



How social care staff can support people with learning disabilities and dementia

Dementia and learning disabilities



Dementia is the term used to describe a set of symptoms that occur when some of a person's brain cells stop working properly. The main sign of dementia is memory loss but people might also have difficulty with thinking, speech, problem-solving, co-ordination and everyday activities.

Dementia gets worse over time, though not necessarily at a steady rate. There is no cure for dementia but anti-dementia drugs can slow down the process.

Dementia is more common in people with learning disabilities.

It is particularly common in people with Down's syndrome who are often get dementia in their 40s and 50s.



It can be harder to diagnose dementia in people with learning disabilities because they would often score badly on the tests used for diagnosis. Families and paid supporters who know well what a person is normally able to do can play an important part in noticing changes which might be signs of early dementia. These include changes in memory, behaviour or personality, or loss of ability to do daily activities.

If someone with Down's syndrome develops epilepsy later in life this can be a sign that they are developing dementia.

If you notice any of these changes you should speak to the person's GP or the community learning disability team. They may just be part of normal ageing or signs of other illnesses such as depression, but should not be ignored.

It is a good idea for people with Down's syndrome to have a baseline assessment by the time they are 30. This looks at the skills that someone has and can help identify changes in the future. The community learning disability team can help with this.



Sharing the information



It may be difficult for the person to understand what a diagnosis of dementia means. They may need it explained to them using simple language. Information should be broken into small chunks. Use an [easy read leaflet](#) to help.¹



Family carers and paid supporters need to understand about the diagnosis and what to expect over time. They should be involved in planning how to support someone with their changing needs. They may need education and training. The community learning disability team might be able to help with this. There are [useful films available](#).²



The person may be living with a partner, friend or other residents with learning disabilities. It is important to think about what it is like for these people to live with someone with dementia.

What can social care staff do?

There is easy read information about anti-dementia drugs [here](#).³

Try to understand what the person is experiencing and use that to think about the support they need.

Dementia will affect how someone communicates. Use short sentences and simple words. Give someone plenty of time to respond.

There might be environmental changes that can help. For example, using pictorial clues, such as a picture of them on their bedroom door. It might be that they need physical adaptations made.

Helping someone make a life story book or a memory box can be positive. This is a way of capturing their memories and stories about their life. They might enjoy looking at this when their memory gets worse. There is guidance to help supporters do this.⁴

Help the person to have as much control as they can over their life. Support them to maintain their friendships. Their friends and housemates may also need support.

Don't forget to think about other physical illnesses they may have, such as epilepsy. It can be hard to recognise pain in someone with learning disabilities and dementia. There is an [information sheet](#) about this.⁵

Think about what helps them to relax. This might be massage or listening to music. Familiar songs are often remembered after much else has been forgotten. Shared singing can help people to feel connected again.

Think about their capacity as this will change over time. There is an [information sheet](#) about this.⁶

Plan for the changes that will come. Over time they may need help with safe eating and drinking. Talk to them about end of life wishes. There is an [information sheet](#) about this.⁷

Key messages:

- people with learning disabilities are more likely to develop dementia than other people
- people with Down's syndrome have a particularly increased risk of developing dementia and at a much younger age
- social care staff should be aware of changes that might suggest someone has early dementia and should seek advice from health professionals
- there are drug and non-drug treatments that can help
- dementia is a progressive condition and it is important to work with the person and other important people in their life to plan ahead

This is the 11th in a series of health factsheets for social care staff. You can find others and more [guidance](#) for social care providers.

There is a [supporting set of slides](#) for this document that can be used by social care staff as a training resource.

The pictures in this factsheet are from Photosymbols: www.photosymbols.co.uk

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¹ <http://www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/mental-health/illnesses/Dementia2.pdf>

² <http://www.scie.org.uk/dementia/resources/dementia-videos.asp>

³ <http://easyhealth.org.uk/sites/default/files/null/Tablets%20for%20people%20who%20have%20Dementia.pdf>

⁴ <https://www.dementiauk.org/for-healthcare-professionals/free-resources/life-story-work/>

<https://www.fons.org/resources/documents/Tools%20and%20resources/LifeStoryWorkResourckPack.pdf>

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