

Deaf and dementia: What causes dementia? (BSL)

Transcript in English

Carolyn: There is a lot of confusion and fear around dementia in the Deaf community. We are going to look at some of the most common questions and concerns that people have.

What is the first word that a lot of Deaf people remember about dementia?

Clark: Maybe something like 'old', 'suffering', 'victim', that 'he/she is not all there'. It is the same as how some of the hearing society label us being Deaf. Some of the labels you dislike. So you can see a lot of these words are overwhelmingly negative. This is why it's so important to raise awareness about dementia – to get the facts right and challenge these labels.

The first thing you need to know is that not everyone who gets older will develop dementia. We all forget a name or face sometimes, especially as we get older. You can have grey hair, skin wrinkles, brittle bones, eat and sleep less, and even forget things – all of these are signs of your body getting older, but it doesn't mean you will develop dementia.

Dementia is something different. A person with dementia can forget things. But they can also think, feel, communicate and act differently to normal. They may be confused. The changes can be small to start with, but they will deteriorate over time.

It's true dementia is most common in people over 65 years old, but people in their 20s, 30s, and 40s can get dementia although it is much rarer when you are younger.

Carolyn: What is dementia?

Clark: Dementia describes a range of symptoms that show the brain has a disease. Only some people get dementia. It does not happen to everyone as they get older.

Dementia is progressive so the symptoms will gradually get worse over time – but it depends on the type of dementia that someone has and remember everyone is different so their disease will develop in a unique way.

Carolyn: So there are different types of dementia?

Clark: Yes, the word dementia is an umbrella term – there are over 100 different types of dementia. Most people with dementia have Alzheimer's disease or vascular dementia. Fewer people with dementia have dementia with Lewy bodies (DLB) or frontotemporal dementia (FTD). There are other types of dementia that smaller numbers of people get.

Information about all four of these types of dementia, as well as a general guide about dementia, have been translated into BSL by BDA Scotland, with permission from Alzheimer's Society.

Carolyn: What should you do if you are worried about yourself or someone else?

Clark: The important thing first is to get the right diagnosis. If you're worried about your memory or changes to your behaviour, or you are worried about someone you care for, make an appointment with the GP. There are lots of other reasons why someone might be showing confusion or memory loss – they might have a UTI, or have depression, or have some other health problem rather than dementia. It is often difficult for a Deaf person to get the right advice about their health – getting a diagnosis is the first step to accessing further information and support.

Carolyn: Tell me about the diagnosis journey for the average Deaf person with dementia?

Clark: There are few dementia support services that are accessible for Deaf people and their carers. Not many hearing health professionals have met a Deaf person before, so have little understanding of Deaf community or culture. Arranging an interpreter can be a big barrier as GPs can sometimes assume a Deaf person will lipread. A lot of Deaf people either don't know their rights or don't feel able to ask for an interpreter as they are not often offered one.

And of course dementia can affect your communication – so it's really important to have the test in your own language. But don't give up. The thing to remember is that a Deaf person should not have to accept an assessment for dementia that was designed for the hearing community.

Tell your GP that there is a test available designed for Deaf BSL users – this came from a research project called 'Deaf with Dementia' which was funded by Alzheimer's Society. The GP will need to refer you to the National Hospital for Neurology and Neurosurgery in London – there will be more details at the end of this film.

You will meet a psychologist fluent in BSL, and you can be referred if you are an adult Deaf BSL user and are able to travel. It is only for people who have recent problems with memory or thinking – not lifelong problems. The GP **must state in their referral letter** that you are a Deaf BSL user as the clinic can only test Deaf people who can communicate in BSL.

Carolyn: Why should someone try to get a diagnosis if it is so difficult?

Clark: Because then you know what you are dealing with – you can find out more information and understand what support you might need or how to support the person you care about. Remember with the right support and understanding, the person can stay a lot more independent and connected with their community and friends.

In Films 3 and 4 we will be talking about how to support Deaf people with dementia.

Carolyn: What causes dementia to develop?

Clark: Dementia is caused by changes in the brain that happen because of disease. It describes a group of symptoms like confusion, memory loss or changes in behaviour. These changes happen when brain cells become damaged and stop working properly.

Carolyn: What is happening in the brain?

Clark: A very simple way of looking at it is like Christmas fairy lights. Imagine the brain is made up of thousands and thousands of little lights. Each light represents a different part of the brain that controls different things, so one light might be a memory, one light might be a taste, one light might be a particular movement, or logic to help you work out a problem and so on. Dementia makes some of those lights flicker, fade or switch off completely. For each person with dementia, different lights will be affected at different times and in a different order.

Carolyn: So once a light is switched off, can it come back on?

Clark: Dementia is progressive – that means that over time the symptoms will gradually get worse. This happens quickly for some people and more slowly for others. Different types of dementia can damage different parts of the brain, and this can happen in different patterns over time. For example Alzheimer's disease tends to start slowly and progress gradually. Vascular dementia after a stroke is often a more 'step-like' progression with a stable period then symptoms can suddenly get worse before stabilising again.

But remember every person is different and will experience their dementia in their own way. Lots of things can affect this including their physical and mental health.

Carolyn: So are there things that we can all think about to reduce our risk of getting dementia?

Clark: There are reasons why a person might be more likely to get dementia. This includes some factors that we can't alter like getting older or our genes that we inherit. But there are some modifiable risk factors that we can try to control including our lifestyle.

Carolyn: Do you mean what we eat and drink, how much we exercise?

Clark: Yes - cutting down on alcohol and smoking, doing regular exercise and eating a healthy diet are all things we can do to help reduce our risk of getting dementia. What's good for your heart is also good for your head!

Carolyn: So the first two key messages to learn are:

- **dementia doesn't happen just because you get older**
- **it is caused by diseases in the brain.**

In the next films we will look at the symptoms in more detail, and how we can all support someone living with dementia in the Deaf community.