BREAKING BAD NEWS TO PEOPLE WITH LEARNING DISABILITIES AND DEMENTIA

Irene Tuffrey-Wijne and Karen Watchman provide guidance on communication informed by knowledge of the person’s understanding and capabilities

Abstract
People with learning disabilities are now enjoying a longer life expectancy than ever before as a result of enhanced medical and social interventions and improved quality of life. Some, particularly individuals with Down’s syndrome, are susceptible to dementia at a significantly younger age than the average age of onset in the rest of the population. Currently, there is limited guidance on how to talk to people with learning disabilities about dementia and, until such information is shared, individuals cannot be positioned as an authority on their own condition. The new model presented here suggests a way of supporting staff and families to have enabling conversations about dementia that centre on the person’s current situation, level of understanding and capacity.

Keywords
Breaking bad news, communication, dementia, disclosure, Down’s syndrome, intellectual disability, learning disability

BREAKING BAD news to someone with a learning disability is never easy. Add dementia to the mix and the challenge may seem insurmountable. In-depth studies of the experiences of people with learning disabilities who had cancer and those with dementia showed that breaking bad news and giving explanations about the illness to them was a major concern for all those involved (Tuffrey-Wijne et al 2010, Watchman 2014). Staff and families worry about how much people with learning disabilities understand and how much explanation they should be given.

People with learning disabilities continue to be protected from all kinds of bad news (Bernal and Tuffrey-Wijne 2008, McEnhill 2008) and difficulties remain in sharing a diagnosis of dementia even if everyone agrees that it should be discussed with the ill person. There are concerns that the person will not be able to understand, or that the news will be too upsetting. Sometimes the family opposes disclosure, or it may simply be that nobody feels they have the skills to break bad news. However, there is evidence that people with learning disabilities cope better with difficult situations, such as illness, loss and bereavement, if they understand them (Blackman 2003, Tuffrey-Wijne et al 2013). Bad news usually means that someone’s life is changing in some way, and people need help to understand these changes in their lives.

In this article, we aim to provide some guidance in helping someone with learning disabilities understand that they have dementia and the implications of this diagnosis.

We start from the premise that people with learning disabilities receive some support, and that it is provided with due consideration for individual needs and preferences, which could include the need or preference not to know. We will explain new
Guidelines for breaking bad news to people with learning disabilities (developed by the first author, see Box 1) and demonstrate how these guidelines can be adapted for use with people with dementia, using the real-life example of Alice (described by the second author) in the case study opposite. Alice is a pseudonym.

Bad news

Attitudes to breaking bad news. Half a century ago, doctors did not usually tell patients that they had a serious illness such as cancer (Oken 1961). Attitudes in Western societies started to change in the 1970s. Now there is an overwhelming consensus among healthcare professionals and patients that it is best to be open and honest about the diagnosis (Novack et al 1971, Seale 1991, Innes and Payne 2009).

It is widely understood that the way bad news is communicated can have a significant impact on how patients and families adjust to serious illness.

It has been found that patients with dementia in the general population do not experience a catastrophic emotional reaction when told their diagnosis; rather, they experience relief that there is an explanation for their symptoms and that a treatment plan can be developed (Carpenter et al 2008). There is no reason to believe that this would be any different for people with learning disabilities (Watchman 2013).

These early developments originated in the field of oncology. The change in attitude towards disclosure of a dementia diagnosis is more recent, but since the start of the 21st century there has been a shift towards thinking that early disclosure is beneficial to the patient, and is the starting point for medical and social interventions (Werner et al 2013).

National dementia strategies across all UK countries state that everyone should be given their diagnosis (Department of Health (DH) 2009, DH, Social Services and Public Safety 2011, Welsh Assembly Government 2011, Scottish Government 2013).

National Institute for Health and Care Excellence guidelines (2006) state that a diagnosis of dementia should only be withheld from someone in exceptional circumstances. Instead, discussion should take place soon after diagnosis to enable the person to be involved with future planning before their capacity and ability to communicate deteriorates.

How to break bad news. An overview of the process of breaking bad news in relation to someone with learning disabilities and dementia is shown in Figure 1, page 20.

What is the bad news? The following may seem obvious and perhaps even unnecessary, but imagine a scenario where a man with learning disabilities has never heard of dementia and has a limited capacity for abstract thinking. Telling him that he has dementia and will gradually lose his skills is unlikely to be experienced as ‘bad news’. It may be that for this person ‘bad news’ is being told that the swimming pool is closed or that there is no custard to go with the apple pie.

Bad news is ‘any news that drastically and negatively alters the patient’s view of his or her future’ (Buckman 1985). Someone’s experience of news as ‘bad’ is therefore dependent on their concept of time and future, as well as their capacity for abstract thinking. There is a need to establish not only whether this is actually ‘bad news’ for an individual, but also which aspects of the bad news they need to be helped to understand.

Framework of knowledge. Any new information needs to make sense to the person; it needs to fit in with their current understanding and experience of life. To do so, we need to establish what someone’s existing ‘framework of knowledge’ is so that we can build on it. To do this, we will need to try to stand in the person’s shoes. How do they see, experience and understand the world? Without a fairly detailed knowledge of someone’s experience and current framework of knowledge, it will be difficult to know whether, and how, new information will be understood and processed.

It can be helpful to break down someone’s current knowledge into chunks that fit into these three categories:

- Background knowledge. This can include, for example, knowledge about how the world works; general knowledge about illness and death; memories; life experience; knowledge about how
Alice is 49 years old. She has Down’s syndrome and has been diagnosed with dementia. She lives with her sister, Claire, and brother-in-law, Jamie, an arrangement that was agreed with Alice and Claire’s mother before her death three years earlier.

Alice attends a day centre three days a week. She is becoming agitated and recently started hitting friends and staff at the centre and crying for no obvious reason. At home she is becoming more confused and often sits quietly, whereas previously she was usually animated and sociable, and attended dance classes twice a week.

Day centre staff alerted Claire to changes that they had observed in Alice over a number of months; she no longer engaged with activities that she had previously enjoyed. When Claire thought about it she realised that she had noticed subtle changes herself, but had not realised the implications.

In fact, Alice had been showing symptoms of dementia for over a year before her family and staff realised that something was wrong. Advice was sought from the community learning disability nurse.

This led to further referrals and the process of making a diagnosis of dementia over a period of eight months. Claire and Jamie are unsure what to say to Alice about her diagnosis, or even if they should say anything at all.

The first step is to find out about Alice’s current framework of knowledge. Any new information will only make sense to her if it fits with this. We need to establish her understanding and experience of the following:

- Background information regarding dementia and illness.
- What she thinks is happening to her right now.
- What she thinks will happen in the future.

Figure 2 (page 19) depicts what Alice’s current framework of knowledge might look like. The next step is to decide which small, separate chunks of information can be simplified so that she can understand them more easily.

She has no awareness of what it means to have dementia, so using the words ‘dementia’ or ‘Alzheimer’s disease’ will not have meaning without further explanations.

It is important to focus on the immediate implications on a day-to-day basis. ‘I don’t like going to the day centre, it scares me,’ and, ‘something is wrong with me’ are examples of day-to-day issues. ‘I am scared of hospitals’ may become an issue as medical intervention increases.

Any discussion of the future needs to focus on these issues to ensure that Alice’s sense of wellbeing increases.

The third step is to give Alice new pieces of information, one by one, that fit in with her current framework of knowledge. While Alice’s background knowledge is correct, she associates her mother being ill and hospital stays with her subsequent death, so discussion about this will need to be handled sensitively.

Alice has indicated that she has concerns herself by asking: ‘What is wrong with me?’ At this stage, it will help Alice to understand that these changes and difficulties are caused by her illness – ‘You are not well’ – although the word ‘dementia’ should not be used without further explanation as it is not within her framework of knowledge.

The focus can then be on what it means for her on a day-to-day basis. This will reassure her that the changes she is experiencing are not her fault and that family, friends and staff will help her. She may have her own ideas about what this help should be.

It will also be helpful to address some of Alice’s perceptions about the future, as there may be choices to be made about attending the day service.

If she can think about relevant issues now, then she will have been helped to understand her future situation. In this way, Alice can be involved in her future care planning.

It is important to include all those who provide support for Alice in any discussions and for everyone to use the same words to describe her illness. For example, she may be able to arrive later and leave earlier at the day centre, which would avoid some of the busiest, noisiest times.

Everyone can help her build her framework of knowledge, although what is ‘current’ for Alice will change as dementia progresses.

The fourth step is to keep checking with Alice whether she still understands what she has been told, whether she needs to understand more, or if something different is needed. Rather than Alice’s knowledge and understanding growing, it will start shrinking. Those around her will need to rewrite Alice’s framework as often as is needed.

A particular feature of dementia is that older memories can become an experience of the present day. Alice’s memory of her mother may become more prominent; she may forget her mother has died. If this happens, there is no need to put that piece of knowledge back into her past by reminding her that her mother is dead, as this doesn’t fit in with her new framework of knowledge.

Correcting her can cause unnecessary confusion and distress. Instead, you can affirm her experience: ‘Yes, your mum liked to go shopping, didn’t she?’ or ‘Ah, you’re thinking of your mum, that’s nice,’ depending on the context of the conversation. Then you can change the subject: ‘Perhaps Claire can help you choose your new shoes?’ ‘Shall we make a cup of tea now?’

The most important thing is for Alice to feel safe and supported.
we and other people have been feeling in the past; or a concept of time. There may be many gaps in someone’s background knowledge.

- Knowledge about what is happening in the present. This includes both current events and current feelings. The knowledge framework of people with profound learning disabilities or advanced dementia may be limited to this; they may have little knowledge of the past or concept of the future.

- Knowledge about what will happen in the future. How much of the future someone understands will be influenced by their intellectual capacity, their capacity for abstract thinking and their concept of time.

Information about the person’s framework of knowledge should be gathered from as many people as possible; the insights of families and carers are of particular importance. Figure 2 shows a simplified example of Alice’s framework of knowledge.

**Break the information down** A seemingly simple statement, such as ‘you have dementia’, is actually very complex. It can include:

- Background knowledge. For example, ‘dementia is an illness of the brain’.

- Knowledge about the immediate implications on a day-to-day basis. For example, ‘I can’t find the toilet and it scares me’.

- Understanding of future changes. For example, ‘dementia gets worse, not better’. New information needs to be broken down into singular, distinct, small chunks. How small depends on the individual.

**Decide which chunks of new information to add** You then need to try to establish which of these chunks the person already possesses, which will make sense now, which may not make sense until later, and which are unlikely ever to be retained or make sense at all.

Having an understanding of someone’s current framework of knowledge will help to decide which chunks of new information to add. It is only useful to explain to someone that they have dementia if their ‘background knowledge’ includes an understanding or experience of dementia. You can then focus on the implication of the diagnosis for this person. But if someone cannot grasp the concept of a brain that can get ill, then there is no point trying to convey this information. You may need to simplify it to ‘you are not well’ (sticking to information about the present moment) and ‘it is not your fault’ (adding a small but important chunk of background knowledge about the nature of dementia).

Indeed, if background or future chunks of knowledge are absent, it may be best to stick...
with information about the present moment. One way of doing this is by affirming (and not denying or glossing over) worrying things that are happening (‘I can see you don’t like going down the stairs; let me take your arm and we’ll go together’ – or, if the person’s verbal understanding is limited, simply taking their arm in a calm and reassuring manner). This is particularly relevant for people with complex and profound learning disabilities, who often live life completely in the present moment and find it hard to link previous experiences to current situations or to anticipate the future.

Further important considerations include:

- Does the person like to think about what is going to happen tomorrow or next week, or do they live life day to day?
- Denial of bad news is a valid and important coping mechanism; it is important to respect this.
- How well does the person cope with anticipation, change and uncertainty? Usually, people need enough support to understand the current changes in their lives and benefit from being able to anticipate these changes in some way, but there are also people who find such anticipation too difficult. It makes them so anxious that they find it hard to cope; for example, they may be better off not knowing that they need to go to the dentist until the morning of the appointment.
- Always bear in mind the person’s capacity to understand. The laws on mental capacity must be adhered to. People should be given the best possible chance of understanding, so it is important to consider what and who they need to help ensure the best possible communication, and how information can best be given.

Give chunks of new information one by one

New knowledge, including an understanding of bad news, is not just gained through explanation and education, but also through experience and reasoning: ‘My mum had dementia and went into a nursing home; therefore if I have dementia I will have to go into a nursing home.’

For many people, including those without learning disabilities, ‘experience’ is a much more powerful way of gaining knowledge than an ‘explanation of facts’. It will help to have an insight into how the person usually processes new information. Does he or she benefit from verbal explanations, pictures, experiences, or lots of repetition? (Box 2, page 22)

The case study on page 19 offers an example of how Alice associates hospital with a negative experience because her mother died in one: ‘I didn’t see her, she went to hospital and didn’t come back.’ Alice’s concern is not about having dementia, as this has no meaning for her. However, fears will be exacerbated by activities that happen as a result (such as hospital appointments) because of her experience when her mother died. Alice may benefit from only being told about a hospital appointment on the morning it is due to take place, or it may be possible to arrange home visits or appointments in a clinical setting beyond the local hospital.

Staff and carers often worry that they are not the ‘right person’ to impart or consolidate new information. However, everyone with a significant involvement in the life of the person should be included and involved in sharing the diagnosis. They will all have a role to play in helping to understand the changes.

Check and reassess It is important to assess on an ongoing basis how much someone has understood, how their framework of knowledge has changed, and how their actual situation has changed. This will help to establish what other new knowledge needs to be added or explained.
Support for everyone The support needs of everyone should be considered; not only the needs of people with learning disabilities. Family and care workers may be particularly affected by bad news. Helping people with learning disabilities understand and cope with bad news is difficult, and everyone involved needs emotional, practical and spiritual support.

Box 2 Additional reading


Learning (Intellectual) Disability and Dementia website: tinyurl.com/nvgom18


How dementia affects knowledge Usually, someone’s framework of knowledge grows over time. However, when people have dementia, their framework is shrinking and their chunks of knowledge are gradually shifting. The boundaries between background knowledge and ‘what is happening right now’ may become blurred.

Knowledge that consists of memories can begin to disappear, especially those memories that are more recent. Background knowledge that consists of the person’s world view, or an understanding of how the world works, may also change. Values and behaviour learnt in recent decades may gradually disappear, leaving the person with an understanding that is related to a much earlier time in their life.

Additionally, knowledge that is expressed through life skills may also disintegrate over time. Knowledge and understanding of what is going to happen in the future, whether that is next year or tomorrow or in five minutes’ time, will also start to disappear. Over time, the ability of someone with dementia to understand or even experience what is happening right now will be reduced to an ever-decreasing window.

Assessing what and how much someone with dementia should be told about their diagnosis

References


needs a constant re-evaluation of their framework of knowledge.

If someone’s current experience and understanding is that their father is alive and present today, it is not helpful to insist on repeated explanations that their father is dead. Such explanations will result in unnecessary distress: it does not fit with the person’s current experience and it is a devastating chunk of bad news to be processed again and again.

During the earlier stages of dementia, people are likely to notice that things are changing for them. Without an explanation of the changes that are being experienced this can cause unnecessary distress that can be alleviated by explaining, in appropriate words or pictures, that this is part of an illness. Family, peers or a partner need help to understand this, too. (Some useful resources are shown in Box 2.)

An assessment of how someone with a learning disability and dementia can be helped to understand should include a consideration of future changes. The changes in someone’s framework of knowledge mean that their capacity to make decisions will gradually be lost, along with the ability to understand implications for the future.

Any involvement in decision making should therefore take place as early as possible, before such a capacity is lost.

Conclusion
In this article, we have discussed the challenges around sharing a diagnosis of dementia with people with learning disabilities. Understanding how to support conversations about dementia is complicated by a lack of guidance on how to break bad news to people whose cognitive function is limited and will deteriorate further due to their dementia.

We have explained new guidelines for breaking bad news to people with learning disabilities, and explored its use for individuals with dementia. In our case study, the guidelines were helpful but further evidence from practice and research is needed to refine them and to understand how they can best be used in practice.

Feedback
The authors welcome any feedback on this article and are interested to hear practitioners’ experiences.