UKHCA Article

Dementia care – How to deal with the challenges of communication

July 2012

Prepared for UKHCA member organisations by:

Jennifer Roberts, UKHCA Dementia Lead and Consultant

United Kingdom Homecare Association Ltd
2nd Floor, Group House
52 Sutton Court Road
Sutton
SM1 4SL

Telephone: 020 8661 8188
E-mail: policy@ukhca.co.uk
Website: www.ukhca.co.uk

Company Registration Number 3083104
Registered in England

© United Kingdom Homecare Association Limited 2012
Dementia care – How to deal with the challenges of communication

Jennifer Roberts, Dementia Lead for UKHCA, looks at the communication challenges in caring for a person with dementia – and offers some practical tips for care staff, in the first of two topical articles for Homecarer magazine (in May and July 2012 editions respectively).

Communication is something many of us take for granted. In fact it's a very complex process. Speech involves choosing the right words and forming them into sentences.

To have a conversation we need the ability to listen, understand what is being said - and to be able to ask and answer questions.

Concentration is also critical in allowing us to follow and participate in conversations or discussions.

How do we communicate?

When you ask this question, the most common answers are talking and writing. But body language and emotions - and art and music – are also powerful ways of communicating.

Most people believe that verbal (or vocal) skills are only about talking. But they also relate to the words used, the tone they are said in and the speed at which they are spoken.

Non-verbal (or visual) skills relate to body language - our facial expressions, posture and emotions.

Research suggests that more than half of communication is visual. How many times have you expressed your feelings more effectively when using a particular look or expression? When we question what we are being told, it is often the body language rather than the words that make us uncomfortable.

A person with dementia may well struggle to find the right words or understand what is being said, but may have strong emotional senses.

Consequently, the person may focus on your body language - thus making face to face interaction vital.

Communication difficulties in dementia
Communication difficulties are one of the earliest signs of dementia. A care worker may notice a person having difficulty in finding or pronouncing the right words, losing the thread of a sentence or conversation and repeating words or questions.

The person may struggle to follow a TV or radio programme or have difficulty reading a book or paper.

The person may become quiet and withdrawn or very animated (for example, inappropriately interrupting conversations by talking over people or making whistling or other noises to gain attention). As the dementia progresses, verbal communication becomes more challenging (we will explore this further in the next article for Homecarer).

How can you help?

**The verbal handshake**

Positive face to face interaction is critical. You need to attract the person's attention and clearly introduce yourself. Make sure you have eye contact (sometimes a gentle touch will help with this). Call the person by their name of choice and use it frequently at the beginning of sentences or in conversations. This acts as a clear reminder that you are still communicating and will help the person to concentrate on what you are saying.

Background noise can make it difficult for a person with dementia to hear what you are saying. So try to remove or reduce as much noise as possible (for example, turning down the TV or radio or closing windows).

But remember that you are in someone's home - so always ask before taking any steps to reduce background noise. Be aware of your body language. Don't rush. Be sure to smile and offer reassuring gestures.

**The conversation**

To encourage understanding when communicating, don't just rely on verbal communication. Make use of visual and auditory clues. Be patient, calm in manner and reassuring in your tone of voice. Try to talk clearly at a slower pace (but not in a patronising way) and look speak.

Offering choice is good. However, a person with dementia may become anxious and confused if offered too great a choice. For example, if you said to the person: "what would you like to wear today?" the choice is too wide. It would be much better to offer a limited choice (for example, "would you like to wear your white shirt or your blue shirt today?"). And if you have the clothes in your hands and point at them at the same time, you are giving the person plenty of prompts.
Try to keep sentences short. Avoid long, complicated sentences that may be difficult for the person to follow. Give the person time to think. Don't jump in to finish a sentence or find a word the person may be struggling to find. If you do, be prepared to repeat, rephrase, or summarise what you have said to make sure you have made the right assumptions.

Be a good listener and be aware of the person's expressions and mood. It is often easier for a person with dementia to talk about the past than try to remember what they did a few hours ago or the day before. Encouraging them to talk about the past may help trigger positive communication on current issues that may be important to them (for example, how they are feeling, things they would like to do and visits they have to make).

If verbal communication is difficult, consider writing or drawing to encourage a response. Music is another great way to communicate. It can lift a person's mood, particularly if you know the person's favourite song or piece of music. It can also help break down any barriers that may be stopping or hindering communication.

**The verbal goodbye**

Make sure when you leave someone's home that you say goodbye - so they know for sure that you have left and are not thinking you may be in another room. If you are due to visit later, make it clear when that will be (for example, "I will be back this afternoon at 2 o'clock" and leave a note close by rather than say "see you later"). Leave the person with a smile. You may be the only person they see that day.

Communication is important. It stimulates the brain and can reduce isolation. It can also leave the person with a good or bad feeling. It takes the same time to have a good conversation as it does to have a bad one, so those caring for people with dementia should strive to leave the service user with a positive frame of mind.

**Dementia care – Understanding and responding to challenging behaviour**

Jennifer Roberts, UKHCA Dementia Lead, looks at how difficult behaviour can present substantial challenges for care workers – and offers guidance on how to deal with it, in the second of two articles on communication.

Our behaviour – good, bad or indifferent – is a clear expression of our feelings and needs. It’s a form of communication and will be demonstrated in a myriad of ways.
Before we think about challenging behaviour in people with dementia, let’s think about our own behaviour. How do you behave when you are happy, sad, frustrated or angry? When you have behaved badly what caused it? What did you do? How did you behave or express your feelings and what happened that helped you to resolve the situation?

Memory, concentration, communication and the ability to reason things out or make sense of what is happening are often impaired in people with dementia. Some challenging behaviour is as a direct result of the type of dementia the person has (e.g. someone with frontal temporal lobe dementia can become extrovert, aggressive in speech and behaviour and lose their natural inhibitions). The most challenging behaviour is not related directly to the type of dementia; it occurs when a person with dementia has a need we are not meeting or is trying, perhaps unsuccessfully, to express their feelings.

**Common signs of challenging behaviour you may experience while caring for a person with dementia**

There are many forms of behaviour that can challenge you when caring for a person with dementia. You may find they repeat things over and over or ask you the same question several times (for example, “I want to go home” or “Where is my mum?”). They may become un-cooperative, push you away, become irritable, agitated or aggressive while you are trying to provide care or support for them. You may feel uncomfortable if their mood changes and they start shouting or swearing at you or appear to have no interest in themselves or their care. They may pace around or wander off.

Some people with dementia experience hallucinations (seeing things that aren’t there). This can be difficult behaviour to understand, especially if time with a person with dementia is limited.

**What might be the cause of the challenging behaviour?**

There are many reasons that might cause a person’s behaviour to become challenging. To understand or make sense of challenging behaviour, as care workers it is important that you try to see things from the perspective of the person with dementia. The person may:

- Be frustrated, fearful or stressed
- Feel lonely or be suffering from pain and discomfort
- Misunderstand what is happening
- Feel ignored, overlooked and not in control of their life
• Feel disorientated

All of the above can lead to challenging behaviour. The more you know about the person with dementia you are caring for, the more likely you are to understand the message behind their behaviour. It is therefore very important that you see and understand the person behind the dementia (that is, what makes him or her tick, what they have done in their lives, personal likes and dislikes and important relationships). For example, if the person you are caring for spent their working life as a teacher they may prefer to stand up and walk around as they did in class or you may see them become very active around lunchtime or when school has finished. You can make sense of this behaviour if you know their background and by working with and around it you can reduce the risk of it becoming challenging.

Sometimes you may experience challenging behaviour because of a change in roles. A wife who has cared for her husband and children all her life may find receiving care difficult.

Sometimes challenging behaviour is as a result of a memory being triggered that produces a reaction while you are providing care and support. On other occasions it may be related to surroundings. For example, a person with dementia sees their reflection in a mirror and does not recognise themselves. This can lead to anxiety that another person is in the room. Net curtains blowing in a breeze can cast shadows across the floor, perhaps giving the impression that someone – or something else – is in the person’s home.

How can you help?

• Stay calm and don’t take challenging behaviour personally – it is rarely aimed at you as an individual;

• Show that you recognise and understand the person’s feelings;

• Use reassuring words and speak in a calm, respectful manner;

• Avoid making the situation worse (perhaps stop the activity you are doing and try something else);

• Focus on what they are able to do well rather than on things they find challenging.
You may recognise the message behind the behaviour and feel you can offer a solution (perhaps a person who is pacing up and down, and banging on the window, is feeling frustrated or trapped inside and may just want to go outside). By taking the person for a walk you may reduce their anxiety and frustration and release energy. It is important at all times to respect their personal space and maintain their dignity.

**What do you do if a challenging situation occurs?**

Think about what happened just before the behaviour changed. For instance – who was there, did something you said trigger an angry response, did you speak too quickly, ask too many questions or ignore or talk over them? Did anything in the person’s surroundings change? Could difficult behaviour be down to something you did (for example, approaching the person from behind, perhaps startling them, or touching or moving a part of their body that may be painful). Could the behaviour be related to the person’s history or personal preferences? Perhaps you are trying to put them to bed when their favourite programme is on, or maybe you are talking when they are trying to listen to the news.

**Observe and record**

It is important to observe the behaviour you are seeing and record it. Be specific, using descriptions rather than one word. It is not enough to say a person was angry. That can be interpreted differently by different care workers. You need to describe how they expressed their anger. By describing what you saw it will make it easier for another care worker to recognise the signs more easily.

**How did you resolve the situation?**

Care workers often work alone. It is important to record how any situation involving challenging behaviour has been resolved. Make sure you describe what actions were taken and how the person responded. Their personal care plan can then be adapted to meet their needs and reduce the number of situations where challenging behaviour may occur – a more satisfactory outcome for all concerned.

**Jennifer Roberts**  
**UKHCA Consultant**  
**dementia@ukhca.co.uk**