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Why you should read this article

- To understand the complexities of communication when breaking bad news
- To develop self-awareness and improve confidence in your own practice when communicating bad news
- To count towards revalidation as part of your 35 hours of CPD, or you may wish to write a reflective account (UK readers)
- To contribute towards your professional development and local registration renewal requirements (non-UK readers)

Communication skills and breaking bad news to people with learning disabilities

Abstract

Breaking bad news is one of the most challenging aspects of the caring role and it is essential that practitioners have the skills required to support people with learning disabilities and their families effectively. This article discusses bad news and the experiences of people with learning disabilities. It considers barriers to breaking bad news and the importance of practitioners' own values and beliefs. Crucially, the article describes toolkits available to support practitioners and focuses on one to guide practitioners in developing their practice.

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Keywords

Communication, breaking bad news, ~~values~~, learning disabilities, person centred care,

Aim and intended learning outcomes

The aim of this article is to develop the knowledge and confidence of practitioners in breaking bad news to people with learning disabilities and to facilitate the exploration of the practitioners' own attitudes, beliefs and values in this challenging area. It will provide a platform for practitioners to develop their communication skills to apply to their day-to-day work. The article will be most relevant to registered nurses, nursing associates and healthcare assistants or support workers who provide care for people with learning disabilities. Throughout the article the term practitioner will be used in reference to anyone from these professional groups.

After reading this article and completing the time out activities you will be able to:

- Define 'bad news' and discuss the complexities and different perceptions around what can be considered 'bad news'.
- Identify specific challenges in breaking bad news to people with learning disabilities.
- Recognise the importance of parents, carers and an individual's support network within this process.
- Be aware of recognised models and toolkits to improve your practice when breaking bad news to people with learning disabilities
- Explore the role of the nurse or practitioner in breaking bad news to people with learning disabilities and working collaboratively with families.

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A note about language.

The focus of this article is breaking bad news of end of life or serious illness. In end of life and palliative care, the terms ‘difficult’ or ‘challenging’ conversations are often used (Costelloe et al 2018, Johnston and Beckman 2019, McMillan 2019). However, because people with learning disabilities require consistent and simple language, this article refers only to the term breaking bad news throughout.

Introduction

Breaking bad news is challenging for practitioners in any setting and can elicit complex emotions (Bousquet et al 2015). In learning disabilities settings, practitioners may have known the person for many years and built a strong bond with them (Tuffrey-Wijne and Rose 2017). We cannot guess the impact the news will have on each recipient as it will depend on their understanding and expectations (Baile et al 2000). In learning disabilities settings, breaking bad news can be complicated by legal and ethical issues such as the person’s mental capacity and a desire to protect them from distress (Tuffrey-Wijne et al 2013) but a lack of information may also be distressing. A study by Salander (2002) found that some oncology patients were made anxious by a lack of straightforward information, preferring to know the facts even if it was bad news. Similarly, Tuffrey-Wijne et al (2010) found that people with learning disabilities were upset when given no information at all.

However difficult, breaking bad news is a professional duty and the Nursing and Midwifery Council (NMC) are clear that engaging in difficult conversations, including breaking bad news, is a required proficiency of the registered nurse and nursing associate (NMC 2018). This article discusses some of the challenges in breaking bad news to people with learning disabilities, describes the skills needed and presents some of the models that have been developed to support practitioners.

Defining bad news

Bad news is often defined as “Any information which adversely and seriously affects an individual’s view of his or her future” (Buckman 1992). Bad news may therefore include a serious diagnosis, or the illness or death of a loved one, or a significant unwanted change such as a house move (Tuffrey-Wijne et al 2013). Whilst we focus on news relating to serious illness, death and dying here, it should not be underestimated that someone with a learning disability may categorise bad news differently. Learning of a change to a cherished routine, or the day centre being closed, may be more difficult since it has a more immediate and concrete impact than an illness that may affect them in the future.

Time Out Activity 1

Pause now to consider how you had defined bad news previously. What have service users you work with perceived as bad news and how did they react?

The experience of people with learning disabilities

McEvoy et al (2012) found that most people with learning disabilities had only a partial understanding of death and dying and a systematic review by Lord et al (2017) found that death is still taboo in learning disabilities settings and there is a culture of silence. People may be told what is wrong with them but are less likely to be aware that they are going to die (Tuffrey-Wijne et al 2020) and are less likely to be asked about their care preferences (Hunt et al 2020).

People are more likely to be told that they may die if they have cancer (Tuffrey-Wijne et al 2020) but cancer prevalence is lower in people with learning disabilities than in the general population (Hosking et al 2016). For some people with learning disabilities, it may be the circumstances around the diagnosis that are difficult, such as frequent hospital visits or being too ill to enjoy their usual activities, rather than the diagnosis itself (Tuffrey-Wijne and Watchman 2015). Unexpected death is more common in people with learning disabilities (Hunt et al 2019, Todd et al 2020), meaning there is less time for the person and their family, friends and carers to plan, and it is less likely that the person can die at home (Todd et al 2020). People with learning disabilities are not always given the opportunity to make choices about important decisions (Tuffrey-Wijne et al 2018, Noorlandt et al 2020).

People with learning disabilities are also less likely to be informed of the deaths of family members or friends, irrespective of ability (Tuffrey-Wijne et al 2020) or to be involved in funerals or other rituals (McRitchie et al 2014). Brownrigg (2018) concludes that there is a tendency to not disclose bad news to people with learning disabilities both in relation to disease prognosis and the illnesses and deaths of people important to them.

Barriers to breaking bad news

Breaking bad news to people with learning disabilities can pose several additional challenges due to cognitive and communication difficulties. The National Institute for Health and Care Excellence recommends people should be involved in decisions about their care (NICE 2021) but the capacity to make difficult choices affects how much people with learning disabilities are involved in shared decision making when planning end of life care (Noorlandt et al 2020). Prognostic uncertainty often makes conversations about death challenging (Anderson et al 2020) and this is more difficult if the person struggles to understand time periods. People with learning disabilities may have some understanding about what is happening now but remember little of the past and have limited concept of the future.

People may struggle to process and retain health information (Oosterveld-Vlug et al 2020), abstract concepts such as death may not always be understood and people may also have limited life experiences and missing ‘chunks’ of knowledge (Tuffrey-Wijne 2013). Breaking bad news can be especially challenging if the person also has dementia with worsening memory and a shrinking knowledge base (Tuffrey-Wijne & Watchman 2015).

Language is another consideration, with the use of complex language and jargon a barrier to understanding. The recent pandemic has led to an increase in breaking bad news over the phone (Collini et al, 2021), which will hinder understanding without the help of facial expressions, body language and assisted or augmentative communication methods. Environmental factors may include a lack of privacy, unfamiliarity or spaces that are cluttered, noisy, too bright or too dim for the individual, adding to processing difficulties.

Carers may be reluctant to break bad news because it is difficult for them or because they lack medical knowledge (Tuffrey-Wijne et al 2013), whilst professionals may lack knowledge or training around learning disabilities. Where someone struggles to understand the concept of death and dying, people can be less confident to plan and talk to them about this issue (Gallagher et al 2018) and may avoid it altogether if unsure how to best communicate with the person, or if unclear about areas such as consent and capacity (Kirkendall et al 2017). This lack of knowledge may explain why people with learning disabilities often hear bad news from carers rather than professionals, in contrast with the general population (McEnhill 2008).

Time Out Activity 2

What factors do you think might be different about breaking bad news to people who have learning disabilities compared to other people?

Practitioner's own values and beliefs

Practitioner's own beliefs and values can also impact breaking bad news. There are often several stakeholders involved with differing views. Families and carers may be concerned that their loved one with a learning disability would find the information too distressing, be unable to cope or lack resilience. They may want to hear the news first to decide themselves what to tell their relative, whilst professionals are more likely to think the person should be informed, which could lead to conflict (Tuffrey-Wijne et al 2013). Carers worry that disclosing bad news may cause harm (Tuffrey-

Wijne et al 2020) but not giving people all the information could affect their treatment decisions with potentially serious consequences (Tuffrey-Wijne et al 2010). Nondisclosure is often justified on compassionate grounds, but the reasons for not sharing bad news can be situated with the practitioner or family rather than the person themselves (Tuffrey-Wijne et al 2013). Individual staff attitudes and experiences can influence their willingness to talk about death and people from different cultures can have different perspectives (Tuffrey-Wijne and Rose 2017). It can be challenging to ensure practitioners are not making the decisions they think are right for the person (Gallagher et al 2018).

Time Out Activity 3

Pause now and reflect on your own beliefs, attitudes and values about breaking bad news. How might this affect how you would approach breaking bad news to people with learning disabilities?

Toolkits and protocols

Despite the challenges there is a growing body of contemporary guidance that practitioners can draw on, some of it specific to people with learning disabilities. The generic protocols and resources (summarised in Fig 1 and 2) can provide underpinning knowledge and support for practitioners; however, they need supplementing with more specific guidance when communicating with individuals with a learning disability.

Fig 1

Models for breaking bad news

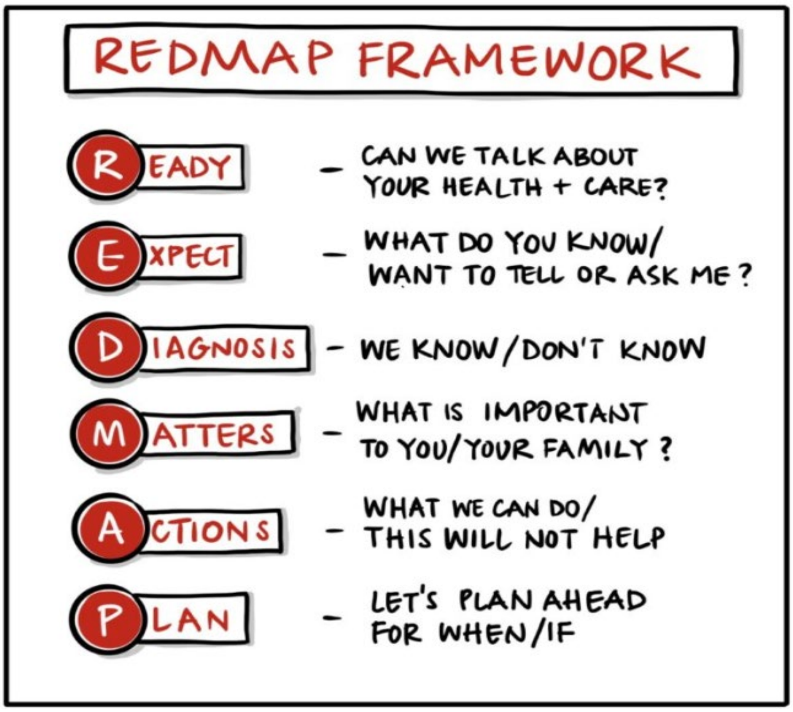
SPIKES protocol (Baile et al 2000) and **BREAKS protocol** (Narayan et al 2010)

- Both 6-step mnemonic approaches to conversations about death and dying
- Developed in cancer care but used more widely
- Both consider current level of knowledge, sharing information, gathering responses from patient, checking understanding and creating a plan

A comparison of the two above can be found here https://www.osmosis.org/blog/2021/03/15/breaking-bad-news-using-the-spikes-protocol-vs-the-breaks-protocol

REDMAP framework (Boyd K 2020)

Readily available resources for practitioners to access.



REDMAP FRAMEWORK

READY – CAN WE TALK ABOUT YOUR HEALTH + CARE?

EXPECT – WHAT DO YOU KNOW/ WANT TO TELL OR ASK ME?

DIAGNOSIS – WE KNOW/DON'T KNOW

MATTERS – WHAT IS IMPORTANT TO YOU/YOUR FAMILY?

ACTIONS – WHAT WE CAN DO/ THIS WILL NOT HELP

PLAN – LET'S PLAN AHEAD FOR WHEN/IF

https://www.spict.org.uk/red-map/

Fig 2

Useful additional resources:

Irish Hospice Foundation (2021) Toolkit for compassionate End-of-life care is a 5 step process. https://hospicefoundation.ie/wp-content/uploads/2021/01/IHF-Toolkit-for-compassionate-end-of-life-care.pdf

Macmillan (2019) 'Courageous Conversations' resource of useful phrases and words. https://macmillan.org.uk/coronavirus/healthcare-professionals/difficult-conversations

National Gold Standards Framework (2018) considers advance care planning more broadly.

https://www.goldstandardsframework.org.uk/advance-care-planning

Models specific to the learning disabilities field include the ADVANCE toolkit (Gallagher et al 2018) for end of life care planning with young people with learning disabilities. This is a values based toolkit covering the areas of: assumptions, dignity, vulnerability, autonomy, non-discriminatory practice, commitment and environment of care.

In the last decade Irene Tuffrey-Wijne has been a pre-eminent researcher specifically considering the communication and support needs of people with learning disabilities when breaking bad news. Tuffrey-Wijne (2012, 2013) proposed a model for breaking bad news to people with learning disabilities (fig 3) using 4 main components (building a foundation of knowledge, considering mental capacity and understanding, considering the people involved and identifying the support they need).

Time Out Activity 4

Pause here to consider the various models and access some of the resources. What aspects of these would be useful for you in your practice?

Using the Tuffrey-Wijne model to support practice

We will now consider the Tuffrey-Wijne model in more detail. This model is specifically for people with learning disabilities and is evidence based. Tuffrey Wijne's model (2012) is discussed further in her book (2013), which contains examples of the model in practice and is an excellent guide for carers and professionals, filled with case examples of people with lived experience. Because of the individual nature and needs of the people we work with, people's stories matter. They are the things that guide us and help build our confidence to try a new way with someone. Seeing how the model is applied provides the springboard for the practitioner to adapt to the circumstances they are in, allowing the breaking of bad news in a way that is systemic, whilst also person centred.

Building a foundation of knowledge

In order to build a foundation of knowledge, which is central to the model, we need to take opportunities whenever we are working with an individual and not just at the time when we need to communicate bad news. This involves ensuring people have a range of experiences, providing opportunities for them to make choices, identifying their ways of communicating and recognising that they may understand information through routes other than verbal (Tuffrey- Wijne 2013). Building a therapeutic relationship with the person and their family is crucial in such a sensitive area. Making time for people, being approachable, communicating consistent information well and being reliable are all key factors in maintaining the relationship (Wright, 2021). In building a relationship, we provide people with the language and permission to have ongoing conversations about what is important to them.

Building a foundation of knowledge can be a slow process and breaking bad news cannot be 'done and dusted' in one conversation or event. Verbal communication may only be a small part of how someone understands. Experiencing place, using pictures, photos and objects of reference could all be necessary. Breaking information down into chunks and using repetition can help develop knowledge over time, building on the experiences of the individual. Chunks of 'what is happening right now' may be the easiest to understand and this can be developed with chunks about 'what will happen in the future' (Tuffrey-Wijne 2012; 2013; 2015). Showing what remains the same in both these scenarios using visual format such as Talking Mats© (Cameron and Matthews 2017) can be reassuring to someone who dislikes change. It is important to use concrete language and avoid the use of jargon and misleading euphemisms. Both the words used, and the tone of voice are important when communicating with any patient (Ali, 2017; Barber, 2016) and sensitivity, tact and compassion are required. Ultimately, we may need to recognise that a person may not reach full knowledge about the nature of the bad news but that this does not have to stop us from sharing that news (McEnhill 2008).

Understanding

People with learning disabilities can have mixed views about the extent to which they want to hear bad news (Tuffrey-Wijne et al 2013) and so individual preferences should always be assessed. When hearing news, they want concrete and unambiguous information that is easy to understand (Tuffrey-Wijne et al 2013). Understanding will be pivotal in helping a person cope and underpins their potential for being supported to plan, if they choose to, in relation to the things that are most important to them. Even if nondisclosure is appropriate for an individual then this should be reassessed regularly, and the person should still be given support around their changing circumstances (Tuffrey-Wijne et al 2013). The person's capacity must always be considered and the principles of the Mental Capacity Act (2005) adhered to.

The People Involved

The third part of the model is to consider all the people involved. In contrast with the general population, it can often be down to family, carers or residential care staff to communicate bad news and they are often ill prepared or adequately supported (McEnhill 2008, Tuffrey-Wijne et al 2013). There is also often little attention paid to what the impact of the bad news may be on these individuals (Ibid). Death and dying are relatively uncommon in learning disabilities settings, compared to other care home settings and staff may lack experience in this situation, as well as training, possibly leading to a more complex bereavement (Todd et al 2020). Tuffrey-Wijne and Rose (2017) also highlight the challenges for staff members who may have known the person for many years.

Providing accessible and available information for caregivers who are not regularly working with that individual or supporting them to enlist the help of the people around that individual may be crucial. (Lewis et al 2017, Gallaher et al 2018). The family carer often knows the person best and is likely to be able to help with what goes unsaid as well as what is communicated (Gallagher et al 2018), how it is communicated, and in what order. The work of Tuffrey-Wijne (2013) has shown that consideration should be given to who breaks the news to the person with learning disabilities. If the bad news is medical, the nurse or doctor may be best placed as they understand the biological context, but the family or carer, with their understanding of the person and their communication needs, may help translate the information into a person-centred format. Even if a medical professional gives the news, it will be the staff or family carers who must continue to support the person with learning disabilities at home in developing their understanding and managing distress (Tuffrey-Wijne et al 2013). Rauf and Bashir (2021) highlight the importance of involving palliative care specialists and other member of the multi-disciplinary team as well as families and carers to ensure that best practice is implemented.

Time Out Activity 5

Write down what you think good practice would look like in collaborating with parents, carers and an individual's support network when breaking bad news.

Support Needed

.Whatever the extent of people's understanding about what is happening to them, we need to identify how best to support the person to cope with their changing circumstances. Finding out how people have coped with challenging circumstances in the past, either from the person themselves or their carers is important. People with learning disabilities can employ a range of coping strategies when experiencing stress (Burns & Lamparki 2016). Active coping (problem solving, finding information and seeking support) is seen as beneficial and can reduce psychological distress in people with learning disabilities (Goswami & Mohapatra 2015 Hartley & McClean 2005). Some people may be able to access cognitive therapies such as CBT (Giannaki and Hewitt 2020). Emotional support will be important and spiritual needs may need to be considered (Tuffrey-Wijne 2012).

Family and any carers working with the person will also need support to cope with the changes that are happening. A study into the coping strategies of paid and family carers looking after people with learning disabilities and dementia by Perera and Sanden (2014) found several coping strategies including solution focussed strategies, practical resources and getting help from others. Getting away was an important coping strategy, ranging from 5 minutes in the garden to weekend respite. Creating a narrative about the looked after person, their previous lives and their positive characteristics was a key theme and this is an area where practitioners can assist, by helping put together life stories, photo albums and care plans. If the family member is breaking the bad news, they should be supported by professionals and carers rather than left to do this by themselves. Working collaboratively, in partnership and having a key contact to liaise between the family and services is important (Michael 2008, Bishop et al 2015, Gallagher et al 2018).

Practitioners should continuously and deliberately reflect on practice in order to increase self-awareness, knowledge and insight (Anderson 2019) and improve future patient outcomes. Support from peers and managers and clinical supervision is key as practitioners often need permission from others, as well as themselves to self-care and be self-compassionate in this challenging role (Andrews et al 2020).

Time Out Activity 6

Identify how communication skills and breaking bad news to people with learning disabilities applies to your practice and the requirements of your regulatory body, if relevant.

Conclusion

Breaking bad news is an important but challenging part of care provision. Understanding the available models and toolkits can provide practitioners with the knowledge and confidence to engage in this complex activity. The Tuffrey-Wijne model (2012, 2013) provides a clear framework specifically to support good practice in breaking bad news to people with learning disabilities. Finding out what the person knows now and building on this, breaking information down into 'chunks' and relating it to the person's experience can help develop understanding over time. Considering all the people involved and the support each will need to cope with the situation is a key requirement. Each person with learning disabilities, and their families and carers, is unique, and flexibility is required with any model to ensure that care is person-centred. It is also important that practitioners continuously reflect on and in their practice to develop their skills in this area and that they allow themselves time for self-care.

Time Out Activity 7

Now that you have completed the article reflect on your practice in this area and consider writing a reflective account of your learning. See https://rcni.com/nursing-standard/revalidation/reflective-accounts/write-a-reflective-account-90981

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Fig 3

Tuffrey-Wijne, 2012