, the term 'carer' did not sit easily with this group, with many rejecting the label or saying they were not thought of in these terms by significant others, including healthcare professionals, who had assumed that the major caring role had devolved to them.

Official definitions of 'carer' often imply both a level of 'substantial' practical involvement on a weekly basis, and a level of dependency that this group do not easily relate to. For example, one person who did not relate to the term 'carer' did not do so because she considered her spouse to be 'self-reliant' and 'self-controlled'. Poignantly for one survey respondent, being told by a member of staff 'of course you care, you are her mother' was a telling moment of validation which had not always been forthcoming in other relations with forensic mental health services staff. Interviewees used a range of alternative words such as 'supporter' or simply referred to the nature of their relationship with the person:

> *"It's my job as his mother" (mother)*

When supporting someone in hospital for a long period of time, forensic carers might deny that they are a carer, preferring instead to see their role as 'visitor', for example:

> *"He's taken away from me now. I'm not a carer… I found that really strange going into the State Hospital and saying 'carers' you know but you're not caring for them anymore." (mother)*

However, as 'visitors' they still clearly took an active role in the support of their relative, and were likely to continue supporting them in some way after discharge from hospital in the future.

Being a friend rather than a relative was a factor in whether or not interviewees referred to themselves as carers. It should be remembered though that the majority of people we interviewed were relatives or partners rather than friends. This could be because very few friends identified themselves as carers sufficiently to engage with our study. Friends who were visitors did not give the same accounts of emotional turmoil that close relatives described, nor did they consider a need to be kept more informed about the person's care and treatment.

Some interviewees had only come to call themselves a 'carer' as a result of the role being thrust upon them when their relative entered forensic mental health services, as the following extract from one interview illustrates:

> *Interviewer: Would you have described yourself as a carer before he was in forensic mental health services?*
>
> *Mother: No, definitely not, I mean because I mean he was very much his own person, I mean he was 21 when this happened you know. (mother)*

Others used the term 'carer' to denote the change in their status from family member to having a distinct role and responsibility as a carer:

> *"Yeah I **do** use the word (carer), I probably wouldn't have before… I'm his sister, so I would have just, you know, sister, that goes hand in hand, you've to support your family. But carer, yeah, because I'm dealing with everything yeah." (sister)*

For some, the trauma of the initial reason for admission to forensic mental health services, mixed messages from their relative, a lack of involvement in services, and isolation from other family members and sources of support, combined to make being a forensic carer an extremely trying situation. To describe how they felt about being a forensic carer, interviewees used terms like 'anxiety', 'upset', 'frustrating', 'very scared', 'in a dark place', 'sadness', 'bleakness', 'fear', 'draining', 'a real struggle' and 'duty'. It sometimes felt like no-one was on their side:

> *"Not only can you be up against [relative's name] who doesnae always have her own best interests at heart – and she can tell ye: 'aw, ye don't care, ye don't love me, you're no doing this for me'. You've got carers, nurses saying tae you, 'well, why are you making this decision?' and you go, 'because she's unable to make this decision'. You know, I find that quite hard…"* (sister)

They had mixed feelings about how much to get involved. The experience could result in them feeling powerless and institutionalised:

> *"Sometimes I've been guilty of laying off for a while, I feel guilty about it. I didn't talk to him for maybe a month at a time but it's because he does get very ill at times you know and very hard to handle you know."* (father)

Forensic carers' role

The caring role in a forensic context was said to be 'a difficult one to define' according to some of those we interviewed. This was on account of the nature of secure hospitals or living in the community under a restriction order, resulting in carers feeling 'inadequate' in their role, even 'institutionalised and intimidated'. Providing practical and emotional support were core elements of the role. Commonly, forensic carers supporting their relative or friend in the community were giving practical help, offering emotional support including a check on reality, being a point of contact for services, accompanying their relative to appointments and being aware of triggers to ill-health. Some felt burdened in this role and felt they ought to do less:

> *"I've always been the one that went and did things for whoever I could but now I've got to take a wee back step and say to myself `how long am I going to last at this rate?'"* (partner)

On entering a secure hospital setting it was often assumed by carers themselves and others that the caring role was suspended. However, for forensic carers the reality was that they continued to support their relative, including practically through visits, taking food and other items into hospital, being involved emotionally, being a named person, offering support with rights, maintaining contact with other family members, and being a point of contact for services through phone calls and visits.

Thinking and worrying about someone who is away from home in this situation, as well as the circumstances of the index offence that may have led to admission to

forensic mental health services, was a significant emotional burden. The impact of the index offence on family members cannot be underestimated:

> *"It broke my mum's heart." (sister)*

> *"There's no-one else, I'm the only person, me singularly and it's hell on earth at times, it's hell, it's a living hell." (sister)*

Forensic carers advocated for their relative, for instance, assisting with securing legal services and other information, writing letters to MPs and councils, being involved with the press, and securing accommodation when the person was discharged from hospital. As one interviewee commented:

> *"The good thing about being a carer is that you know at least that you can be there to speak for them when they can't." (mother)*

The forensic carers' role was not constant or fixed. It changed over years, with some interviewees acknowledging that this could be the work of a lifetime, although they may not have anticipated this at the start. Their role was 'reactive rather than proactive', responding to whatever was needed by their relative:

> *"Your experience as a carer is always influenced by your relative's situation and experience." (sister)*

Whereas services assumed that many people within forensic mental health services were no longer in touch with family and friends and had no-one they could call a 'carer', the participants in our study were all in regular contact and did not see that as ending:

> *"I will never stop fighting for him." (father)*

Feeling stigmatised

The impact of stigma was highlighted as problematic by 29% of survey respondents, and some said this was the biggest challenge they faced. Those we interviewed reported losing friends and becoming isolated themselves in their own communities:

> *"I hid myself away from people for months and months and months, just because I was terrified of going out and seeing anyone and being faced with any questions." (sister)*

All members of the family can be affected, as this case shows:

> *"The hardest time was… and it was so hard for her (his sister), I really did feel for her, I actually felt like moving and it was when she was in secondary school and having to go through all that of people talking [about her brother]." (mother)*

Family members can become defined in terms of their relationship with a stigmatised relative, rather than being seen for themselves, in their own right:

"It was all about his brother and the fact that his brother had been you know admitted to the State Hospital and his brother was this and his brother was that. So he walks into situations not as himself but as [brother's name]."   (father)

Stigma about dangerous madness and secure services is a societal phenomenon, and can cut both ways for carers, who can fear for the safety of their relative. Such is the reputation of some institutions that this fear extends to concerns about danger from other patients and staff. Carers might feel stigma in their contact with services. The process of becoming an authorised visitor and navigating the security regimes of forensic institutions can all have a negative impact upon carers:

"You'd to fill in all this documentation and send it off before you're accepted as a visitor, so again that was quite traumatic, you actually feel you're like a criminal to fill in all this like… we're not bad people … Very hostile and very much… I don't know, I just felt... what's the word I could use, I just felt that I was like some sort of a criminal or I was associated with a criminal." (sister)

Stigmatised identities within the system can be a barrier to fully realising a philosophy of recovery, grounded in encouragement and promotion of autonomy and responsibility. One forensic carer commented how staff might have too low expectations of individual patients, reporting that her son's aspirations to undertake an undergraduate course were ridiculed. This reflected how such staff attitudes play into processes of institutionalisation and unfulfilled potential, as another carer commented:

"The reaction of the hospital staff was to hand him a bucket and mop and tell him to go and clean the floors and he was never going to amount to anything and why did he think anybody would ever employ him." (father)

Carers were anxious that even successfully coming through forensic mental health services and out again into the community will not be the end of this stigma, for them and their relative:

"It's not gonna be done and dusted. It gonna be sitting there as a big flag, saying THIS IS WHAT YOU DONE… it's just the general public at large who feel they're entitled to give vent to their feelings, you know. So that's always been a concern and a worry over the years as well." (sister)

That these are not ungrounded fears is evidenced in the following experience:

"We started to realise that you can put a person into the community but it doesn't mean the community will accept them, so he spent a lot more time on his own. A couple of times when he went out into town he met quite severe reactions from people who had known him in the past and threatened him, so

he stopped going out this sort of thing. So he became, in many ways, a lot more isolated." (father)

The impact of such stigma and prejudice also intersects with levels of felt support, and the family in this case questioned whether the appropriate level of support was in place: 'he was almost not returning to the community but getting dumped in the community'. On a more mundane level, but still nonetheless distressing, ex-patients' attempts at rehabilitation, such as enrolling for college, can be accompanied by their previous circumstances being made known to peers on the grounds of health and safety. Similarly, individuals can experience direct discrimination such as one carer reporting her son was refused entry onto a housing list.

Some carers reported feeling no stigma and talked about living in very supportive communities. Similarly, one carer reported that her relative was not believed when telling people he had been 'in Carstairs', as if this was an unbelievable fact. Some reported that, as much as they may have lost the support of some friends and neighbours, others had rallied round, such that people were able to know who their true friends were.

Impact of caring for someone in forensic mental health services

Interviewees and respondents to the survey reported a range of sometimes profound consequences to assuming a caring role in a forensic context; these effects could relate to their relationship with their relative, relations with services, or the effects of stigma. For many, this had implications for their personal sense of well-being and resulted in, at different times, experiencing a variety of intense emotions including, variously, sadness, searing grief, frustration, anger, shame, fear, and anxiety. At times, carers reflected upon deeper effects of an almost existential nature, impacting at some essential level on their sense of self. For some individuals, caring was viewed as such an implicit part of their life that the personal consequences were not always at the forefront of their thinking, revealing a tendency to minimise impact on occasion:

> *"I would probably, my first reaction would be to say, that it hasn't. And the reason I would say it hasn't is, she is my sister, and I've always done it. So that's why I would say, no, it hasn't impacted. On the flipside - my God, it's impacted greatly. You know, my husband, kids, my job – it affects everything." (sister)*

However, for many, there was a common theme around the all-consuming, life-changing role of being a carer – 'it changed my life'. Typically, forensic carers identified stress and strain as profound and life-changing effects of the caring role:

> *"I had one episode where I had an anaphylactic shock which I was absolutely sure it was related to high stress, yeah so absolutely, sleepless nights yeah." (mother)*

Increased stress had physical consequences such as reduced resistance to illness:

"It's made me really ill cause I'm never out the doctors surgery, and I take like this cold, is the mother and father of all colds I've ever had you know, it's just been flooring me." (partner)

One carer identified the long term impact of caring on her mother:

"Obviously as she's got older, the stress levels, mum actually suffered a stroke a few months ago, I don't think you could pinpoint it to anything in particular, but obviously her ability to deal with things as well as she did 25 years ago is lessened." (sister)

Another identified the insidious wear and tear of dealing with stress over the years, including having been a carer for many years prior to her relative's admission to forensic mental health services, the stress of interacting with mental health services, such as, in this instance, dealing with medical staff:

"The downside is that it's wear and tear on yourself, it's pretty stressful trying to maintain that without… and keeping calm so I think calm probably did go out of the window a few times, but that whole... because of just the whole journey that I have had and yeah it's been hard fighting with doctors and getting... having to run back and forwards trying to get medicine for him, it just... aye wear and tear and just kind of just brings you down... " (mother)

In addition to the impact on their physical health, carers also identified mental health issues:

"I think I have found it at times challenging because it's affected my own mental health a wee bit, apart from that it's been… the whole experience of it, the whole yeah experience of it, meeting my partner has been good and I've got better through it and I hope and I think he has too so..." (wife)

Indeed, some forensic carers took on the caring role at a time when they were already under treatment for mental health problems of their own, rendering them more vulnerable to stress, complicating their own potential for recovery, and indicating particular support needs. They did not always identify mental health issues directly but outlined the compound impact to their well-being and wider life:

"I can't move on with my life, I feel like I'm stuck, I mean my job, I go to work but I don't enjoy it and I can't wait till the day is over, I don't know if that's because with my son or what but yeah I think it's changed me as a person, I haven't got any desires to go on holidays and do things, I feel I've changed quite a bit really..." (mother)

Difficulties coping with their relative's illness or challenging behaviour also had a financial impact, including on the ability to work effectively or maintain themselves in employment:

"I'd been considering working part time so that's partly down to why I now work part time because well about 16 years of that is just probably taking its toll." (mother)

For others, however, work offered some degree of 'distraction' or relief from the stress of caring or dealing with powerful emotions:

"At one point I was almost overwhelmed by stress but what kept me going was my work. I couldn't bear the thought of being at home and thinking about [name] all day. I felt dreadful guilt at that time. Felt I had failed in her upbringing in some way and caused the illness." (mother)

There was a seeming inconsistency in responses to the carer survey between qualitative information confirming a litany of negative health effects (with only two out of 56 free responses stating no such impact), and the quantitative data reporting a sense of good health. In this regard, 62% of survey respondents rated their physical health as good or excellent, yet 20% declared a disability, including a number of quite serious chronic physical illnesses. The qualitative responses articulate some carers' view that some of these chronic conditions may have been brought on or exacerbated by the caring role. That one respondent could report that this 'was just part of life', might reflect the stoicism of the caring role, as well as the difficulty in drawing causal links between caring and ill health.

A few carers went on to point out factors that helped mitigate stress. Some found family and friends supportive, while others found it helpful to be able to share the responsibility of care:

"…probably because we are quite a close family, and if I'm really tied up with something, you know, at this stage in my life, I'll say to my older sister 'can you make sure you're there for [name], can you phone her, can you do this.' And my mum as well. The fact we've each got some buffers wi each other and wi her, support for each other, I suppose that lessens the impact..." (sister)

Despite all the stress and strain described, carers could identify personal growth from the experience:

"It's made me more understanding of what other people have got to put up with, more empathetic to other folk you know. A lot of things I took for granted a lot of the time like when I was single."(mother)

"It has been positive to look after someone else and I have got to know them better because of this." (survey respondent)

Named Person Role

Forensic carers had extensive experience with the named person role under the MHCT Act. Fifteen out of 19 people interviewed and 63% of survey respondents were, or had been, a named person for their relative or friend. While several acknowledged that there were benefits, including that services were more willing to

share information with a named person than with carers generally, they associated the role with stress and hard work. For some this resulted from their assumptions about the role:

> *"Thank goodness I'm not a named person because they're expected to have enormous amounts of knowledge…"* (father)

> *"When you're the named person you feel that you have to make an effort to understand the system and the person involved and what's been done for them and be prepared to ask questions."* (mother)

There was mixed experience of the role, and some confusion about it included:

> *"So it's very stressful for me as well because he's always... if I do go to the tribunal he's always wanting me to ask for him to be released and if I think he's not well enough to be released then and if... you know, then what do I say? I'm completely put on the spot you know and if I were not to say what he wants me to say then he thinks… and he's in this incredibly negative frame of mind anyway about the medical staff, so then I'm part of the betrayal, so I just find it just horrendous…"*
> (mother)

Not only did some forensic carers feel 'in the dark' about the named person role, they found that when they contradicted their relatives' perspective they could be removed as the named person. Some had experience of the named person role changing without explanation, leaving them with little sense of control:

> *"They accepted me as named person for about a year until [name of relative] decided she didn't want me to be her named person anymore because I wasn't representing her views."*
> (father)

Changes of named person meant the role could be swapped repeatedly around different family members. Some mentioned that they felt that staff influenced the occupancy of the named person role.

Key Findings

The survey and interviews with carers resulted in the following key messages about the experience of being a forensic carer:

- The term 'carer' did not sit easily with this group; many rejected the label and preferred to call themselves 'supporter', 'visitor' or simply referred to the nature of their relationship with the person such as 'mother', 'brother', 'sister' etc., or said they were not thought of as carers by health professionals when the person entered forensic mental health services.
- However, a distinct role and sets of circumstances emerged that suggests it is useful to collectively refer to people in this situation as 'forensic carers'.

- The forensic caring role was difficult to define, but at its core involved practical and emotional support provided to relatives or friends across different secure settings. Forensic carers carried a significant emotional burden.
- There were important differences between the experiences of carers who were relatives and those who were friends of the person. Caring as a friend rarely brought the same emotional turmoil that close relatives described, nor was it felt by friends as important for them to be kept informed about care and treatment issues.
- Many carers reported not being listened to when raising concerns about their relative's deteriorating mental health prior to admission to forensic services.
- Carers commented on tangible improvements within forensic services in recent years. Some, however, commented there was still some way to go before the individual needs of their relative were met.
- Feeling stigmatised was highlighted as a challenge for carers, some losing friends and becoming isolated in their own communities.
- The impact of being a forensic carer was profound, impacting on all aspects of people's lives including their physical and mental health. For some, being able to share the responsibility for care helps mitigate the stress felt.
- Forensic carers had extensive experience of the named person role. 15 out of 19 people interviewed and 63% of survey respondents were, or had been, a named person for their relative or friend.

4   FORENSIC CARERS' EXPERIENCE OF SUPPORT

Introduction

This chapter focuses on the carers' views and experiences of support from forensic mental health services, including information and involvement in their relatives' or friends' care and treatment, the benefits and issues with current carer support groups, and what they identify as gaps in support. We specifically focus on forensic carers' experience of visiting relatives and friends in secure hospital settings as one aspect of that support. Finally, we consider the ways in which carers propose that support to them could be improved.

It is difficult to disentangle the issues of support, information and involvement within carers' reflections on their experiences, so these are all covered in this section. For instance, good quality information or a sense of being involved can both be implicitly supportive measures. Specific interventions, such as carer support groups or family therapy offer a combination of support, information and involvement.

Carers' Evaluation of Support

Just short of half of survey respondents rated the quality of support received from forensic mental health services as either good or very good. However, a fifth felt this was poor or very poor. Carers report different and inconsistent experiences of support from various forensic units, and the staff within them, which they contrast with each other. Encounters with key staff coloured the whole impression formed of a particular service or discipline. There was an apparent demarcation of responsibility for attending to carers' interests between ward-based personnel and specialist workers situated in centres away from main ward areas. It might be unfair to overgeneralise, but carers quite often identified positive contributions from a range of specialist personnel, but were typically critical of those ward nurses who appeared to them as indifferent or uncaring, and concerned more with a custodial rather than a supportive role.

Identifying and accessing support appeared to be a struggle for a significant proportion of carers in the study. This is not always the fault of services per se. It could just as easily reflect difficulties in targeting support on a group of carers with complex and divergent needs grounded in their geographical location, individual circumstances and particular experiences. From the survey, around 33% of carers had found it either easy or very easy to access support when they needed it, in comparison with 31% who had found this difficult or very difficult.

Only 53% of carers completing the survey reported receiving any form of advice, information or support on first admission to forensic mental health services. For some this might reflect an historical state of affairs, and levels of support may have subsequently improved. For others, a perception of lack of support has persisted such that they stated they have 'never at any time felt supported' (survey respondent).

Carers felt supported when they were confident their relative was getting the best care and treatment possible:

> *"They have undoubtedly helped my daughter in a way that I would never have believed possible. Always with compassion and understanding, what more could any carer want?" (survey respondent)*

This also intersects with the service's disposition towards information exchange and involvement in care pathways. Carers needed to share their personal experiences and stress, hence being listened to was immensely important:

> *"I needed at the time to get a hellova lot of things off my chest and we did have… a Community Mental Health Nurse who in a very informal way `oh I was just passing' would come in and he'd sit down by you know where I'm sitting here now, and I would babble on for an hour or so about my latest frustrations and he'd just sit and nod and occasionally say `oh crikey'" (father)*

Although there were only a few comments about the Mental Welfare Commission for Scotland's (MWCS) role in supporting carers, it had mixed reviews, with some forensic carers feeling it was more likely to support 'the system' than the carer or their relative.

Carer Support Groups

Around 70% of survey respondents were aware of a carer group, though not all attended one (50% reported joining a carers group). Experiences and views of carer support groups was a major focus of interviewees' comments on support. Carers highlighted the benefits of mutual support:

> *"It feels like being in the dark for the last 19 years. Now someone has turned on the light at last!" (survey respondent)*

Carer groups were organised in and by the hospital, or externally by a voluntary sector or carers organisation. These were appreciated by carers for also facilitating access to information and the opportunity to question and learn from each other's experiences, which helped mitigate stigma:

> *"You support each other as well because you're offloading things in a safe environment to people that are going through similar experience so you know people aren't going to judge you or make assumptions or... you know, you feel very safe." (sister)*

For others, however, the connection with shared experience is limited; a community group may involve a number of long term members whose relative is now living in the community, so their experience is somewhat removed from those carers whose relative is being newly admitted to secure settings. Similarly, another carer with a relative in high secure care felt out of place in a group dominated by a focus on experiences with medium secure services. The value placed upon support groups indicates the sense of isolation many carers feel or have previously felt in their dealings with services:

"I just felt I had nobody else to turn to." (mother)

There is a desire for the focus of the groups to lead to healing of wounds and resilience for carers, for there to be some sense of progress and constructive processing of experience:

> *"…a positive approach to supporting people through the denial and blame so that they can become part of the useful acceptance and remedy and I think that needs to be addressed, in my humble opinion… You know as I say, time after time you'll go to a meeting which is completely disrupted by somebody's need to talk about the terrible experience they've gone through and it becomes a recurring theme and you can't get beyond it, but having said that it's not a nuisance it's something that needs to be dealt with."* (father)

The positive contribution of key workers who support or facilitate these groups was highlighted:

> *"She's [carers support worker] amazing and I think they've brought it on you know hugely the work they've done to try and support the carers, it's been a huge help..."* (sister)

Carer support groups provided a much appreciated source of information, and staff involvement in these was valued, including the involvement of guest speakers:

> *"It's fantastic… if there was specific concerns… it's an opportunity of a little bit of a fuzzy boundary… if there was a very specific thing then there's a chance for a five minute conversation, sometimes that's all it takes just to express a concern or ask a question."* (mother)

Such groups were a vehicle for connecting with clinical staff, including nurses who attend, as a way of influencing care or raising concerns and questions with more confidence that they will be taken seriously and acted upon. In some sense, this was indicative of the context changing the quality of relations:

> *"An opportunity which never existed before of having interaction with the staff, being able... in a more relaxed and informal setting to have relationships."* (mother)

Forensic carers participating in carer groups also got a sense of personal fulfilment from the contribution they brought to the groups:

> *"I feel I've helped other people… from my experience I've been able to then help other people cause I've been able to empathise with their situation and I've been able to give them guidance and advice through the trauma I've been through… yes that's a positive."* (sister)

To some degree, carers saw support groups as a lever on services to develop more consistent support for carers. For some, there was a tension between wanting any

support group to have influence in the hospital, with a desire for the group to be independent, enabling freer discussion of concerns.

Advocacy and Other Support Agencies

Only a minority of forensic carers had used independent advocacy at some stage, which reflects the low level of carer advocacy provision generally. Of those responding to the survey, over half were unaware of the existence of independent advocacy support for carers, and the majority (68%) of these had never been offered it. Just over a tenth of respondents had used a carers' advocate. Some had experienced a conflict of interest between an advocate working on behalf of their relative and expectations for their own needs. One said they had found themselves in a position where they were having to inform the advocate.

Others had experienced important specific support at different times in their journey, such as family liaison services in the courts, or support akin to advocacy, or moral support whilst in court from groups like Support in Mind Scotland. Some reported receiving practical support from voluntary agencies, such as help with transport or transporting patients' effects between units. Some had used transport services arranged by SACRO; this included a free bus service for visitors and a volunteer driver scheme taking visitors door-to-door. Other forms of support around visiting included a counsellor providing moral support and helping the carer with travel arrangements.

For those relatives putting up with violent or aggressive behaviour prior to admission to secure services, some had received support from groups like Women's Aid, including offers for refuge or somewhere else to stay. For those relatives with family members discharged into the community, some reported a level of neighbourhood support.

Clinical Staff Roles

Professional staff can be key sources of support and are appreciated by carers for their input, especially in terms of making time to talk:

> *"His Mental Health Officer is superb and his Consultant that looks after him is amazing and they're very open and very helpful to me, very supportive, so from that point of view I can't say anything but praise them for the help they've given me." (sister)*

Staff with good interpersonal skills, empathy and insightfulness helped reduce a sense of isolation:

> *"…and we sat and had a chat and I was just like `wow there are people that can kind of get into my head and see what I'm having to put up with' you know." (mother)*

Respondents to the survey reinforced these factors in rating the most important benefits of carers support as contributing towards them feeling understood and being treated as 'part of the solution, not a problem'. Carers valued staff responding to

them with openness and warmth, and being prepared to discuss their decisions with them.

Some forensic carers had received a carer's assessment and viewed this positively. Others had more negative or mixed views and questioned the time taken to get a carer assessment. One carer had low expectations of support, not feeling it was merited as she was 'only a carer' (survey respondent). Relatives appreciated any efforts by the clinical care team to help support, smooth conflict or help strengthen family ties:

> *"My relationship with my daughter was protected by the Consultant...*
> *She wanted our relationship to build up again into a positive one."*
> *(mother)*

This may also involve support to enable a wider range of relatives to visit, including children. Occasionally, forensic carers reported taking active steps to try and shield certain family members from any burden of care.

Some carers had a significantly critical disposition towards nursing staff, but also acknowledged a range of different degrees of supportive personnel:

> *"…the nursing staff, very poor actually, very poor, I feel... again there's*
> *good and bad in every you know place but I just feel they don't show*
> *any empathy to you, I think not all of them but a lot of the staff they just*
> *seem to be going through the motions… some have been quite rude,*
> *some have been quite power heavy, you know they seem to have this*
> *power thing that they try and dictate and I think they forget that that's a*
> *hospital and not prison." (sister)*

For some carers, there was a paradox in that staff seemed to have plenty of time which could be devoted to building relationships with patients and their carers, but this was not always capitalised upon. Additionally some of the most positive views on staff were expressed by carers who had at a different time held very critical views on staff in the same establishment.

Family Therapy

While in the minority, forensic carers who had experienced behavioural family therapy appreciated this and saw beneficial changes in their relative and subsequent relations with themselves. This has been especially helpful in terms of coping with stress in their relationship and communicating about feelings. Beforehand, there had been some anxiety about taking part. A major component of this form of intervention is psycho-education, which can be conceived of in terms of information exchange. Yet, carers seldom reported experiences of receiving information in this way.

Others identified that they would have appreciated the offer of more simple counselling for themselves to help cope with the feelings of loss, guilt, denial or shock and anguish at the events leading up to admission to secure services. Similarly, some carers spoke of feeling like 'victims' of the index offence, even if they were not first-hand victims of a violent incident. Yet they were seldom treated as

eligible for victim support or counselling at this time. Others spoke of the longevity of emotional needs, mirroring the length of stay of their relative, and changing in character over time. A general need for emotional support for carers was seldom considered or offered by services.

Information

The importance of face-to-face contact was emphasised: few forensic carers valued written information above the chance to talk, listen and question. Being involved in a process of information exchange begins to move onto the territory of involvement and also intersects with carers need for support. For instance, many carers spoke of the sense of feeling included as part of 'the team'. Nevertheless, in their time visiting secure units, slightly fewer than 40% of carers responding to the survey had received information indicating their rights, such as to a carers' assessment. Even amongst these there were some who felt this information had not been timely, commenting that it had been 'too little, too late'.

Different kinds of information identified as necessary by forensic carers included information about:

- Assessment, care and progress
- The institution, rules and regulations, staff, teams
- The support for relatives
- Carers' rights, and/or how to make a complaint
- How to deal with patients' emotions or behaviour
- The ward, how it was run, what to expect
- Specific transitions or events, such as being told in advance of their relative being moved in the system, or if particular incidents have happened

Information flow, communication and quality issues

Receipt of such information was appreciated but some forensic carers emphasised the necessity of certain information needs by remarking on how they were <u>not</u> being met. Written information was not always appreciated as helpful, sometimes being regarded as 'largely inadequate or misdirected' (survey respondent). People's experience of having their information needs met were variable, with a mixture of positive and negative experiences reported around access to information. The quality of information received was rated as either good or very good by just over 61% of carers responding to the survey. Conversely, around a fifth said it was either poor or very poor. There are some mixed experiences. At one extreme, some carers reported receiving little or no information, or had had to seek out information rather than it being offered as a matter of course; some said they had gathered knowledge over time using their own initiative, for example, doing their own 'research' on the internet. Others were very appreciative of staff approaches to information and felt themselves to be involved in a two-way exchange process.

In contrast, a feeling of not being supported flowed from experiences of poor communication of key information:

> *"I was not even told what the visiting hours were. I have never, at any point, felt supported - I do not even know what the plans are for my son (or even if there is a plan). It feels as though he will never get out of that place."* (survey respondent)

There were differences between different members or disciplines of staff, or between different units in their responsiveness to requests for information or whether or not their approach to informing relatives was proactive. Several of those interviewed noted how services had improved over time, including that approaches to information giving were better now than they had been on first contact with forensic mental health services. Some contrasted this favourably with far more negative experiences with mainstream mental health services and personnel, especially in a prior context of not feeling listened to or having their views respected.

On the one hand, some carers felt that forensic mental health services were somewhat closed and insular:

> *"I think the downside of forensic health services for me, I just wish they would be a wee bit more open."* (wife)

Alternately, forensic carers we interviewed appreciated receiving information from staff in an effective and timely fashion, or the fact that staff made time for information giving, and this formed the basis of good relationships with them:

> *"So it wouldnae matter whether it was myself, my mother or my sister that phoned, they're very very good at giving you the information that you're requesting."* (sister)

Receiving valued information can be empowering for carers, but some carers also pointed out the limits:

> *"I mean it doesn't wave a magic wand and change anything, you know. You could be super intelligent about all these facilities, but you… cannae get him tae stop ranting and raving when he's on a high."* (mother)

To some extent, a distinction was made between feeling listened to and actually being able to really make a difference to care, some of which was acknowledged to be constrained by guidelines and protocols. In the survey, around a quarter of carers reported feeling they could influence services, whilst over half felt they could not, with the rest being unsure.

The case for better quality information was emphasised in the range of understandings described by carers, which included a spectrum of beliefs about care from punitive to humane models. Others had become very understanding both of mental health issues and the complexities of providing care in secure units in the course of receiving information and support over the years. For some, information about mental health problems or symptoms was pitched at too superficial a level. They sought information to help them to develop a deeper understanding of their relative's individual behaviour and experience.

Routes to accessing information

Various carers reported positive experiences of getting information via telephone contact. This was not always seen as necessary if visiting frequently, but was valued more if visits were infrequent. For some, phone calls have been a last resort, feeling like a real struggle to chase around information, or they can struggle to get through to the right person, often taking a long time and at a cost to them. Visiting times could be capitalised upon for information exchange, to some extent depending on how adept they were at asking for information. Overwrought relatives found it difficult to comprehend information:

> *"I've been so strung out sometimes that I couldn't take everything in."*
> *(sister)*

Some carers were fairly confident that information requests or asking for explanations would be met positively by staff, but did not always ask. There were, however, variable experiences of different staff, different disciplines and these experiences could change over time:

> *"The only person who told me about my rights was a psychiatrist in the*
> *last year or so." (sister)*

It seems that for many carers, having a good consultant psychiatrist who is committed to information exchange is crucial. Nurses and MHOs were also mentioned positively in this regard, but it seems that impressions of the whole service can be hugely influenced by contact with the psychiatrist, for good or ill. Some reported that in circumstances where information or explanations from staff were minimal or unsatisfactory, they often did not ask further questions or raise this as an issue, preferring to keep quiet and not cause a fuss. Others were more assertive seekers of information, although appreciative that the exchange of information takes up staff time that may be in short supply:

> *"Even spending an hour with a patient's carer can take a big chunk out*
> *of someone's day and I understand that, so whatever time they spent*
> *with me I'm quite grateful for." (mother)*

Sometimes the positive experience around information pivots on a particular member of staff, and forensic carers value their input. But this is vulnerable to being derailed by staff turnover or patient moves through the system. Sometimes information is difficult to decipher because of jargon and terminology:

> *"They come away with their doctor language that you have to just sit*
> *there and nod and pretend that you know exactly what they're talking*
> *about." (mother)*

On the other hand, forensic carers appreciated efforts to make information accessible:

"There's a need for information and a lot more information but also it has to be offered in a way that suits the person that's needing that information." (father)

One interviewee valued a simplified approach because it demonstrated that care was being taken not to use exclusionary language.

Forensic carers reported taking time to prepare for information seeking:

"I write down everything I have a query about, before I go tomorrow I will go through all my stuff and I'll think of anything that I want to ask about and I will write it down before the meeting and I would advise anyone to do that because you know when you're face to face with someone you forget things and I also write down things they tell me." (mother)

Information was sought via books or the internet about mental health, medication or side effects, for instance, or Scottish government information on the named persons role, or advance directives, or information about the unit:

"I'm – inquisitive is a nice word, nosey is a better word. I quite like to know, whenever medication is mentioned I'm right on to the internet, find out what it's for, where it's been tested, you know." (sister)

Internet information would often be used to facilitate discussions with staff, including checking out the accuracy of any self-directed learning.

Accessing information as a named person

The named person role was felt to at least have the potential to empower carers and enable them to exercise rights to access information:

"I think it's (named person role) going to give me a bit more power to be able to talk to the forensic health services." (wife)

Sometimes, however, even requests for information in this context did not automatically lead to relevant information being accessed. Carers could fruitfully become better informed by virtue of being involved in case meetings such as in CPA reviews. Participation in such processes had led to carers querying the quality and content of information. In one instance, a relative's file was seen by the carer to be dominated by attention to risk issues at the expense of focusing on positive developments, or negative experiences as an inpatient ('bad things that have happened to them' while in services).

Forensic carers valued receiving copies of CPA reports and having opportunities to raise questions. Alternately, sometimes they felt there was too much paperwork making it difficult to make sense of it all, especially if carers were the named person and received the often detailed reports sent in advance of tribunals. Similarly, some problems were noted with the amount of notice given for meetings, but for some this had improved over the years:

"I found out about two years ago that (as named person) I was able to attend my brother's clinical team meetings. The communication has been very poor as to when these meetings take place - until recently! I now receive an invite which is very helpful indeed and receive medical notes about the meeting which keeps me up to date with my brother's care." (survey respondent)

Barriers to receiving information

Those interviewed highlighted a number of barriers to receiving information and support. Some forensic carers reported feeling frustrated and blocked in their attempts to access information, from hospitals in particular, but also failing to get replies from agencies such as the Mental Welfare Commission for Scotland (MWCS).

Many carers were subject to significant time constraints, relating to their job responsibilities and patterns of work. This meant they could not always get to carer support groups. Also, the frequency of visiting constrained the quality of information exchange for those who preferred face-to-face contact, this being most acute in relation to the State Hospital if significant travelling distances were involved.

Confidentiality barriers and other limits on information sharing were reported. Interviewees spoke of different approaches or cultures. They appreciated it when units adopted an open approach to information sharing because the service saw this as beneficial. At the other extreme there might be much stricter limits on information sharing:

> *"They don't like people sharing things because, you know because there's this kind of veil of silence."* (mother)

Examples given demonstrated there are different standpoints on what is or is not confidential relating to, for instance, information about significant events and interpretations of what could be disclosed, which can vary between staff and by situation. For some forensic carers, issues around confidentiality had become a significant barrier to them providing support for their relative:

> *"It is very distressing to see someone who you care about who you can see is suffering and in distress and that there is nothing you can… you know that you are actually being obstructed by the system to being able to help them in any way."* (father)

What frustrated some forensic carers was that the notion of confidentiality could be used to close down any conversation that may be more nuanced, and to explore key concerns without actually breaching any confidence. Some forensic carers feel that staff could do more to persuade, especially when the person is paranoid, that it might be beneficial to share more information with families. Conversely, one forensic carer complained that impressions of her relative's well-being she had passed onto staff, seemingly in confidence, had then been shared, subsequently placing her in a difficult position.

Experience of Visits

Visiting their relative or friend in forensic settings was identified by forensic carers as an important part of the support for carers. There were issues for forensic carers around the level of support and contact readily accessible when visiting someone in secure hospitals or units, often a considerable distance from their home. In the survey, around half of respondents had experienced challenges in terms of travelling to and from hospital to visit their relative or friend, and 44% had experienced difficulties with being able to visit when it suited them.

Travel issues

There are many factors that can impact on the frequency and quality of visits, including the travel time and distances to and from forensic units. Having to travel considerable distances, often making a round trip of at least 50 miles, was a common experience and clearly impacted on the frequency of visits. Invariably, a long drive to visit someone in the high secure hospital restricted visiting to weekends. Some carers interviewed said that if they lived nearer to the secure facility they would visit more often, though others mentioned that the regularity of visits was dictated more by their relative and whether or not he wanted them to visit. Moving from high secure services to medium or low secure services nearer to home had increased how often some carers were able to visit:

> *"It's far better now in the [name of medium secure unit] because you go to visit him quite often, as often as you wanted to, whereas it's very difficult being away in the wilderness you know because it is very far away you know." (father)*

Ease of travel was another important factor, and the availability of services like free transport helped to relieve some of the strains of visiting. Juggling the demands of the rest of their lives (if they were in employment and/or were looking after a family, for instance), with the practical realities of travelling to and from forensic units, together with the emotional challenges of visiting, added to the 'daunting' prospect of the experience. One couple visited their son every weekend but caring responsibilities for other family members meant they could not always both go.

In addition to distance, ease of travel was an important factor influencing frequency of visits. Using their own transport or making a trip that did not involve excessive bus or train changes had an impact:

> *"I had the over 60's card right from the start so it was… and I mean it's clearly an easier trip because you don't have to change stations at Glasgow you just… yeah it's a dead easy trip although it's time consuming... (father)*

Financial help to support visiting people in forensic mental health services appeared to be limited to travel to and from the State Hospital, and if available in respect of medium or low secure facilities, carers had not heard about it. Only 21% of survey respondents were aware that there was any financial support for carers. Further, only a minority of those interviewed commented on financial support, either saying

they had received a set amount of £12, mentioning the free bus service from parts of Scotland to the State Hospital, or expressing surprise that such help should be offered:

> *"No, I've had no advice about anything like that no… I could manage without it but you know I do think if there's people probably got to get buses and things like that and haven't you know got much money I suppose that would help them really." (mother)*

Free bus services co-ordinated by SACRO transported people from different parts of Scotland (specifically Edinburgh, Aberdeen, Dundee, Glasgow) on scheduled fortnightly services to the State Hospital. One interviewee identified this as the main form of transport she used to visit her relative:

> *"Well obviously because it's so far away there is a bus laid on for carers which comes from Aberdeen every fortnight and it comes from Aberdeen, it brings carers from Aberdeen, it stops in Dundee and it takes us down, that runs every second Sunday and that's a free service... but yeah generally I get the free bus every fortnight." (sister)*

Despite practical and potential monetary challenges, all those we interviewed and many of the survey respondents had managed to maintain a schedule of regular visits to their relatives to remain in contact.

Hospital environments

The facilities available for visiting were important and affected carers' perceptions of forensic mental health care. Having a relaxing atmosphere, some flexibility in visiting times, and good staff support were vital components of a 'good experience'. Equally important was feeling that there was a comfortable space for visiting with facilities for visitors, like the ability to have a 'real cup of tea', especially after a long journey.

For some, the particular forensic mental health service environment, if coupled with a detached attitude of the nursing staff, was off-putting. Some forensic environments seemed more prison-like than health or therapeutic environments. In the words of one forensic carer, the secure care setting was 'a strange, strange environment'. Many forensic carers reported feeling intimidated by early (and sometimes subsequent) visits, especially to high secure units:

> *"Even for myself, to be fair, the first couple of times in fact the very first time… it's really intimidating having never been in that environment. Extremely intimidating for me and, you know, I'm no' really a lily-livered character, I'm quite a strong person..." (sister)*

> *"It's just a feeling, but you always felt you were visiting a prison rather than a hospital and I suppose you know the sort of high fences and the razor wire didn't quite fit in with a hospital image." (father)*

One interviewee kept referring to the nurses and staff as prison guards, and then would correct herself, but she was not unique in making this reference:

"Everybody goes about wi keys, you know, like, they're like gaolers, and that is how it feels. That is how it feels. And sometimes [name of patient] still refers to it as 'I'm still in jail', you know." (sister)

"We used to feel we were like a criminal yourself… although all the security is understandable, the staff behave like prison wardens… you don't experience courtesy. My stomach used to be in knots, my mouth bone dry – it was a hugely difficult and unpleasant experience every time we went." (sister)

"Walking in wasn't a very friendly atmosphere, it was all locked doors, it was you were left waiting in the waiting room before you could get in, there was just… there was no kind of welcoming, it wasn't that welcoming a feeling and it felt quite charged." (mother)

Views about experiences of visiting someone at the State Hospital were repeatedly contrasted with those of visiting medium secure units, usually making the comparison that it was more relaxed in the latter:

"The [name of medium secure unit] is far better you know, it's far better… it's just a better feeling about it you know." (father)

"It was much more a case of you know between the hours of... and you know you didn't feel you were racing to get there [name of medium secure unit] because you might be 10 minutes late and miss the bus and things like that, so that was a lot more relaxed." (father)

That said, there were reports from carers of positive visiting experiences at the State Hospital's Visitors Centre:

"Skye Centre because that's like a communal lounge area and there's a big TV and there's a little shop that the patients can go to and there's sort of a tea and coffee area and you're not so... you're still supervised but it's not so in your face you know it's a bigger area so you're more spread out and the nurses are further away so they're not like in your face." (sister)

"[Name of person] likes to go to the Skye Centre. He identified it's a nice place with comfortable chairs and real teacups." (friend)

Interviewees identified the importance of visiting areas being welcoming for families and friends. Carers felt that many of the places where visits took place were overly restrictive and unsatisfactory, even taking into account appreciation of the need for security. Places that were lacking as far as the carers were concerned had 'hard wooden dining chairs', no or poor tea and coffee facilities, felt like 'goldfish bowls', lacked privacy and were generally clinical environments that inhibited interactions between carers and their relatives:

> *"There was no kind of visiting area, there was no tea or coffees, toilet, there was nothing and I've travelled an hour and a half up the road."* (mother)

> *"There is nowhere that the family can walk outside the wards with their relative. This should have been planned for. Visitors have to go to the ward and sit in the dining room."* (father)

An ability to be flexible around when visits take place was also identified by forensic carers as important in determining the quality of their visit. As 44% of survey respondents identified not being able to visit when it suited them, this is clearly an area of importance for forensic carers. There were positive examples of such flexibility:

> *"Basically the arrangement is that you know you decide or you say when you want to come and visit and provided there's no… you know they'll look in the diary and I mean obviously if he had… if either of them had got something else at that time they would say so and if I'm booked in for a visit then presumably they would manage it, but they have managed."* (father)

> *"I'm allowed to stay longer than normal if, for example, I have to travel back on say a Monday… I'll be allowed to see my daughter whenever. They [name of medium secure unit] always say `yes no problem' once I ask, I say `look I'm going back tomorrow can I come in the morning?' `yes it's no problem'"* (mother)

Stresses of visiting forensic settings

Carers can dread going to visit their relatives and many interviewees talked about the impact that the person's state of mind can have on the visit as well as the outcome of the visit, for example, one carer commented:

> *"It depends on how the patient is feeling and as I say you know speaking to quite a lot of the carers, we all go in with that `oh god what's it going to be like?' I had a visit last week with my brother and I know my son was very much looking forward to seeing my brother and it was disastrous."* (mother)

Several interviewees referred to 'dreading visits' and when a visit went badly, taking a break from visiting in order to cope. However, this could lead to feelings of guilt:

> *"If I took Saturday or Sunday off I'd feel guilty now… my wife used to visit him every week also through the week."* (father)

Some noted that it had been helpful when staff were able to let them know in advance if the person was not feeling up to a visit, and potentially save them a wasted journey:

> *"…support from the staff is that if he's a bit out of sorts he says `oh I
> don't feel like a visit', and that's so much better, it's so much better
> than us driving down 15 miles and having a bad visit with him."*
> *(mother)*

There are many stresses experienced by forensic carers in relation to visits and one
of the key sources of stress was when they were not consulted and kept informed
about their relative. Their relationship with the person could have its own difficulties,
and having staff that were able to support the caring relationship made all the
difference.

Lack of privacy

The lack of privacy for visits at the State Hospital was repeatedly commented upon.
Forensic carers found this challenging even if they understood in principle that there
was a need for security measures at such facilities. This lack of privacy, for what
can sometimes be quite fraught interactions, severely impacted on communications
between carers and their relatives in secure services:

> *"We go into the, it's like the dining room that the patients eat for their
> meals, but we go in, our visit is from two till four so you're in a dining
> area which is just a room… probably with maybe three or four tables
> and it's all glass so all the other patients are in the lounge watching the
> TV. You feel as if you're in a goldfish bowl because they're looking in
> and I can see them out, because it's all glass. There's no privacy, no
> privacy at all." (sister)*

The experience of visits to other forensic settings was often mentioned as a contrast
to this. Staff at the medium secure units were said to be 'discreet' and afforded
families a degree of privacy, which seemed to be largely absent from visits to people
in high secure. In one medium secure unit visitors were able to see their relative in a
private room – 'they're very accommodating towards leaving us on our own. That
helps hugely'. In another medium secure unit:

> *"The last time it was about four weeks ago we went into an interview
> room and just me, my other son and him and the male nurse just sat
> outside and gave us privacy so that was good yeah." (father)*

Privacy is an interesting and complex issue in the context of secure services,
however, raising issues about the boundaries on wards, which carers perceive as
the home of their relative or friend. Forensic carers experienced frustrations with not
being able to get to know more about the environment where their relative or friend
lived, sometimes for many years, nor to meet the people they shared this
environment with. They understood this to be because of concerns that the privacy
of other patients would be compromised, though the practice of organising open
days went some way to addressing this:

> *"Well the big disappointment I think is that you know there's no chance
> of meeting the ones that she's associating with, you know her peers in
> those circumstances…" (father)*

Even though forensic carers understood the implications for confidentiality and protecting the interests of other residents/patients, they felt it would be beneficial, not just for their relative, to have opportunities to interact with people other than ward staff.

Challenges and Improvements

Respondents to the survey were asked to indicate if they had experienced any particular challenges in the carer role, and were also able to identify additional challenges experienced but not listed on the questionnaire. Just 11% had not experienced any challenges. The proportion of forensic carers identifying with specific challenges are accounted for in the following table:

Table 11: Challenges for forensic carers in getting the support they needed identified by survey respondents

Type of Challenge	Percentage
Being appropriately involved in decisions affecting the person I care for	55%
Getting information about forensic mental health services	50%
Being listened to and respected	50%
Getting information and advice about the Mental Health Act	48%
Travelling to and from hospital	48%
Ensuring appropriate health services for the person I care for	46%
Being able to visit as and when it suits me	44%
Getting emotional support	39%
Involvement with prison or the courts	35%
Getting support in the community	33%
Feeling stigmatised	30%
Changing between services	24%

Table 11 shows that the most prevalent challenges identified by forensic carers relate to their involvement in the care and treatment of their relative, which includes being listened to and respected and getting information about the forensic mental health service. In addition, almost half had experienced challenges in getting the information and advice they needed about the MHCT Act, as well as in travelling to

and from forensic mental health services. The challenges self-identified by survey respondents included funding issues and a perceived lack of meaningful activities for people within services. The long term nature of caring in this context was also emphasised:

> *"There should be a recognition that family of patients will be involved for the rest of their lives as opposed to professionals who come and go and leave carers with consequences of any decisions they make."* *(survey respondent)*

Respondents reported a range of emotional impacts of caring for a relative detained in forensic mental health services, including feelings of guilt and responsibility or, at times, feeling powerless and helpless. One survey respondent expressed satisfaction with regard to all the areas suggested as possible challenges for carers, so clearly some forensic carers are having their needs fully met. Other responses imply there are inconsistencies in supporting carers, between different units and sectors of the forensic mental health services, and between different staff. It was not untypical for a transition between units to bring different, more or less supportive, practices into stark relief.

Forensic carers called for increased communication with them, and for staff in forensic mental health services to listen to, inform and consult carers more. They sought to build a relationship with the staff caring for their relatives, and to know where they fitted in. They wanted to know about the support within forensic mental health services, as well as about the support available for them as carers. They wanted to be involved in the care plan. They asked for 'more caring staff', 'patients being treated as human beings', 'better food', and also somewhere 'more homely' for visiting. One respondent to the survey suggested:

> *"More involvement. More communication. More humanity. More transparency."* *(survey respondent)*

Key Findings

The survey and interviews with carers resulted in the following key findings about forensic carers' experience of support:

- Just short of half of survey respondents rated the quality of support received from forensic mental health services as either good or very good. However, nearly a fifth felt this was poor or very poor.
- A third of survey respondents had found it either easy or very easy to access support when they needed it, in comparison with around a third who had found this difficult or very difficult.
- Only just over a half of survey respondents had received any form of advice, information or support when their relative was first admitted to forensic mental health services. There was evidence to suggest this could, in part at least, be attributed to historical rather than current experience.
- 70% of survey respondents were aware of a carer group, though fewer attended one.

- Carer support groups played an important role in supporting carers, although geographically-based groups felt less relevant to some carers supporting relatives in high or medium secure elsewhere in Scotland.
- Over half of survey respondents did not know about independent advocacy support for carers, and of those who did, the majority said they had never been offered it. Only around one in ten said they had used an independent advocate.
- Carers valued interactions with staff with good interpersonal skills, empathy and insightfulness and who made time to talk with them. The importance of face-to-face contact was emphasised; few forensic carers valued written information above the chance to talk, listen and question.
- Slightly fewer than two fifths of survey respondents had received information indicating their rights, such as to a carers' assessment. Even amongst these, some felt this information had been 'too little, too late'. Three fifths of respondents rated the information as either good or very good, but a fifth said it was either poor or very poor.
- Forensic carers wanted to be listened to and respected more by services, and to get information they needed. Where individual professionals were seen to communicate actively and positively with carers, this was hugely valued.
- Almost half of survey respondents had experienced challenges in travelling to and from forensic mental health services and 44% had been challenged by the lack of flexibility around visits.
- Forensic carers in this study reported feeling frustrated and blocked in their attempts to access information, from hospitals in particular, but also failing to get replies from agencies such as the Mental Welfare Commission for Scotland. Issues surrounding confidentiality were also a barrier.
- The factors that can impact on the frequency and quality of visits include distance to and from forensic units and ease of travel; the environment and having a comfortable space for visiting and with some flexibility for visits; and the level of privacy afforded for what can sometimes be quite fraught interactions.
- Carers felt that many of the places where visits took place were overly restrictive and unsatisfactory, even taking into account the need for certain levels of security.
- A key source of stress around visiting was not being consulted or kept informed about their relative. Having staff that were able to support the caring relationship made all the difference.

5   DISCUSSION

This study has looked at carer support from the perspectives of both forensic carers and forensic mental health services in Scotland, examining perceptions and experiences of what carer support there is currently, and seeking to understand better the reasons why some carers feel unsupported by forensic mental health services, critically reflecting on what has worked well. In this final chapter we aim to draw together key themes across all of the data, and to discuss the implications for forensic mental health services for improving support to carers, as well as the implications for developing a national carer strategy that takes account of forensic carers.

Being a Forensic Carer

From the outset, applying the term 'carer' to family members and friends who support individuals in forensic mental health services in hospitals and the community was problematic. They did not always define themselves as carers, and health professionals in forensic mental health services did not necessarily view them in these terms, both of which had an impact on our ability to reach those who were the focus of this study. Even some of those who completed our survey of forensic carers or took part in interviews preferred to identify themselves as someone's mother, father, sister, a supporter or a visitor rather than as a carer.

Some, on the other hand, did specifically identify with being a carer and some felt they had entered into the role of carer when their relative or friend entered forensic mental health services. Applying the label 'carer' to those going through this experience is therefore complex and highly contentious. Notwithstanding this, the study shows that the experience of being a forensic carer brings its own specific challenges: it is clearly a substantial role associated with significant responsibility (as described by our carer participants), a role that is, perhaps, insufficiently recognised in national strategies and by some professionals in their dealings with family members.

The findings from this study demonstrate that being a forensic carer is a complex and challenging role. Service level responses to carers therefore need to be equally sophisticated. A lack of understanding about carers' needs was found by other studies (Canning *et al*, 2009) to be a barrier, but one of the benefits of providing support is that it facilitates better understanding of the needs of carers. Information exchange in particular can enhance carers' satisfaction with services (MacInnes *et al*, 2013). This reaches beyond forensic mental health services to other agencies working with this group of carers, including police, advocacy services, and housing, as well as to general mental health and learning disability services who may be supporting these families prior to their use of forensic mental health services. There are also implications for official strategic responses to meeting carers' needs which need to move beyond general reference to 'substantial' and 'weekly' care to embrace the specific emotional and practical challenges that forensic carers face.

The caring role presents numerous specific challenges that have to be surmounted. Staff in forensic mental health services need to appreciate that carers often need help and support when their relative moves between secure services, as well as on

admission from prison or general psychiatric services. This research has shown that during such transitions carers do not always feel supported by forensic mental health services. Preparation and support prior to the first visit to any secure unit, for example, was identified by carers as essential. They also highlighted gaps in information about forensic mental health services, the MHCT Act, as well as about their rights as carers, even though services identified this as major part of their existing support to carers. While the majority of services reported providing information leaflets, the quality of these varied greatly. Others (e.g. Canning *et al*, 2009) have found that the usefulness of information packs is clearly dependent on their content. Overall, there was limited evidence of consistent good quality information and support being available from forensic mental health services in Scotland.

It was very clear that carers welcomed the opportunity this study represented to talk about their experiences. The stigma surrounding forensic mental health services can prevent carers from sharing their stories and worries with others, so that they feel isolated and perceive their experience as unusual. For some, there had not been institutional opportunities to speak and work through these experiences either in informal conversations or in a more therapeutic relationship.

Availability of Carer Support

Given that our survey of forensic mental health services was modelled on the previous study of high and medium secure units in England and Wales by Canning *et al* (2009), we start by making comparisons between some of the results. A response rate of 79% enables us to generalise with greater confidence, and perhaps evidences a high level of support and interest within Scotland's forensic mental health services for this agenda. Services self-identified a wide range of carer support in existence, and our finding that all Scottish forensic mental health services reported providing at least one form of support for carers is greater than the finding of the survey in England and Wales (Canning *et al*, 2009), which found that 74% of services were providing support. Additionally, fewer Scottish units reported difficulties with setting up support. However, while being able to contact a key worker could be an important support to some carers, it may be more limited in reality. After support from a key worker/named nurse, the next best provision was of information, which we found was of variable quality.

Our findings indicate that carer support was not a widespread or consistent part of forensic mental health provision across Scotland. Indeed, this study found inconsistencies and variability in carer support between services and areas. Considerably fewer respondents in our survey (65% compared to 96% in Canning *et al*, 2009) recognised the benefits of providing carer support, which further indicates that forensic mental health services' disposition towards engaging with the carer agenda was variable.

The average of 69% of patients in contact with their relatives reported by forensic mental health services is remarkably similar to the findings of Canning *et al* (2009), which estimated this at around 70%. This does, however, mask a wide variation, ranging from as little as 20% to an estimated 100% of patients with carer involvement across different forensic mental health services. There is the potential

for some service respondents to have understated as well as to have overstated the degree of contact with carers given that these were estimates. During our communications with staff in some forensic mental health services, it came to light that even when relatives visited patients regularly, they were not recognised as carers as such because nursing staff were caring for the person when in hospital. This supports our earlier assertion that the real levels of patient/carer contact in forensic mental health services may be underestimated, and also that amongst some forensic mental health staff there is a lack of appreciation of the carer's role.

The survey of services revealed far lower perceived levels of uptake of support amongst carers than might be expected in view of estimated patient/carer contact. On average, just 43% of carers were reported to be accessing available support, which is comparable with that estimated by staff in high and medium secure services in England (44% in Canning *et al*, 2009). Similarly, our finding that nurses and social workers were the staff most likely to be providing support to carers was matched in the previous survey.

Scottish services also reported less provision of specialised carer support, for example, for those caring for a relative with learning disability, with only 20% providing such support compared to 42% in the English study. Similar proportions (57% in English survey and 58% in Scottish survey) claimed that they catered for Black and Minority Ethnic (BME) carers, although this was generally limited to accessing translation and interpreter services. Future research should aim to better understand differences in socio-cultural views on caring, acknowledging that for BME forensic carers there may be additional challenges to those faced by white British/Scottish forensic carers.

Responses from both forensic mental health services and carers indicated a general awareness of a wide range of types of carer support. However, we also found that many forensic mental health services were limited in the types of support they actually offered to carers other than general information and/or links with the patient's key worker or named nurse. Even so, some carers commented that after two years or so they still had not been told who the named nurse was for their relative, which does question its value as the lynchpin of carer support.

Carer support groups were reported by services as not being available in 42% of areas. It was also likely that we heard from an over-representation of carers using carers support groups as the study was promoted successfully through two carers groups in particular. Carers attested to the value of such groups, emphasising the many benefits of peer support, including fostering a greater sense of co-production with the clinical team. The limited provision of carer support groups linked to high and medium secure services or organised by the voluntary sector meant that the diverse needs and interests of forensic carers with relatives in differing types of secure services were not met by available support. Also, carers need to know about the existence of carer support groups and be offered support to attend if they need it: some study participants only heard about such groups by chance and often from other carers rather than through staff promotion. Overall, our findings suggest that both provision of carer support and the extent to which it may be accessed are inconsistent within and between forensic mental health services.

Challenges Involved in Getting Support

This study found that the views and priorities of services and carers sometimes conflict, and there are discrepancies between what services believe they provide and what carers experience. The biggest challenge identified by carers was in getting the support they wanted from services to ensure they were meaningfully involved in the care of their relative. Despite some positive experiences, many felt they were not listened to by clinical teams, and certainly did not feel they had been treated as partners in caring for their relative. Carers in this study did not always feel respected or adequately informed, including about forensic mental health services and their rights as carers. The range of carer involvement is clearly highly variable and demonstrates that some forensic mental health services recognise the value of engaging with carers and are actively working to foster collaboration with carers and to meet their support needs, while others are not. Those forensic mental health services with low engagement could learn from their colleagues who have achieved high levels of carer engagement about how to overcome the barriers to, and increase, carer involvement.

According to services' estimation, fewer than half of carers were involved in Care Programme Approach (CPA) review meetings. This is worthy of note given the consistently high value carers placed on being involved in their relatives' care and shared decision making. These findings suggest a need for forensic mental health services to reconsider the mechanisms in place for inviting relatives to formal reviews and meetings, and the extent to which they are supported to attend. This needs to include recognition of the difficulties for those carers who have additional responsibilities as named person. Carers described the challenges of this role, including that they were unclear about their remit and how this could work if they disagreed with their relative.

Carers also emphasised the difficulty of presenting their views in front of their relative, especially given their potentially fluctuating and unpredictable nature. Carers valued an opportunity to speak honestly to staff, and discussing views which may feel uncomfortable and distressing for their relative.

There have been innovative developments elsewhere, including user-led standards for CPA that place the patient at the centre of proceedings: this includes supporting the service user to write the various invitations, including for carers (McKeown *et al*, submitted). Various other initiatives on forensic care pathways make the case for more systematic involvement of carers, linking this with risk management, discharge planning and formal carer assessments (Kelly *et al*, 2002; Kennedy, 2002; Gill *et al*, 2010). The *Triangle of Care* is in use in English high secure settings to encourage carer recognition and involvement.

Carers identified being challenged by the travel distances to and from forensic mental health services, as well as by the nature of the institutional regimes and environments they visited. This is unsurprising considering the large catchment areas of secure units especially the high and medium secure units. The considerable travelling distances to and from secure services make it challenging for carers to maintain contact with their relative or friend, but also for them to attend support groups based at these services.

It is noteworthy that staff in services explained low uptake of carer support in terms of carers choosing not to engage, whilst carers identified numerous barriers including distance, information sharing, confidentiality, respect for the carer's role, and so on. Ironically in this regard, Arksey and Glendinning (2007) remark on the actual limitations on choice for carers in general. This implies a need to develop a variety of valued support opportunities that appeal to diverse needs (widening choice), paying attention to factors that impede carer uptake of support. Furthermore, if forensic mental health services improve the ways they meet the needs of carers, they should be better placed to meet the progressive policy rhetoric that underpins recovery goals for mental health services (Drennan and Aldred, 2012).

More Supportive Environments

As highlighted in the literature (Ferriter and Huband, 2003; Hughes and Hughes 2000; McKeown and McCann, 1995), this study found that carers can experience stress as a result of the forbidding nature of visiting secure settings, and/or because of the emotionally tense nature of meeting with their relative under forensic mental health services. Several of the forensic carers we interviewed referred to 'dreading visits' and when a visit went badly, needing to take a break from visits in order to cope, although this can lead to feelings of guilt. There is a clear case for focused support for carers around visits to assist them to make more rewarding contact with their relatives and also to build trust with staff. Consultants and managers have a pivotal role to play to ensure the right culture is created to support positive, open (non-defensive) relationships with carers.

Some carers identified unwelcoming and prison-like environments, coupled with poor staff engagement as contributing to the sense of dread at visiting their relative. Carers can be fearful of voicing concerns in case this 'rocks the boat'; or might be poorly placed to advocate when feeling upset or under pressure at visiting times. At least one survey respondent reported feeling 'abused' by the system, and in interviews, forensic carers reported being reticent to raise concerns if they thought this might impact on their relative's treatment. There were others who reported positive experiences of being supported by staff when there had been conflict and difficult issues to resolve in the relationship with their relative.

A distinct lack of privacy and/or of decent facilities for patients and their relatives to share a 'cup of tea' – a sense of normality in a foreign environment - increased the gulf between carers and their relatives, negatively reinforcing the custodial rather than therapeutic element of forensic care and treatment. In this respect, the visitors centre at the State Hospital appears to be a missed opportunity to enhance support to carers: visitors congregate at the visitors centre with access to refreshments, before being transported to the wards, but the only staff they meet at this time are security personnel and some carers felt that they should not speak to other visitors because of perceived confidentiality issues. There is an opportunity here to encourage and develop peer support as well as for staff engagement.

Throughout this study, the most unreserved criticism from carers centred on the State Hospital. However, there was ambivalence: it was clear for example, that some of the practices most welcomed by carers are offered at the State Hospital,

and that some staff are committed to providing support to carers and implementing bespoke practices, such as published accounts of efforts to develop a range of psychosocial interventions (Walker, 2004; Walker and Connaughton, 2012). High secure services such as the State Hospital also appear to be off-putting for carers because of public image and its reputation as a 'prison rather than a hospital', all of which are live concerns for progressive service managers and staff. That said, it is clear from our findings that attempts were in progress to improve visiting arrangements for carers across forensic mental health services, which reflects national developments (Cormac et al, 2010), including major works modernising the built environment at the State Hospital and some development of carers centres at other sites.

The location of secure units, particularly of medium and high secure, within the Scottish geography creates practical challenges for carers wishing to remain in regular contact with their relative. In this regard, a commitment from key staff (including named nurses and consultant psychiatrists) to engage in telephone contact with carers had proven invaluable. In the wider literature, innovations in the deployment of digital technologies have been suggested as various solutions for communication issues in wider health care services, especially when distance and separation are at stake (MacInnes et al, 2013); for example, Absalom-Hornby and colleagues' (2012) development of family intervention utilising web-cameras for secure settings. In our survey of services, however, minimal use of new technologies such as Skype or email were reported as being used to assist families to stay in contact. Such circumstances might reflect security restrictions on the use of digital technology by service users. As carers become more knowledgeable about possibilities this could raise questions about how patient access to technologies such as e-mail and mobile phones is regulated or supervised. Particularly given the challenges of the Scottish geography, there might be room for more sophisticated appraisal of individual capabilities and risk in relation to such access, or supervised access, rather than relying on blanket restrictions that merely reflect the level of security of the unit as a whole.

Recommendations

The following recommendations are based upon the findings of this study and are directed at policy makers and practitioners wishing to reduce inconsistent provision of carer support and implement best practice. As a minimum, we underline the importance of the following general recommendations from the *Triangle of Care*:

1. Carers and the essential role they play are identified at first contact or as soon as possible thereafter.
2. Staff are 'carer aware' and trained in carer engagement strategies.
3. Policy and practice protocols regarding confidentiality and sharing information are in place.
4. Defined post(s) responsible for carers is/are in place.
5. A carer introduction to the service and staff is available, with a relevant range of information across the care pathway.
6. A range of carer support services is available.

To meet the specialist needs of forensic carers in Scotland, we further recommend:

- Acknowledging and sharing across the forensic estate information about existing good practice in fostering a culture of partnership with carers and supporting them to be a core part of forensic mental health services.
- Having designated staff within forensic mental health services who are responsible for advancing the carer agenda, driving the agenda forward and being a point of contact for new carers.
- Forensic mental health services providing a comprehensive and accessible information pack for carers, taking into account their diverse communication needs.
- Forensic mental health services considering what information, advice and support planning needs to be in place to alleviate uncertainties for carers associated with transitions.
- Forensic mental health services working to minimise the stigma that forensic carers experience, and doing so in partnership with carers who have direct experience of this stigma.
- Involving carers in support planning and review processes including active encouragement and support to be involved in CPA reviews.
- Forensic mental health services holding regular carer events such as open days at secure units.
- All forensic mental health services organising and/or supporting a regular forensic carer support group serviced by the unit or in partnership with the voluntary sector or carers, along the lines of existing successful forensic carer groups.

Conclusion

In considering the issue of carer support from the perspectives of services and carers, this study has attempted to explain identified discrepancies in service delivery. Examples of good practice in the support of carers were noted throughout the study, and these included investment in information exchange, carer support or development workers, carers support groups and behavioural family therapy. However, a significant finding was that carer support is inconsistent across Scotland and within some units, and secondly that the reasons for low uptake of available support are understood differently by staff and carers. Staff identified carer choice as a main reason for this, whereas carers identified a number of access barriers.

From carers' perspective, the most important change that can be made is for staff to perceive carers as important to engage with, with needs of their own, as effective allies in a triangle of care, and to relate to them consistently in a welcoming and respectful manner. The increased emphasis in health and social care policy on the importance of supporting and involving carers needs to become widespread practice. The fact that carers can attest to the benefits of such an approach suggests that this is achievable in forensic mental health settings without compromising confidentiality or risk management. While there is good practice, the most pressing issue would seem to be the need to further increase the range and spread of support, and to address the current inconsistent and patchy provision of carer support.

This study has a number of limitations including that it adds little to the literature on the separation of forensic patients from their children (Chao and Kuti, 2009), or the experience of diverse forensic carers, especially those from BME groups. It has not

specifically explored issues that may be specific to women who require forensic care or the needs of disabled people, but arguably these remain important areas for further research and practice development.

The notion of staff being 'carer aware' needs to extend to all staff working in forensic mental health services, and to include attention to the crucial importance of forging warm, respectful and constructive relationships with carers at all levels of the organisation. If this can be consistently achieved, services would be better placed to improve first impressions, iron out perceived discrepancies between different parts of the service, particularly ward-based care, and to maximise the positive contribution that carers can bring to improving patient care and safety.

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appendix 1: literature review

This review of the research and wider literature aims to highlight innovations and best practice in supporting informal carers caring for someone in forensic mental health services.

The Literature

The scholarly literature includes different types of studies and some commentary, with variable quality of research as judged by the comparative prestige of journals in which this research is published. As such, the relative impact of this entire body of knowledge is likely to be limited. The research papers include a number of interesting surveys (including surveys of staff and relatives' perspectives on services), qualitative analysis of carers' accounts of their experiences, and some service evaluations. There are few experimental design projects and no trials comparing the efficacy of different initiatives and this is a significant gap in the literature. Some researchers have published several papers that cluster around particular studies or small programmes of research.

The UK has a more extensive published literature than other countries, with a certain amount of interest in Canada and Australia. In the UK, various broader developments have been influential in driving forward key initiatives. These include the advent of Care Programme Approach (CPA) as a means of organising case management, the impact of key public inquiries into failures of care in secure settings, notably the two focused on Ashworth High Secure Hospital, and interest in staff training and service models associated with psychosocial interventions (PSI). More latterly, the fashion for recovery-orientated services is having an impact within secure services and the implicit holistic framing offers an opening to consider more thoroughly the needs and involvement of carers (Allen, 2010; Drennan and Aldred, 2012; Chandler *et al*, 2013).

Needs of carers in a forensic context

A number of the studies have explicitly sought to define the needs, experiences or concerns of relatives associated with being a carer for a detained person or their interaction with services (McKeown and McCann, 1995; McCann *et al*, 1995; McCann *et al*, 1996; MacInnes and Watson, 2002; Ferriter and Huband, 2003) and there is one published literature review (Tsang *et al*, 2002). Other papers make mention of specific needs or difficulties in the course of reporting broader findings (McCann, 1993; Canning *et al*, 2009; Absalom *et al*, 2010; MacInnes *et al*, 2013). There are also commentaries which offer a view on carers'/relatives' needs (McCann and McKeown, 1995), and at least one first person account from the perspective of carers (Hughes and Hughes, 2000).

The literature on provision of different forms of support for relatives recognises the various needs highlighted in the studies of carers' needs and experiences and reports on attempts to address such needs. Taken together, these studies and commentary describe key issues for carers that include:

- The physical separation involved in visiting institutions at some distance from home, which can undermine levels of support and contact (McKeown and McCann, 1995; McCann *et al*, 1996; Canning *et al*, 2009; Absalom-Hornby *et al*, 2011a; 2011b).
- Increased stress or burden of care compared with carers of non-forensic service users, including fear of experiencing violence (McInnes and Watson, 2002; Tsang *et al*, 2002; Ferriter and Huband, 2003).
- Troubled family relationships can increase burden severity, with main problems being between the primary caregiver and other relatives (McInnes and Watson, 2002).
- Stress in their dealings with services, including the forbidding nature of security regimes (McKeown and McCann, 1995; McCann *et al*, 1996; Hughes and Hughes, 2000; Ferriter and Huband, 2003).
- Stress resulting from experiences relating to the actual index offence and treatment by the police or the courts, or anxieties associated with negative media coverage of forensic services; the latter might include fears of abuse from staff or other patients towards their relative (McKeown and McCann, 1995; McCann *et al*, 1996; Hughes and Hughes, 2000).
- The double stigma of mental health in the family along with offending, sometimes including hostility from neighbours or in the media (McKeown and McCann, 1995; McCann *et al*, 1996; Hughes and Hughes, 2000).
- Specialist and general information needs (McCann *et al*, 1996; Hughes and Hughes, 2000; McInnes and Watson, 2002; Canning *et al*, 2009; MacInnes *et al*, 2013), complicated by the use of confidentiality issues by services to effectively exclude relatives from information or involvement (Jubb and Shanley, 2002).
- Practical and emotional support needs (McCann, 1993; McCann *et al*, 1996; Hughes and Hughes, 2000; McInnes and Watson, 2002; Canning *et al*, 2009).
- Uncertainties around how to deal with their relative's mental health problems (McKeown and McCann, 1995; McCann *et al*, 1996; Hughes and Hughes, 2000).
- Guilt and self-blame (Ferriter and Huband, 2003).

The latter point is also relevant to difficulties and challenges arising in the contact time between carers and the person they are visiting. As such, visiting times can become stressful and emotionally fraught encounters for everyone concerned (McCann *et al*, 1996). Carers of forensic service users also report more extreme perceptions of the burden of care, including fear of experiencing violence (MacInnes and Watson, 2002; Tsang *et al*, 2002) and certain commentators have argued that deinstitutionalisation policies increase the risk of carer victimisation (O'Brien, 1998). A Swedish paper makes similar points whilst stressing that parents in particular might be relatively unaware of the character of their son's mental distress, confusing how they make sense of violent behaviour, possibly hampering relations with officialdom and services (Nordstrum *et al*, 2006).

Carers' previous contacts with psychiatry can be disappointing or unhelpful (Hughes and Hughes, 2000; Nordstrom *et al*, 2006; MacInnes *et al*, 2013). Good practice in services concerns itself with involving relatives in discussion or decision making at key times, especially when discharge planning is at stake and there might be an option for seeking community accommodation near to the relative's neighbourhood or at their home, or, indeed, ruling this out. A lack of involvement in such future

planning can be a major cause of stress for relatives and feed into any anxieties for the future. The experience of carers across all mental health services has been that staff can be over-cautious in balancing service users' right to privacy with carers' rights to share in information (Gray *et al*, 2008; McInnes and Watson, 2002). In the secure context, Jubb and Shanley (2002) remark upon the extent to which confidentiality can be used as a reason for not involving families, sharing information, or even allowing access to ward areas, leaving relatives feeling excluded and isolated. Interestingly, this state of affairs was to some extent remedied in one secure unit using action research methods (Jubb and Shandley, 2002).

Szmukler and Holloway (2001) provide a persuasive rebuttal of the idea that confidentiality should be a catch-all rationale for not involving families. This does not have to mean that forensic patients' rights to confidentiality are ignored (Kaul, 2001), rather that there is scope for attending to some important limitations on confidentiality while negotiating the practicalities and value of sharing information between all interested parties/stakeholders. Geelan and Nickford's (1999) survey of use of family therapy in secure units did not identify confidentiality as a major staff concern, and associated this with the advent of the CPA possibly opening up possibilities for information sharing. The value of information sharing may not, however, be fully realised within services because of perceived complications such as confidentiality and a lack of appropriate local policy development to support best practice (Rapaport *et al*, 2006; Slade *et al*, 2007; Rowe, 2012). Slade and colleagues (2007) undertook a policy review combined with interviews with staff, patients and carers to derive a framework to guide information sharing in mental health settings. They recommend a distinction being made between general information and personal information that is new to the carer, with only the latter requiring consideration of confidentiality and consent to disclose, and emphasising good clinical judgement as pivotal in this process.

The first-hand account written by John and Clare Hughes (2000), parents of a young man admitted to a high secure hospital, though not recent, is a sobering read. As relatives they faced a series of stressful events and negative experiences, from the index offence, through the courts, to their son's admission to forensic care. This included feeling somewhat excluded from contact with the care team in the initial stages, with their relationship with services confined by the imposition of a series of rules they should not transgress rather than any positive sense of what they could offer or what support they themselves might need. Eventually, with the advent of a relatives support group, these experiences became more positive, leading them to be strong advocates for such interventions and also to make the case for a positive charter of rights for relatives in such settings.

Assessment tools

Assessment of carers' needs is a logical consequence of accepting that they have needs separate from those of the person they care for, and services might attempt to address them. A specific assessment questionnaire for relatives' needs in a forensic setting has been developed in the course of one of the psychosocially-orientated research projects: The *Relative Assessment Interview Schizophrenia in a Secure Environment* (RAISSE) (McKeown and McCann, 1995), itself based upon more general available assessment tools such as the Relative Assessment Interview

(Tarrier *et al*, 1988). Arguably, other more general tools such as the *Carers' and Users' Expectations of Services – Carers' Version* (Lelliot *et al*, 2003) could be adapted or utilised for forensic settings. The RAISSE focuses on relatives of patients diagnosed with psychosis, and as such is not necessarily applicable to all service users or carers. However, some of the issues or experiences of relatives will remain fairly common, as the tool, for instance, inquires into the relationship with the institution.

Staff views

The literature makes a distinction between relatives/carers and professional staff caregivers. Staff views about meeting the needs of relatives are relatively under-researched. Absalom-Hornby and colleagues (2011b), for example, focus on psychosocial family interventions, and forensic staff identified barriers to such service developments and offer their views on how to overcome them. Five barriers are described which include constraints on staff time, lack of training, poor support for interested staff, problems around information sharing and limitations due to geographic distance. Seven solutions are discussed that include clear pathways for family intervention training, protected staff time for family work, effective family policies and service structures, appropriate supervision contracts, managerial support, education for families and service promotion, and the use of new technologies. The authors call for a designated family team at each forensic unit with a lead therapist running the service and information and awareness events for staff and patients. This study belongs to a small portfolio of recently published papers that identify some interesting innovations largely concerned with PSI. In another paper, this same research team undertook a Q methodological study of both staff and relatives' views towards family intervention, finding that both held family interventions in positive esteem. The survey by Canning *et al* (2009) ascertained the views of key staff on the responsiveness of different forensic services to the support and involvement of relatives. We now present specific types of service response in the relevant section below.

Service user views and involvement processes

There is limited research eliciting the views of service users on the issue of support and involvement for relatives in secure settings. The notion of 'service user involvement', however, can be used in practice as shorthand for 'service user and carer involvement' and a couple of studies of user involvement make reference to the involvement of carers in secure settings. A review across England undertaken by The National Survivor User Network (NSUN) and WISH (Voice for Women's Mental Health, previously Women in Secure Hospitals) (2011) identified some examples of carer involvement and also the potential for more. For example, in one unit there would be regular open days for carers were they would be able to question staff and see activities. Carers might also be recipients of minutes from patient councils, and future plans in another unit included provision for regular carers meetings. Similarly, an evaluation of service user involvement (McKeown *et al*, 2012) across secure care in the Yorkshire and Humber region focused on service user and staff alliances, but also elicited ideas for future work. In this study, service users were engaged in workshop exercises to translate the research findings into future strategic action plans. A priority for these actively engaged service users was

better support for carers/relatives and a recommendation for getting them involved in extant strategic involvement processes which to date had been restricted to service user involvement, effectively excluding the voice of carers (McKeown *et al*, 2012).

Types of support and services for carers in forensic settings

The key paper by Canning *et al* (2009) found that although a focus on carers has increased in general psychiatry, it has not done so to the same extent in forensic psychiatry. The services identified benefits of providing support as improving relationships and communication between staff and carers and improving patient well-being. Difficulties identified by NHS staff included lack of resources and stakeholder issues, such as carers' previous negative experiences of services having an adverse impact on future engagement. This paper recommends minimum standards for supporting relatives to include:

- Comprehensive information pack for all carers
- Regular carer events
- Ideally, a regular support group
- A small group of staff to collaborate on carer support, driving the agenda forward and becoming a point of contact for new carers

An earlier survey by Geelan and Nickford (1999) remarked upon the relative lack of systematic family therapy available across English and Welsh medium secure units, with wholesale lack of staff training identified as a key limiting factor. What work was undertaken with families was poorly focused and targeted, with insufficient attention paid to desired outcomes.

The most recently published survey of this kind makes some telling criticisms of medium and low secure services in England and Wales (Cormac *et al*, 2010). This postal survey inquired into facilities for relatives and found that many forensic services were not meeting legal obligations for carer's assessments and services addressing relatives' needs were of variable quality. The authors urge that services are improved to meet standards for involving relatives and comply fully with legislation. 63% of services claimed to operate a support service for relatives, but of those that did not, 60% had no plans to develop one. Only three units out of 68 responding to this survey employed carers support workers. Only half replied that they were aware of appropriate local accommodation for visiting relatives, with only three units providing their own accommodation. Only 28% offered a carers support group with slightly fewer units offering family therapy. Just over half of the units informed relatives of their right to a carer's assessment on discharge. The picture for ethnic minority carers was particularly bleak. While services had relatively large proportions of BME patients, 82% of the units offered no special facilities for their carers.

Carers support groups

Support groups are one of the simplest ways in which relatives can have their needs met, yet they are not at all routinely available (Cormac *et al*, 2010). One of the earliest papers in the field is an evaluation by McCann (1993) of a carers support group in Ashworth high secure hospital originating in 1990. This was designed in

such a way to promote autonomous self-organisation by the relatives themselves following an earlier period of staff facilitation. The timing of the group was organised around visiting arrangements, so as not to inconvenience relatives having to travel long distances. Reported benefits included: being better informed, feeling less isolated, appreciating a notion of shared experience with other relatives and improving the interface with staff and care teams, especially in terms of the quality of relationships. Some relatives felt that the patients they visited also benefited from the existence of the relatives support group; for instance, in the mediation of problems and complaints and increasing levels of influence on the part of the relative in care team decisions and patient welfare.

Previous surveys (Canning *et al*, 2009; Cormac *et al*, 2010) note the patchy availability of support groups in forensic settings and recommend that these circumstances are improved. In the course of a literature review focused on service users in forensic settings who have a dual diagnosis of illicit substance use, Richards and colleagues (2009) highlight the NICE recommendations that relatives should receive information about support groups. This is also one of the principles of more general carers' charters (see Carers' Advisory Group: the London Mental Health Carers' Charter, 2002).

Carer support workers

Small numbers of secure units are reported to have employed dedicated carer support workers (CSW) (Cormac *et al*, 2010). In a published conference abstract, MacInnes and Bressington (2011) describe the intention and methods for evaluating such a service being developed across the forensic units belonging to two NHS Trusts. The service itself aims to provide practical support and basic counselling interventions to carers with the CSWs trained and inducted into the role and also involved in developing bespoke information and publicity materials. The evaluation methods include interviews with carers and analysis of amount of contact and types of support provided. The findings have yet to be published but the authors anticipate that the service should begin to meet the demands of carers for better information and support and possibly remedy previous dissatisfaction in this regard.

Visiting arrangements

The first Ashworth Public Inquiry led by Louis Blom-Cooper (1992: 233) made particular criticisms and recommendations regarding unmet needs for relatives:

> *…regrettably, the regime at Ashworth… seems to have been designed to deter rather than encourage relatives to participate in their relatives' care.*

The programme of psychosocial work commenced around this time led by Ged McCann and colleagues was boosted by the publication of the Inquiry report in 1992 and was instrumental in establishing a Visitors Centre, which was a newly built facility that included bespoke meeting space for off-ward visits and bookable en-suite accommodation for relatives having to travel long distances. A manager and team of staff were appointed to better service the needs of visitors and relatives. Unfortunately the later Public Inquiry into security failings, the Fallon (1999) Inquiry,

was influential in the closure of the Visitors Centre after a small number of visitors to wards were implicated in serious security breaches, including one startling child-protection issue. Arguably, this small piece of history shows how strategic thinking concerning relatives has been lacking, especially in terms of applying blanket policy prescriptions without attention to specific needs, either for relatives or regarding security arrangements (McKeown, 2007).

A number of services have attempted to improve visiting arrangements, including the provision of more comfortable rooms and toys for children (see Cormac *et al*, 2010). Canning *et al* (2009) found that some units provided free telephone calls for service users to keep in touch with family or assistance for carers claiming money to defray the costs of travelling. Dimond and Chiweda (2011) describe a welcome meeting arranged soon after a person is admitted to their unit as a feature of a systematic approach to improving the therapeutic environment. Though not primarily about meeting carers' needs, relatives are invited, and positive relationships between carers, patients and care staff are valued.

Children of forensic patients

Only one paper was found with a focus on service users' relationships with their children following admission to forensic services. This paper by Chao and Kuti (2009) confirms the anecdotal sense that many patients have lost contact with their children. In a survey of two medium secure units in London, 69 had children but only 25 remained in contact. The authors conclude that the children of forensic patients should be seen as a neglected group because there are only limited attempts to offer them support. Forensic services should judiciously assist in maintaining contact or re-initiating contact.

Information for carers

Receiving good quality, relevant information about a range of issues is highly valued by carers in a mental health context generally. This goes beyond simply offering information, but carers also value receiving good quality information about aspects of care provision and information aimed at improving understanding of mental health. For some time, UK mental health policy has recognised this and recognised the need for two forms of information for carers:

- Specific information about the person they care for and their progress - illness, medication, side effects
- General information on a wider range of issues – research into effectiveness of treatments, legislation, MHA, local services, benefits, professionals and their roles

Within secure services, further information is required that is specific to the secure setting and the operating policies of specific units (including issues concerning interface with the criminal justice system) and practical issues such as visiting arrangements and local transport and amenities (Cormac *et al*, 2010; MacInnes *et al*, 2013). Similarly, carers in the forensic context will have information needs relating to how best to care for a family member who may have imposed significant burdens on their relationship, linked to their offence and/or violent behaviour (McInnes and

Watson, 2002). MacInnes *et al* (2013) in a survey of two London medium secure units found that carers' satisfaction with services pivoted on the quality of information provided, and that novel ways of exchanging information ought to be considered. Going back to possibly the start of any published interest in working with families in secure settings, Cordess (1992) identified prime aims as imparting information <u>to</u> carers and obtaining information <u>from</u> them.

Many units produce information leaflets or packs for carers, and some offer newsletters or internet-based information; written information can be posted directly to relatives, strategically placed where carers might find it, or supplied in the context of other communication with staff (Canning *et al*, 2009). From a policy perspective, it is desirable that service users and carers have a role in the production of such information (Kelly *et al*, 2010; NHS Education for Scotland, 2013). Uptake of written information by carers is high, and this is often provided as part of the admission process (Canning *et al*, 2009). Culturally-specific information for families of ethnic minority service users is less often available (Canning *et al*, 2009).

Published literature describing or evaluating information provision for carers in secure settings is thin (MacInnes *et al*, 2013). However, the provision of information addressing carers' needs and negotiating access to personal information regarding the care of their relative is an implicit part of many of the initiatives described elsewhere in this review, especially psychosocial and psycho-educational approaches to support and involvement, which are difficult to disentangle in the literature (Scottish Intercollegiate Guidelines Network, 2013). For example, the early study at Ashworth (McCann *et al*, 1996; McCann and Clancy, 1996) involved both the production and dissemination of information for carers relevant to the high secure setting and a mixture of discussion of information, psycho-educational and support group work which was found to be beneficial for the carers. Staff suggest that barriers to the uptake of psychosocial family intervention in secure settings could be addressed by the production and dissemination of information leaflets promoting the service (Absalom-Hornby *et al*, 2011b).

A survey of support provided to carers in secure units found that some units referred people to voluntary sector sources of information, such as Rethink or Mind (Canning *et al*, 2009). The NSUN/WISH (2011) recommendation that all forensic units identify a person responsible for service user involvement could equally be extended to carer involvement.

Psycho-education

Psycho-education approaches involve engaging service users and/or carers in learning about mental health and services so as to better realise benefits from care provision and promote mutual self-help or support-seeking (Mannion *et al*, 1994; Pekkala and Merinder, 2002). Such initiatives can be enacted in group or one-one formats. Typically, these efforts have been associated with the PSI approach, and the majority of studies are within mainstream, community mental health services. These have focused upon people diagnosed with psychosis and/or their carers, and the content has emphasised understandings of illness and medication, though there has also been interest in self-coping, mutual support, and various psychological understandings and interventions. A smaller number of studies have evaluated

psycho-education in forensic settings, with service users alone (Aho-Mustonen *et al*, 2008; 2009; Vallentine *et al*, 2010; Walker *et al*, 2012; 2013) or carers alone (McCann *et al*, 1996). Klimitz (2006) has suggested that it is optimal to deliver psycho-education with carers and service users together, but Vallentine and colleagues (2010) point out that this is not always possible in forensic settings, especially if the index offence has been committed within the family.

Educative approaches range from simple didacticism to experiential and action methods of learning, including peer-peer learning (Perlick *et al*, 2011). There is a general literature on psycho-education that takes a fairly positive view of its impact, and stresses the value of enhancing carers' knowledge so as to better enable them to resist stigma and support individual patients, and that this may help with relapse prevention (see Budd and Hughes, 1997; Sibitz *et al*, 2007). However, the value of psycho-education on its own to prevent relapse is limited unless also accompanied with more structured and systematic support for families, such as family therapy (Fadden, 1998; Tarrier *et al*, 1998).

The most commonly undertaken family work reported in Geelan and Nickford's (1999) survey of forensic units was psycho-education. In an early Australian paper, a psycho education programme was implemented in community settings where families were caring for individuals with forensic histories (James, 1996). In this initiative, the psycho-education component was combined with emotional and practical support and was aimed at reducing anxiety levels, and preventing relapse or re-offending.

Psychosocial interventions

A significant amount of the available literature concerning carers and secure settings has focused upon the promotion and evaluation of initiatives informed by psychosocial understandings of mental disorder, specifically psychosis. Fundamentally, this conceives of psychotic experiences as negatively influenced by stress, treating the psychosocial stress in close personal relationships as crucially influential, and working systematically with people in the patient's social network to better understand these links and communicate and relate to each other in less stressful ways. Some have argued that better information sharing between services and carers is the active ingredient of such approaches (Slade *et al*, 2007). Psycho-educational interventions and the provision of information for carers are often incorporated into broadly conceived psychosocial interventions, typically as a precursor to a more structured process of family support, or possibly as stand-alone initiatives.

Various research studies in general community settings demonstrated the value of this approach, resulting in significantly reduced relapse rates and reduced stress and burden for relatives (Pharoah *et al*, 2010). From the 1980s onwards, gathering pace in the 1990s with the establishment of training programmes such as the Thorn Initiative, this thinking led to a call for wholesale adoption of so-called psychosocial interventions (PSI) into services. The cornerstone would be systematic family support or family therapy, but also included were a range of individual therapies such as Cognitive Behavioural Therapy (CBT). Arguably, the rhetoric around PSI and the increased numbers of staff trained to deliver these interventions has not been

matched in uptake into services, forensic or otherwise. That said, since the 1990s there have been various attempts to adopt and adapt PSI approaches, largely developed for general community settings, into forensic practice, and this was the focus of the 1999 survey by Geelan and Nickford.

The work of McCann *et al* at Ashworth involved the earliest programmatic undertaking to implement PSI in the high secure environment (McKeown and McCann, 1995; McCann and McKeown, 1995; McCann *et al*, 1996; McCann and Clancy, 1996; McKeown and McCann, 1999; McCann and McKeown, 2000) which ultimately was limited in success due to organisational impediments to systematic uptake (McKeown, 2007).

One of the interesting features of secure settings, or indeed other inpatient mental health environments, is that patient contact time with carers is limited, but contact with staff is potentially maximised. Despite carers possibly having less contact time with their family member, the psychosocial stresses involved can be substantial, making the case for concerted efforts to provide psychosocial support. For example, face-to-face visiting times can become emotionally loaded, with each person not always knowing what to say for the best, or perhaps avoiding the things they would most wish to talk about, such as the circumstances of the offence, or issues of current well-being, for fear of provoking a negative reaction or causing upset (McKeown and McCann, 1995; McCann *et al*, 1996). Staff could take fairly simple measures to support relatives/visitors to cope with these stresses and improve the experience of visiting. The PSI ethos is not only about support for carers; it can include the involvement of carers in the care of their family member who is detained, for example, with regard to better planning for holistic care and recovery informed by the experiences of someone who knows the person well, hence improving assessment and engagement.

A number of sources have taken forward the idea of PSI within forensic settings and how these might underpin service developments; these include at different levels of security and with different client groups such as forensic learning difficulties, psychiatric intensive care units (PICU or IPCU in Scotland) and forensic liaison, dual-diagnosis services, forensic child and adolescent mental health services (CAMHS), and community forensic services (Savage and McKeown, 1997; MacInnes, 2000; Baker *et al*, 2002; Walker, 2004; Isherwood *et al*, 2004; Gleeson *et al*, 2006; Lawless, 2008; Peddie, 2009; Atchinson *et al*, 2009; Richards *et al*, 2009; Absalom-Hornby *et al*, 2010). Walker (2004) described the adoption of PSI practices into the State Hospital at Carstairs.

Most recently, Absalom-Hornby and colleagues at Manchester University published an interesting cluster of papers reporting their research into PSI in secure settings. This has involved the innovation of using web cameras to conduct family therapy remotely for families who cannot visit frequently because of distance (Absalom *et al*, 2010; Absalom-Hornby *et al*, 2011a; Absalom-Hornby *et al*, 2011b; Absalom-Hornby *et al*, 2012). The use of digital technology to facilitate family support was found to be successful, was not off-putting for families and indeed was appreciated, positively impacting on social, emotional and practical outcomes for the families concerned (Absalom-Hornby *et al*, 2012). These authors surveyed 11 wards in secure units in the North West of England across all levels of security. They found that only 18%

offered any form of family intervention, despite 72% of patients having high levels of contact with their carers (Absalom-Hornby *et al*, 2010). This confirmed the findings of an earlier audit as to whether any forensic service was meeting NICE guidelines for the care of individuals diagnosed with schizophrenia. In this study none of the 30 patients were offered family intervention and only half reported having received relevant information about their diagnosis or treatment; in short, the unit failed to meet any of the NICE standards (Gough *et al*, 2007).

Community settings

Forensic community services are surprisingly under-represented in the literature regarding carers. An Australian paper by Gleeson *et al* (2006) makes recommendations supported by a literature review for what they refer to as preventive forensic PSI within mainstream adult community mental health services to better meet the needs of patients with a history of offending. McKeown (2001) presents a single case study focused on the community support of a family along with their relative recently discharged from a low secure unit to live at home with his mother. The care team provided family PSI to good effect, with a significant positive impact on well-being, illicit drug consumption and associated criminality and reduced levels of stress in relationships at home.

Case management and risk assessment

It is generally accepted in the professional rhetoric of policy and mainstream services that the involvement of carers can make a positive contribution to case management and the operation of holistic models of care (Hervey and Ramsay, 2004; Wallcraft *et al*, 2011). Policy urges more involvement of carers in the care of forensic patients (NIMHE, 2004). Some authors have made the case for a more systematic approach to involving carers in the risk management approaches salient to forensic services, such that services should view carers as a resource in this regard (McCann and McKeown, 2002; Nordstrom *et al*, 2009). In any event, in general community settings carers report a number of informal ways in which they attend to risk in the care of family members, though they speak of this in a different language from professionals (Ryan, 2002). Kennedy (2002) proposes a system for stratifying risk across the different levels of secure care which takes account of the degree of supportive family involvement as a positive factor in risk management.

In the Irish context, Gill *et al* (2010) propose adoption of an Integrated Care Pathway approach to re-engineer services from a traditional focus on security towards a more recovery-oriented system, opening up the possibilities for enhanced service user and carer involvement. This would involve a number of implications for practice including: provision of a framework whereby patients and carers are enabled to identify and understand risks and needs, improving partnerships with carers and patients in consideration of the foundations for recovery. Similarly, Kelly *et al* (2002), writing in the Australian context, propose a model of community forensic care that positions carers as key partners in drawing up risk management plans and actioning them. The general requirement to undertake a carer's assessment and for carers to be involved in discharge planning could be neatly tied into such ideas around

collaboration, partnership and risk management (see Simons *et al*, 2002; Rapaport *et al*, 2006).[1]

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[1] A carer has a right to ask their local authority to carry out an assessment of his or her needs. The local authority has a duty to carry out the assessment within 14 days of the request. If it does not it must let the carer know within this time whether they or the Health Board will carry out an assessment. If the local authority decides not to carry out an assessment they must give their reasons for this (Scottish Executive, 2006).

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