



**DementiaUK**  
Helping families face dementia

## Alzheimer's disease



### What is Alzheimer's disease?

Dementia is an umbrella term for a range of conditions affecting the brain that get worse over time. Alzheimer's disease is the most common form of dementia: over 500,000 people in the UK live with the diagnosis.

Alzheimer's disease is caused by a build-up of proteins in the brain. These cause 'plaques' and 'tangles' which affect the ability of the brain cells to transmit messages effectively. As time passes, more and more brain cells are damaged, leading to worsening symptoms of Alzheimer's disease.

### Who is at risk of Alzheimer's disease?

The biggest risk factor for developing Alzheimer's disease is age. It affects one in 14 people over the age of 65, and one in six people over the age of 80 – and the older we get, the more likely it is that we will develop the condition.

However, it is not just a condition of old age – around 7% of people with

dementia are under 65 (this is known as young onset dementia).

Women are more likely to develop Alzheimer's disease than men, and there is some evidence that people from African-Caribbean and South Asian backgrounds may be more at risk. People with Down's syndrome are also more likely to develop the condition due to the extra chromosome 21.

In a very small number of cases, Alzheimer's disease is 'familial' – in other words, caused by a genetic fault that runs in families – but this affects fewer than 1% of all people diagnosed with the condition.

Other factors that could increase the risk of Alzheimer's disease include:

- smoking
- obesity
- diabetes
- high blood pressure
- high cholesterol levels
- hearing loss
- untreated depression
- loneliness and social isolation
- an inactive lifestyle
- a previous severe head injury



## Symptoms of Alzheimer's disease

In the early stages, the symptoms of Alzheimer's disease are often very mild, but they can be extremely frustrating for the person and for those around them, who may not understand why the changes are happening.

It is most commonly associated with memory loss, and this is often one of the earliest and most noticeable symptoms.

A person with Alzheimer's disease might:

- forget about recent events or conversations
- frequently misplace items or

put them in the wrong place (eg putting their keys in the fridge)

- forget appointments
- forget the names of people, objects or places
- find it hard to think of the right word
- repeat themselves or keep asking the same questions

The person might also:

- experience mood changes
- feel uncomfortable in new or unfamiliar situations
- be unsettled by changes in routine
- become withdrawn
- find it hard to make decisions

Alzheimer's disease is a progressive condition, and always gets worse over time. In the middle stages, symptoms may include:

- increasing confusion and disorientation, eg getting lost in familiar places
- delusions (believing things that are not true, eg that a family member is trying to steal money from them)
- hallucinations (seeing or hearing things that are not there, eg a stranger in their home)
- obsessive or repetitive behaviours
- problems with speech and language
- disturbed sleep
- difficulty with spatial awareness, eg judging speed and distances

In the later stages, these symptoms often worsen, and the person may develop new symptoms including:

- verbally and/or physically aggressive behaviour
- incontinence
- difficulty eating and swallowing
- gradual loss of speech

- difficulty moving around
- weight loss
- becoming increasingly weak and frail

## Preventing Alzheimer's disease

Although there is no guaranteed way to prevent Alzheimer's disease, certain steps may help reduce the risk:

- Stop smoking
- Keep alcohol consumption within safe limits: for guidelines, please see [nhs.uk/live-well/alcohol-advice/calculating-alcohol-units](https://www.nhs.uk/live-well/alcohol-advice/calculating-alcohol-units)
- Eat a healthy, balanced diet with at least five portions of fruit and vegetables a day
- Aim to exercise at least five days a week for 30 minutes or more at a time
- Ensure you take any medication prescribed for diabetes, heart conditions, depression and other physical/mental health problems
- Ask your GP for regular health checks including blood pressure checks and blood tests
- Ensure you have your hearing and eyesight checked regularly



- Stay mentally and socially active, for example by taking part in group activities, volunteering, reading, or learning a new skill like a language or chess

## Getting a diagnosis of Alzheimer's disease

If you are concerned that you or someone close to you is showing symptoms of Alzheimer's disease, it's important to see the GP. If it is diagnosed early, there may be more treatment options available, and support can be put in place for the future.

It's a good idea for a family member or friend to go to the appointment with the person – they may have

noticed other changes and can also provide vital support.

Firstly, the GP will want to rule out any underlying physical or mental causes of the symptoms – many of which can be treated. These could include depression, anxiety, vitamin deficiency, diabetes, hormonal conditions or menopause.

They will ask the person:

- what their symptoms are
- when they started
- how they affect their daily life
- about their family history

It is a good idea to keep a record of symptoms, triggers and how they affect the person to show the GP.

The GP is likely to ask the person to do a short memory and concentration test. This may include:

- stating the day, date and year
- naming pictures of some common objects, eg keys, kettle
- remembering and repeating a list of items
- completing a simple drawing, eg putting numbers on a clock face

The GP should also order investigations such as blood tests, an ECG (a check of heart rhythm) and a head scan.

If the tests rule out other conditions that may be causing the person's symptoms, the GP should refer them to a specialist memory clinic for more detailed assessments. These may be carried out by a nurse, psychiatrist, neurologist or elderly care specialist.

The person may also have further scans such as an MRI or CT scan – these produce detailed images of the brain and may show changes associated with Alzheimer's disease or other conditions.

It may take several appointments and tests over a number of months to get a confirmed diagnosis of Alzheimer's disease.

Receiving a diagnosis of Alzheimer's disease can be a relief for some people, as they have an explanation for what is happening to them and can access the support they need. For other people, it can be upsetting and overwhelming.

However, many people with a diagnosis of Alzheimer's disease still live happy and fulfilling lives with support from family, friends and professionals. Our specialist dementia nurses are also here to help – please see Sources of support on p11 for details.

### **What to do if someone is reluctant to seek a diagnosis**

Sometimes, a person with symptoms of dementia may be reluctant to see their GP. They may not be aware of the changes in themselves and think there is no need to seek help. Or they may be afraid of getting a dementia diagnosis and how it might affect their life. This is completely natural and understandable.

If the person is unwilling to seek a diagnosis, you could:

- explain that their symptoms may be caused by another condition that could be treated
- explain that if they do have Alzheimer's disease, an early diagnosis will mean that support can be put in place



to help them live as well as possible with the condition

- offer to go to the appointment with the person for support
- ask another trusted person – such as a family member, friend or professional – to speak to the person. Sometimes, people are more willing to listen to someone who is less closely involved in the situation
- write to or email the GP about your concerns. They will not be able to discuss the person without their consent, but may decide to call them in for a health check

## Medication for Alzheimer's disease

There is currently no cure for Alzheimer's disease. However, for some people, medication could improve the symptoms and slow its progression.

The main medications are donepezil, rivastigmine and galantamine. These work by increasing the levels of a chemical called acetylcholine in the brain, which helps the brain cells communicate with each other.

They are only effective in the mild to moderate stages of Alzheimer's disease, and they depend on the person being physically fit and well, and able to remember to take the medication at the same time each day.

Another medication, called memantine, may be prescribed for moderate to severe Alzheimer's disease, or if the person can't tolerate the other treatments.

All medications can have side effects: the person's memory specialist can tell you more about these. For many people, side effects will subside after around two weeks, but others may find them unbearable.

The person's specialist will monitor them as they get used to taking the medication. Some people find the side effects outweigh the benefits, but they should always speak to their specialist before stopping taking it.

Medication is not suitable for all people with Alzheimer's disease – it can, for example, affect the heart, so people with heart problems may not be able to take it. This can

feel very disappointing, but there are other ways to manage the symptoms and still have a good quality of life.

### Cognitive stimulation therapy (CST)

CST is a type of therapy that involves taking part in activities to improve memory, language skills and problem-solving abilities. It often takes place in a group, which can also provide opportunities to socialise and share experiences, but may be offered one-to-one. The memory clinic will be able to tell you if this is offered in your area.

### Cognitive rehabilitation

This involves working with a specialist – usually an occupational therapist – along with a family member or friend to achieve particular tasks, such as using a mobile phone or cooking a meal. The aim is to get the parts of the brain that still work well to help the parts that don't. It can also be personally satisfying to accomplish a task that the person finds difficult.

### Reminiscence and Life Story work

Many people with Alzheimer's disease have difficulty with short-term memory, but longer-term memories may remain intact for some time.

Reminiscence work involves the person talking to a family member, friend or professional about their past, often using prompts such as photos, music or favourite possessions.

Life Story work involves compiling a record of the person's life, including their family and work history, important people and places, key events from their past, likes and dislikes, and spiritual/cultural beliefs. A Life Story usually includes photos, notes and keepsakes, and can be a physical book or a digital version. See Sources of support on p11 for more information.

These activities focus on skills, achievements and happy memories, and can improve mood and wellbeing.





## Practical tips for managing Alzheimer's disease

While the symptoms of Alzheimer's disease worsen over time, people who have a good routine and support around them can live well for as long as possible.

These tips may help make living with Alzheimer's disease more manageable.

- When someone is diagnosed, ask their memory specialist for information on what resources are available locally, such as support groups, day centres and memory cafés. You can also contact the Admiral
- Try to keep to a daily and weekly routine. This can help the person remember what happens when, and provide security and stability
- Look for dementia-friendly initiatives, such as the Hidden Disabilities Sunflower lanyard/ badge which indicates that the person may need extra help and support, and the Herbert Protocol, which is a written record of the person's details that can help the police find them if they go missing – see Sources of support on p11 for more details

Nurse Dementia Helpline for information – see Sources of support on p11

- Help the person remain socially connected, whether by continuing with their current activities or introducing new ones, such as a support group or new hobby
- Using a diary or calendar can be useful – strike through the day before bedtime, or turn the page in readiness for the next day
- Look into other equipment that makes daily living easier, such as mobility aids, medication organisers and gadgets that reduce the risk of cookers or taps being left on
- Take a tour around the person's home to identify possible safety hazards – see Sources of support on p11 for our information on making the home safe and comfortable
- A personal alarm can be used to summon help if the person falls. Other assistive technology, such as key locators and door sensors, is also available – contact your local council for information on schemes in your area
- Request a Needs Assessment (for the person with dementia) and a Carer's Assessment (for their carer) to establish what equipment and support would make life easier, and whether there is funding available for these. See Sources of support on p11
- Ensure the person carries a form of identity with their personal details and information about their diagnosis, which can be helpful if they are lost or need assistance outside the home – this could be sewn into a coat or bag so it is not misplaced
- Encourage people to carry on with their daily activities (even if these might not be quite to the same standard) – this will help them maintain their skills for as long as possible
- Be realistic about your ability to care for the person – in the mid- to later stages of Alzheimer's disease, it may be necessary to use paid carers or consider a move into residential care
- If you or someone you care for is struggling, the most important thing you can do is to reach out and ask for help – see Sources of support on p11

## Sources of support

To speak to a dementia specialist Admiral Nurse about Alzheimer's disease or any other aspect of dementia, please call our Helpline on **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm) or email [helpline@dementiauk.org](mailto:helpline@dementiauk.org)

If you prefer, you can book a phone or video call appointment with an Admiral Nurse at [dementiauk.org/closer-to-home](https://dementiauk.org/closer-to-home)

### Dementia UK resources

**Getting a diagnosis of dementia**  
[dementiauk.org/getting-a-diagnosis-of-dementia](https://dementiauk.org/getting-a-diagnosis-of-dementia)

**Creating a Life Story**  
[dementiauk.org/creating-a-life-story](https://dementiauk.org/creating-a-life-story)

**Making the home safe and comfortable for a person with dementia**  
[dementiauk.org/safe-comfortable-home-for-a-person-with-dementia](https://dementiauk.org/safe-comfortable-home-for-a-person-with-dementia)

**The Carer's Assessment**  
[dementiauk.org/the-carers-assessment](https://dementiauk.org/the-carers-assessment)

### Other resources

**Eat well: NHS guidance on a healthy diet**  
[nhs.uk/live-well/eat-well](https://nhs.uk/live-well/eat-well)

**NHS alcohol advice**  
[nhs.uk/live-well/alcohol-advice](https://nhs.uk/live-well/alcohol-advice)

**NHS stop smoking services**  
[nhs.uk/live-well/quit-smoking/nhs-stop-smoking-services-help-you-quit](https://nhs.uk/live-well/quit-smoking/nhs-stop-smoking-services-help-you-quit)

**Herbert Protocol**  
[met.police.uk/advice/advice-and-information/missing-person/missing-persons/vulnerable-people-at-risk-of-going-missing/dementia-missing-risk-herbert-protocol](https://met.police.uk/advice/advice-and-information/missing-person/missing-persons/vulnerable-people-at-risk-of-going-missing/dementia-missing-risk-herbert-protocol)

**Hidden Disabilities Store**  
[hiddendisabilitiesstore.com](https://hiddendisabilitiesstore.com)

**The Needs Assessment**  
[nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/getting-a-needs-assessment](https://nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/getting-a-needs-assessment)

**Find your local council**  
[gov.uk/find-local-council](https://gov.uk/find-local-council)

The information in this booklet is written and reviewed by dementia specialist Admiral Nurses.

We are always looking to improve our resources, to provide the most relevant support for families living with dementia. If you have feedback about any of our leaflets, please email [feedback@dementiauk.org](mailto:feedback@dementiauk.org)

We receive no government funding and rely on voluntary donations, including gifts in Wills.

For more information on how to support Dementia UK, please visit [dementiauk.org/donate](https://dementiauk.org/donate) or call **0300 365 5500**.  
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If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

Call **0800 888 6678** or email [helpline@dementiauk.org](mailto:helpline@dementiauk.org)

Open Monday-Friday, 9am-9pm  
Saturday and Sunday, 9am-5pm



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