Deaf and dementia: Staying as independent and healthy as possible (BSL)

Transcript in English

Clark: We have looked at what dementia is, what the symptoms are and how to support someone to cope with the most common problems they can face. But just because someone develops dementia doesn't mean they lose all of the things that made them become who they are.

How can we support someone who is Deaf with dementia to stay connected with the things that matter to them?

Carolyn: There is more to the person than the label 'dementia'. Just like our fingerprints we are all unique – we have different beliefs, interests, achievements, likes, dislikes...

Staying in touch with friends, family and people we care about is really important. They maybe can continue going to Deaf Club and meeting friends, or other social activities but they may need some support and understanding to help them if they find certain things difficult. They may choose to do new things.

A lot of people worry about staying independent. You might not have to stop driving straight away just because you have dementia, but you **must** tell the DVLA and your insurance company. Dementia will eventually stop you driving. You can also apply for a Blue Badge parking permit for you or your carer.

If managing money and remembering your PIN is difficult, banks can give you a 'chip and signature' card. Plan ahead. Make sure your Will is up to date and put your important paperwork in a safe place – speak to someone you trust to help you. This could really help reduce stress for you or your carers in the future.

Think about setting up a Lasting Power of Attorney so someone you trust can make decisions on your behalf if you are no longer able to. There are two different types – one for health and welfare, and one for property and financial affairs. You can also set up an Advance Decision or Advance Statement to let you have a say in your future medical care.

Clark: What can help family members and carers?

Carolyn: It is easy for carers to become isolated. Sometimes it is hard to ask for help or accept help that other people offer. It is just as important for carers and family members to go to regular activities and see friends – zoom or video call if you can't meet in person.

Being a carer can be very tiring and lonely. If you know a carer, invite them to come out or offer to sit with the person they look after for a while if possible, so they can have a break. It can be so important to connect with other Deaf carers who have gone through similar experiences. The Deaf community needs to be proactive to

reach out and support carers. Even if you could visit for an hour or two to converse or go through old photos with the person living with dementia. This could be at their home, or in a care home if necessary as many Deaf people are isolated in mainstream care homes. You could look at *SHARE: The Deaf Visual Archive* created by the BDA for rich materials suitable to chat about the old days.

Clark: It can also be difficult coping with work and worries about money...

Carolyn: If you are working, talk to your employer about any difficulties you are having. A lot of people worry about talking to their manager, but they may be able to support you and adapt your role so you can manage better.

Carers also have the right to a Carers Assessment through the local Social Services team to see if any extra help is needed at home. You could also ask for a benefits assessment to see if the person with dementia or the carer is entitled to any extra benefits.

Clark: Taking care of yourself is also really important.

Carolyn: Yes – having dementia doesn't mean the person should feel ill. Eating a healthy diet – balanced with fruit and vegetables – and drinking plenty of fluid can help you feel well and increase your energy and concentration. Reduce drinking alcohol and stop smoking where possible as well. Don't forget to look after your mouth – visit the dentist regularly as a healthy mouth will help you eat a healthy diet.

Look after your feet and make sure slippers or shoes fit well and are non-slip - if you are tired and stressed, or struggling with movement or perception then you are more likely to trip or bump into things. Also have regular eye tests and make sure your glasses are suitable and regularly cleaned.

Clark: And staying active can have a positive impact on your emotional health too, can't it?

Carolyn: Yes it can – try regular walking or gentle exercise like stretching, swimming or cycling. Just getting out to see people or spend time with a loved pet can help you stay active and feel more connected with things you love. Remember to see your GP if you are feeling low over a period of time as you might have depression.

Clark: What is the most important message to give a Deaf person who knows someone with dementia?

Carolyn: A person with dementia is still an individual with a lifetime of experience. Look past their dementia and try to learn as much as you can about them as a whole person – this can help you to understand their experiences from their past and also their behaviour now.

Avril Hepner from BDA Scotland has a true story to help us understand how important this is.

Avril: There was a gentleman living in a nursing home, and every day he would sit in the same corridor. Every time someone walked past him, he would get upset and start waving his arms. Staff and residents didn't understand his behaviour, they found it strange and started to avoid him. The man become isolated and lonely.

One day his family came to visit and began talking about his past. During the war he had worked in the bomb disposal team and his job was to sit next to land mined areas and guide people through safely.

The staff realised the man's dementia had caused him to relive this part of his life and when he became upset, it was because he thought people were in danger, walking through the mine field and ignoring his directions.

People's attitudes towards him changed, people had forgotten he was a war hero and a man with a history. The staff changed the way they behaved towards him, and allowed him to guide them down the corridor – it took a bit more time but it made the gentleman happy, gave him a sense of purpose, he took pride in keeping people safe.

Clark: So there is something we can all do – remember who that person is and treat them like an individual who deserves respect.

Carolyn: Yes, don't label them, remember who they are as an individual. There are actions we can all take to support someone with dementia to carry on – even something small like always making time to stop and say hello.

So the key message to remember is that there is more to the person than the label 'dementia'.