

Dementia: assessment, management and support for people living with dementia and their carers

Information for the public

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Dementia: the care you should expect

Dementia changes the way people think, feel and behave. The symptoms vary but most people with dementia have problems with memory, understanding, speaking and getting on with everyday life. Dementia is most common in people over 60, but it occasionally develops before this. It gets worse over time, although how quickly varies from person to person. About 850,000 people in the UK are diagnosed with dementia, and in most people it's caused by Alzheimer's disease. Dementia doesn't normally run in families, so having a parent with dementia doesn't normally mean it is more likely to be passed on.

Because no two people with dementia are affected in the same way, the right care and support is unique to each person. We want this guideline to make a difference to people with dementia by making sure:

- if you or your doctor think you might have dementia you have the right tests to find out what type you have and how to manage it
- your care team explains dementia to you and your family, including how it can affect you and what care you should get at every stage
- you have help to understand the different ways to manage dementia and to decide what would work best for you
- someone in your care team is chosen to organise all your care and be your contact – they should keep you and your family at the centre of all decisions
- your family or carers get support to look after you and stay well themselves.

Making decisions together

Decisions about treatment and care are best when they are made together. Your care team should give you clear information, talk with you about your options and listen carefully to your views and concerns.

They should also:

- make sure you always have a say in your care, or that decisions are made in your best interests if you are no longer able to make your own decisions
- involve family members or carers if you are happy with this
- support you to plan ahead and make decisions now about the future if you want to
- work closely with other care teams and share information so that everyone knows your needs.

If you can't understand the information you are given, tell your care team.

Read more about [making decisions about your care](#).

Helping you decide about treatment

Antipsychotic medicines for treating agitation, aggression and distress

People living with dementia can sometimes become distressed, aggressive or very agitated, and can have hallucinations or delusions. Antipsychotic medicines can help with this, but there are pros and cons to taking them. We've produced this [patient decision aid](#) to help healthcare professionals discuss antipsychotic medicines with people living with dementia and their families and carers, so they can decide together if these are the right choice.

Enteral (tube) feeding for people living with severe dementia

People living with severe dementia often have problems with eating and drinking. For some people, tube feeding may be an option until they can go back to eating and drinking normally. We've produced this [patient decision aid](#) to help healthcare professionals discuss tube feeding with people living with dementia and their families and carers, so they can decide if this is the right choice.

In the news

Read NICE news about how this guideline will help.

People with dementia should be involved in discussions about their care, says NICE



NICE has updated its guidance for the support of people living with dementia.

[See what NICE says](#)

Where can I find out more?

[NHS Choices](#) has more information about dementia.

The organisations below can give you more advice and support.

- [Alzheimer's Society](#), 0300 222 11 22
- [Carers UK](#), 0808 808 7777

NICE is not responsible for the content of these websites.

To share an experience of care you have received, contact your local [Healthwatch](#).

We wrote this guideline with people who have been affected by dementia and staff who support them. All the decisions are based on the best research available.

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