Deaf and dementia: Coping with changes to communication and behaviour (BSL)

Transcript in English

Carolyn: It's important for us to remember that life doesn't end when dementia starts. People with dementia can still experience joy and happiness. They may still be able to work, drive or have relationships.

What they can do and how long they can do it for will depend on their particular circumstances and what they might be struggling with.

If we think about all the different symptoms of dementia that we discussed in the last film, what can we do to support someone who might be struggling with some of those symptoms?

Clark: first let's look at perception or seeing things differently. Try to put yourself in the shoes of the person with dementia. Remember they are an individual with a whole history of memories they might be utilising to help them make sense of their current confusion. Look at their behaviour – are they anxious? What could they be seeing? What could their brain be interpreting? Avril Hepner from BDA Scotland has some useful advice on how to support someone with dementia who might have trouble with perception or interpreting what they see.

Avril: *If you know someone with dementia who might be struggling with interpreting and understanding what they see, try looking at some basic changes to their environment that could help. Can they see you clearly? We always think about not signing in front of a bright light or window, but also consider whether light is evenly distributed across the room – if the person with dementia is also having problems with perception then they might be judging shadows differently. Pools of light and shadows can be really confusing. Could they be seeing something that worries them – like thinking a black mat is a big hole? Or a shiny floor is covered in water?*

Colours can be really important for someone with dementia who is experiencing problems with their perception. Think about the colour contrast in rooms that they use frequently - red and yellow spectrum colours are particularly useful. Maybe their bathroom has cream walls, a white toilet and handbasin, and a pale floor so putting something like a bright red toilet seat on the toilet can help to show them where the toilet is.

Using pictures or objects as well as signs can be useful in your conversation. This can also help someone with dementia to find where things are located in their home to help them stay independent – this could be putting pictures of cups or tea bags on the kitchen cupboards or a picture of the toilet or shower on the bathroom door.

Clark: If we think about communicating, someone with dementia could also get confused about which signs to use. You might need to ask the person with dementia to slow down, especially if they are using signs you are not familiar with – they might be remembering signs they used years ago. Repeat back to them if you are not sure whether you have understood correctly. Remember to allow them plenty of time to respond and try not to interrupt or guess what they are trying to sign as this can make the person even more frustrated and break the pattern of communication.

Carolyn: Should carers also think about the speed of their own signing?

Clark: Yes, it's very important. Slow down if it helps, use shorter, simpler sentences. Communicating can get difficult over time as the person's dementia gets worse. This can be very frustrating for them but also for their family, friends and loved ones. Many carers find it hard to stay calm – don't be too hard on yourself if this happens but try to think of ways that you could support the person with their communication. Get their full attention before you start – phones and screens can be very distracting! Also keep eye tests up to date and their glasses easy to reach and clean.

Carolyn: What if you feel yourself getting frustrated?

Clark: Staying calm will help the person to relax – remember they are probably getting frustrated as well. Think about your body language and keep eye contact. Try to avoid speaking sharply or raising your voice – leave the room if you need a break until you feel calmer.

Don't be afraid of using physical contact to reassure the person and show you care. You can give them a lot of reassurance by holding their hand or putting your arm around them if it feels appropriate.

Carolyn: what about if someone is struggling with their memory?

Clark: Again, try putting yourself in their shoes. Remember that short-term memories are often affected first. What do you know about the person and their past? This can help you to understand what memories they might be using from earlier in their life to help them in their daily life now.

For example, if a person with dementia wants to make a cup of tea but the memories they are using to help them are from when they were in their 20s, they might expect to find the same kitchen they used when they were that age.

Carolyn: Everything would be different! What would they do?

Clark: They might expect to see more old-fashioned appliances like a 'whistle kettle' – and this might lead them to put the electric kettle on the stove. You might think 'that's dangerous!' and take it off them. But try to think 'Why did they do that?' 'What are they remembering?'

It will depend on their abilities and what they can manage safely, but could you buy them a ‘whistle kettle’ instead of stopping them and making the cup of tea for them? It’s really important to remember if you do something for the person when they **could** do it themselves, they will lose confidence and get frustrated.

Carolyn: But even if the person gets frustrated, they are just going to forget what happened aren’t they?

Clark: They might forget the facts about what happened but the feeling of being upset will stay with them for longer.

If we think about two different memory stores in the brain, one that stores factual memories like names, faces, dates and another that stores the feelings about what we experience – did it make us happy, worried, sad? As dementia progresses, the factual memories will get more damaged but the emotions that you felt at that time will stay with you for longer.

Trudi Collier, Psychotherapist and Counsellor, has a helpful explanation of the way dementia can affect the brain.

Trudi: *Hello. I’m going to talk to you about a metaphor I often use, linked to filing cabinets.*

A filing cabinet is full of lots of different files and we can imagine our memories as being the same. Each file represents a memory, going right back to childhood, through our youth, up to the present day. Everything is filed in order and as we go on we make new memories, or files.

When you have dementia, those memories that were recently filed become lost until gradually you can only remember your earliest memories, things that happened when you were a child.

But our metaphor, of the filing cabinet, does not work in the same way for emotions and feelings. When you open your filing cabinet and think back to your younger days, you can probably recall different emotions you felt too. Maybe you remember being excited about going to school and learning. Maybe you recall feeling motivated and enjoying your time there. Through life we experience many emotions, both good and bad, and they are all filed in our cabinet, along with our memories. The most recent files are the things that we most recently experienced.

When you consider the filing cabinet of a person with dementia however, although they are losing their memories of recent events, and their filing cabinet is gradually emptying, their recollection of emotions that they have experienced is still there. They don’t lose this in the same way as they lose their memories. So, they may not remember what happened, but the emotions are still there.

So, for example, if you went to visit a person with dementia and had an argument with them because they couldn’t remember your name or who you were, and they became agitated, you might think that wouldn’t matter, because they won’t *remember. However, whilst they may not remember the argument, the emotional impact will still be there. They may still be left feeling upset, distressed or depressed.*

The same thing is true of positive interactions. For example if you took them, as I did with my mum before, to a café for tea and cake. My mum used to love eating carrot cake and I knew after any little trips like this that although she would soon forget our visit to the café, she would be left feeling positive and happy.

So remember, memories may go as dementia progresses, but emotions and feelings can remain for longer.

Clark: It is not a scientific explanation, but it is a really useful way of remembering that you can still help someone with dementia to have a joyful positive time – even if they forget the facts about what you did together afterwards, they will remember the feelings of happiness and feeling safe and loved for much longer.

Carolyn: Are there other tips to help someone in their daily life if they are struggling with their memory?

Clark: Yes. Try to keep things simple – focus on one task at a time, and break it down into small steps.
Try collecting everything you will need together before you start – e.g. tools for gardening or ingredients for a recipe.
Take things slowly if you need to and try to cut out distractions like the TV or your mobile phone.

Carolyn: Does repeating things make them easier to remember?

Clark: Routines can really help – if you try to do the same things in the same order at the same time each day or week.

You could also try memory aids such as photos to help you talk about what you have done together. Celebrate what you can still do and still remember – there will be many things that you are able to do that you learned in the past.

Remember all of these tips are to help you feel more confident in supporting someone with dementia to stay as independent and involved with the things they love doing for as long as they can. The key message is to remember that **with the right understanding and support it is possible for someone to live well with dementia**.