Communicating with people who have dementia can be challenging, but strategies based on understanding dementia can help health professionals provide supportive care.

Improving communication in dementia care

In this article...

- Why ‘brain failure’ is used to describe dementia
- Communication challenges associated with dementia
- Framework for communicating with people who have dementia

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Abstract

Murphy J, Maidens G (2016) Improving communication in dementia care. Nursing Times; 112: 29/30/31, 18-21. Recognising and accepting the brain changes that cause dementia can help professionals and carers to develop and adopt suitable responses and methods of communicating with people who have the disease. This article looks at different types of conversations that can occur with people who have dementia and suggests strategies that encourage and support communication aiming to meet their needs.

Caring for people with dementia can involve having difficult conversations, and choosing the best response to avoid causing distress can be challenging. There may be times when it is hard to know what to say, when the person is describing situations or circumstances that are difficult to believe, or you have no way of knowing they have actually happened.

It is important to understand why people ask certain questions in order to know how best to respond and offer recognition, respect and build trust. This article aims to increase understanding how these situations originate to enable professionals and carers to develop ways to communicate with patients while preserving their identity and keeping them safe.

What is dementia?

‘Brain failure’ was a term used to describe dementia in the 1970s that fell out of favour because of its associated negative connotations; however, there appears to be a revival in its use (Coope and Richards, 2014). The Department of Health (2014) refers to dementia as brain failure that is similar to failure in other organs, and says “dementia is chronic brain failure and delirium is acute brain failure”.

For example, in heart failure the heart has been irreparably damaged by a disease process or condition and cannot function in the same way that a fully intact heart can. The organ in question is not fully functioning and is likely to deteriorate further over time and may lead to death. Brain failure is no different in that respect. Dementia is the recognised umbrella term that describes the symptoms associated with brain failure and has become commonly used as the term for the condition.

Although we use a more sensitive terminology for the syndrome (dementia) an awareness of the notion of brain failure helps us to understand what is happening. Another way to view dementia, particularly in the earlier stages, is as brain change; where a disease process or condition causes changes in the structure and function of the brain that produces the symptoms associated with dementia. This approach is endorsed by Teepa Snow, an occupational therapist and dementia education expert whose philosophy is to promote a positive approach to brain change. If the structure of the brain is changing as a result of the damage caused by the condition then the way the brain functions will also change. Recognising and accepting these changes will make it easier to respond to people with dementia as their behaviours change (Snow, 2016).

Keywords: Dementia/Brain failure/Communication

- This article has been double-blind peer reviewed
We would not hold people with heart failure responsible for any symptom relating to their failing heart, such as shortness of breath. We accept they are a consequence of the failing heart and try to identify coping mechanisms to ease the burden on the patient. This notion needs to be applied to people with dementia; they should not be blamed for symptoms associated with their failing brain but supported to accept the symptoms as a consequence of the brain failure.

Brain changes can also explain why people with dementia sometimes have moments of insight or suddenly regain abilities that were once second-nature. In these cases, they are not ‘making it up’ or ‘aware of what they are doing’ – the brain is a complex organ with multiple factors involved in its makeup and functioning. These moments of insight or sudden ability are episodes where the synapses in the brain suddenly function almost normally. When patients revert to their post-dementia state, it is a consequence of the intricacies of the brain’s decline.

Understanding symptoms

The term ‘behavioural and psychological symptoms of dementia’ (BPSD) is used to describe symptoms of disturbed perception, thought content, mood, emotions, feelings or actions that frequently occur in dementia. Approximately 90% of people who have dementia will experience BPSD at some point (Alzheimer’s Society, 2011). The term can cover numerous symptoms, which are often typical of the condition but may be experienced intermittently or frequently; the experience is unique to the individual.

Behaviours associated with dementia include wandering, aggression and hoarding. The term wandering is contentious as it suggests people with dementia are aimlessly pacing with no purpose. There are other forms of BPSD for carers include dealing with conversations that may provoke an unexpected response in people living with dementia. For example, it may be difficult to know how to respond when an 80-year-old woman asks where her mother is. Should you tell her that her mother is dead? What is the moral or ethical response? What response is the most appropriate for that person? Supportive and empathetic responses to these conversations, using sensitive communication approaches, may reduce feelings of distress and anxiety, therefore reducing the risk of escalation to less desirable behaviour.

Types of conversations

Some of these conversations may lead to patients displaying other forms of BPSD. For example, when patients ask to see a dead relative or express a desire to go home when they are already there, if they do not receive a satisfactory response to their question or request, they may leave the building to search for the relative or to find their home. These behaviours are generally attempts to express an underlying emotion. Patients may be feeling vulnerable but unable to express those feelings in a rational manner that people around them understand. If these emotions are not acknowledged and are allowed to intensify, the behaviours may start or worsen.

Table 1 lists examples of unmet needs and how to respond. It is useful to consider the potential reasons for patients’ questions or behaviours and to respond appropriately so any potential unmet needs are acknowledged and accommodated where possible.

In addition to the example mentioned above, of asking about loved ones who are no longer alive, patients with dementia may make statements about a caring role that they have held in the past, for instance: “I need to fetch my children”

This communication may well be an expression of patients’ emotional state. For many people, the maternal bond is a comforting and reassuring one, so person with dementia may ask for their mother because they feel anxious or emotional, needing comfort and reassurance, or a loving response that makes them feel secure. The need to be near their children may also be an expression of the need to feel loved and secure (Stokes, 2002).

However, some expressed statements may have a different underlying motivation, so it is important not to assume, for example, that a comment about children is an expression of the need to feel love and warmth. It may also be evidence of a retrieved memory linked to a confusion of orientation to time and place. Patients may be reliving the time when they collected their children from school and may experience that urge to fulfill their parenting role.

As another example, some people may have always found it difficult to use an unfamiliar toilet to have a bowel
Delusions are a psychological symptom of dementia and can cause concern for carers. Movement and may have only felt comfortable using their own toilet at home. A desire to go home might therefore stem from a need to have a bowel movement; asking to go home is a way of communicating that need. It is important to respond in a way that acknowledges the attempt to communicate so that the person feels valued and listened to.

**Repetitive phrases**

Some people with dementia might verbalise repetitive phrases such as:

- “Help me, help me”
- “Nurse, nurse, nurse...”
- “Where are you? Where are you?”

These phrases are often a source of frustration for others as it is difficult to know how to respond and the repetition can be annoying, but they may well be an expression of an unmet need. Constantly repeating “help me” may not necessarily be a request for help – these words may be the only words the person with dementia can bring to mind when other vocabulary is lost.

**Delusions and confabulations**

People with dementia may be able to tell a story with such gusto that they convince you it is true, even if you have evidence to the contrary. This may be where the brain has used older memories to plug a gap in more recent memories, creating an explanation or a situation that has a sense of reality for the person telling the story (confabulation). Alternatively the person may have a fixed belief, created from perceived facts of a situation where there is no potential to rationalise these beliefs (delusions). An example of confabulation is a person with dementia talking about having spent the day going out for tea and chatting to old friends in the street, when there is no way that this could have happened. This occurs when the person has no recollection of what has just happened and uses past memories to create context; when questioned, the person is able to give an account of a full day’s activities.

Delusions differ from confabulations in that they are false beliefs that originate from an incorrect inference about an external reality; the person with dementia firmly believes the delusion despite any proof to the contrary. Delusions may include such statements as:

- “My money has been stolen”
- “These nurses are trying to poison me”
- “The postman came in and had sex with me”
- “My daughter has threatened to kill me”

When people with dementia ask to go home, try to avoid saying “you are at home”, or “you can’t go home until you are better” – these responses are arguing with them or devaluing what they are saying to you. Consider the emotions behind what they have said; it may be an attempt to communicate an unmet need, so try to offer reassurance or act to meet the need and help them to feel secure. Tell them you know how they are feeling and that you want to help.

Try to provide comfort by using words or activities that will make people with dementia feel less lonely and anxious. Remind them you are there to help them. Reassure them that you know how they are feeling and that you want to help.

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**“Try to comfort the person with words or activities that will make them feel less lonely and anxious”**

It is important not to argue with people who have dementia. As Andrews (2015) highlights, one of you will invariably be wrong and the other will not like it. If a person is re-telling a story that is unlikely to have happened but is unlikely to cause anyone upset then there is no point in correcting them. Instead you can use the topics in the conversation to start new threads, such as “did you used to enjoy going on day trips?”

Even when they are expressing delusions it is important not to argue or try to correct people with dementia, or to rationalise accusations by providing evidence that disproves them. This will only increase the sense of distress and create
negative feelings that may escalate behaviours. It is important to validate how these beliefs might make the person feel but it is just as important not to collude and reinforce these beliefs. Perhaps try apologising: “I am sorry that this is happening to you, you must feel very worried”.

Offering to look for a ‘stolen/lost’ item may help if it is in the vicinity. Another suggestion may be to say, “I understand that you believe that the nurses are trying to poison you, this must make you feel very frightened”. Give the person time to process this, then say “I am here to help you and care for you”. This response enables the person to know that you care.

Try to remember that people with dementia are in their own reality. They are making sense of their own world, and need understanding, compassion and responsiveness, acknowledging their sense of reality and adjusting our approach to communicate. If there is no need to draw attention to what they are saying, then do not. If what they are saying is an attempt to communicate something they need, respond appropriately, intuitively and with curiosity to find out what it might be. That way their needs are more likely to be met successfully and any potential distress avoided.

Blackhall et al (2011) developed the VERA framework specifically for health professionals working with people who have dementia. This useful tool describes a stage-by-stage process of communication that helps professionals to respond in a sensitive and compassionate manner. Validation, emotion, reassure and activity are the core concepts of the framework and encourage the professionals to acknowledge what the person living with dementia is saying, and respond to the underlying emotion that may be expressed to give reassurance and offer activity to underpin the reassurance. Table 2 gives examples of how the framework can be used in practice.

Safeguarding

Situations like those described here can be challenging because while they may well be delusions, the person living with dementia is potentially at risk; this means health professionals must seriously consider any associated safeguarding issues that may arise. Unfortunately, there is no straightforward explanation or guidance relating to safeguarding adults at risk with dementia, so it is important to be aware of safeguarding guidance in your organisation or area (Griffith, 2015). Consider whether a referral is required in response to some of the conversations you may have. Fortunately, health professionals rarely have to make these decisions in isolation; advice is available and the right course of action can be a joint decision.

If you feel that a situation should be investigated further, it is vital to discuss this with colleagues and make appropriate referrals. Any conversations that give rise to potential safeguarding issues must also be documented.

Conclusion

Unfortunately, there is no single solution for how to respond to people with dementia when they say something that challenges or causes concerns. However, it is important to consider that any attempt to communicate verbally might be an expression of a need that is currently unmet.

The Alzheimer’s Society (2013) has produced a useful factsheet on communicating with people with dementia, suggesting that speaking in a calm, clear voice, respecting personal space and using short, simple sentences is a positive way forward. Detective work is often needed to work out what this need might be, and that may be more difficult than it sounds. However, acknowledging the attempt to communicate and the underlying emotion is an important response. Talking to family and understanding how the person usually communicates may provide a clue to underlying unmet needs. Overall, a compassionate and sensitive response is more likely to result in a successful outcome and help people with dementia to feel valued and supported in an unfamiliar environment.

References


For more on this topic go online...
- Bit.ly/NTDementia1
- bit.ly/Helpingfamily
dementia
- Bit.ly/NTHelpCarers

**TABLE 2. VERA IN PRACTICE**

<table>
<thead>
<tr>
<th>Validation</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gives value to a person’s behaviour, rather than just ‘blaming the dementia’</td>
<td>“You are looking for your mum Jean?”</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Emotion</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pays attention to the underlying emotion being communicated</td>
<td>“You sound worried”</td>
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<table>
<thead>
<tr>
<th>Reassure</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Using words or actions to give renewed confidence that the person is safe</td>
<td>“You are safe here Jean”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Activity</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Engaging the person in a more structured activity to offer a degree of occupation and maintaining their sense of identity</td>
<td>“Come and help me take these cups to the tea trolley”</td>
</tr>
</tbody>
</table>

VERA devised by Blackhall et al (2011)