

# **Alzheimer's disease**



#### What is Alzheimer's disease?

Alzheimer's disease is the most common form of dementia, accounting for around 60% of all cases. It 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.

Alzheimer's disease is just one form of dementia. There are more than 200 types overall.

#### Symptoms of Alzheimer's disease

Alzheimer's disease is most commonly associated with memory loss, and this is often one of the earliest and most noticeable symptoms. In the early stages, the symptoms may be mild, but they can be extremely frustrating for the person themselves and for those around them, especially if they do not understand why the changes are happening.

In the early stages, 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- become withdrawn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 deteriorates 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, egjudging 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

#### 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, Alzheimer's disease is not just a condition of old age. It is the most common form of young onset dementia (where symptoms develop before the age of 65), affecting around one-third of younger people living with the dementia. For more information on young onset dementia, please see Sources of support on p19.



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 a learning disability – particularly Down's syndrome – are also more likely to develop the condition. Please see Sources of support on p19 for information on learning disabilities and dementia.

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. Please see Sources of support on p19 for information on genetic forms of dementia.

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

- smoking
- obesity

- diabetes
- excess alcohol consumption
- high blood pressure
- high cholesterol levels
- hearing loss
- untreated depression
- Ioneliness and social isolation
- an inactive lifestyle
- a previous severe head injury

#### **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 recommended limits
- 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 photography

#### Getting a diagnosis of Alzheimer's disease

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

It is a good idea for a family member or friend to go to the appointment with the person who is experiencing symptoms – they may have noticed other changes and can also provide vital support.

Firstly, the GP will rule out any underlying physical or mental health issues that may be contributing to the person's symptoms, many

of which can be treated. These 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
- their family history
- their medical 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 should carry out some simple physical tests, such as a blood pressure check, and refer the person for blood tests. They may request an ECG (a check of heart rhythm) and a brain scan. They should ask the person to do a short memory and concentration test, known as a 'mini mental state examination'. 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

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. This is particularly true for younger people, who typically face a much longer wait to get a diagnosis than older people.

It is normal to experience a mixture of emotions after receiving a diagnosis of Alzheimer's disease. It is natural to feel shocked, upset and overwhelmed, but some people also feel a sense of relief as they have an explanation for what is happening to them and can access the support they need.

People with young onset Alzheimer's disease may have additional issues to think about, such as their ability to work, managing financial commitments such as a mortgage, and the impact on any dependent children.

However, support from family, friends and professionals can help the person with Alzheimer's disease to have a fulfilling life for as long as possible. Our specialist dementia nurses are also here to help – please see Sources of support on p17 for details.

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

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. They may be afraid of getting a dementia diagnosis and how it might affect their life. If they are under 65, they may believe they are too young to have dementia. 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 for Alzheimer's disease 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 cannot tolerate the other treatments.

All medications can have side effects: the person's healthcare professional should discuss these with you and monitor them as they get used to taking the medication. Side effects often subside



after around two weeks, but some people find they last longer and are hard to cope with. 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 could, 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 available 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 do not. 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 and life story work focus on skills, achievements and happy memories, and can improve mood and wellbeing.

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, for example:

- personal details
- important relationships with family and friends
- their childhood history
- past and present employment
- important people and places
- key events from their past
- likes and dislikes
- spiritual/cultural beliefs



A life story usually includes photos, notes and keepsakes, and could be recorded in a book, video, memory box, collage or app. Please see Sources of support on p17 for more information on creating a life story, including our template.

#### Practical tips for managing Alzheimer's disease

While the symptoms of Alzheimer's disease always worsen over time, a good routine and support network can help the person with the diagnosis maintain their independence and quality of life for as long as possible. These tips may help:

- When someone is diagnosed, ask their memory specialist for information on any services available locally, such as support groups, day centres and memory cafés. You can also contact our Helpline for information – see Sources of support on p17
- If the person with dementia drives, ensure they notify the DVLA (DVA in Northern Ireland) and vehicle insurer of their diagnosis –

this is a legal requirement. Please see Sources of support on p17 for our information on driving and dementia

- Find out about and apply for any benefits the person may be entitled to please see Sources of support on p18 for more information on finance and benefits
- If the person works, it is a good idea for them to tell their employer about their diagnosis so their legal rights are respected and support can be put in place. Please see Sources of support on p17 for more information on employment and dementia
- If the person has children, consider informing their school/ college of the situation so they can be supported. A GP or social worker may also be able to recommend support for young people, such as counselling or young carers' groups
- Try to keep to a consistent daily and weekly routine. This can help the person remember what happens when, and provide security and stability
- Look for dementia-inclusive initiatives, such as the Hidden Disabilities sunflower lanyard/badge, which indicates that the person may need extra help and support in public; 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 p19 for more details
- 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, dementia clocks, medication organisers and an Alexa or similar smart device that can be used to give reminders, play music and audiobooks etc
- Look around the person's home to identify possible safety hazards see Sources of support on p18 for 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 door sensors that alert you if the person leaves home, 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 p17-19

- Ensure the person carries a form of identity with their personal details and information about their diagnosis in case they get lost or need assistance outside the home – this could be sewn into a coat or bag so it is not misplaced
- Encourage the person to carry on with their daily activities, with adaptations or support if needed. Try to avoid being overprotective – allowing them to continue with tasks that they are still capable of (even if not to their previous standard) will help them maintain their skills and independence 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

Living with Alzheimer's disease can be difficult for the person with the diagnosis and those around them, especially as the symptoms progress. If you need advice or are struggling to cope, it is important to reach out and ask for help – please see Sources of support on p17 to find out how we can support you.

# Sources of support

If you are caring for someone with dementia or living with the condition yourself, you can register for our free online sessions, 'Dementia: what next?' at **O dementiauk.org/** dementia-what-next

To speak to an Admiral Nurse on our free Helpline, call **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email **> helpline@dementiauk.org** 

If you prefer, you can book a phone or video call with an Admiral Nurse at a time to suit you: please visit **O dementiauk.org/book** 

## Dementia UK resources

### Carer's assessment

Odementiauk.org/the-carers-assessment

# Changes in perception and hallucinations dementiauk.org/changes-in-perception-and-hallucinations

Creating a life storydementiauk.org/creating-a-life-story

Life story templatedementiauk.org/life-story-template

**Driving and dementia**dementiauk.org/driving-and-dementia

Employment and young onset dementia
 dementiauk.org/employment

## **False beliefs and delusions** Odementiauk.org/false-beliefs-and-delusions-in-dementia Financial and legal sources of support Odementiauk.org/financial-and-legal-sources-of-support Finance and young onset dementia Odementiauk.org/finance-and-young-onset-dementia **Genetic forms of dementia** Odementiauk.org/genetic-familial-forms-of-dementia Getting a diagnosis of dementia Odementiauk.org/getting-a-diagnosis-of-dementia Learning disabilities and dementia Odementiauk.org/learning-disabilities-and-dementia Living aids and assistive technology Odementiauk.org/living-aids-and-assistive-technology Making the home safe and comfortable for a person with dementia Odementiauk.org/safe-comfortable-home-for-a-personwith-dementia **Stages of dementia** Odementiauk.org/stages-of-dementia Supporting children and adolescents when a parent has young onset dementia Odementiauk.org/supporting-children-and-adolescents-whena-parent-has-young-onset-dementia **Types of dementia**

Odementiauk.org/types-of-dementia

Understanding young onset dementia

Odementiauk.org/what-is-young-onset-dementia

#### **Other resources**

Carers Trust ○ carers.org

Carers UK carersuk.org

Dementia Carers Count
dementiacarers.org.uk

Find your local council Solution of the second sec

Herbert Protocolmet.police.uk/herbert-protocol

Hidden Disabilities storehiddendisabilitiesstore.com

 Needs assessment
 nhs.uk/conditions/social-care-and-support-guide/help-fromsocial-services-and-charities/getting-a-needs-assessment

NHS alcohol advice nhs.uk/live-well/alcohol-advice

NHS Eat Well guidance on a healthy diet
nhs.uk/live-well/eat-well

 NHS stop smoking services
 nhs.uk/live-well/quit-smoking/nhs-stop-smoking-serviceshelp-you-quit

#### To speak to a dementia specialist Admiral Nurse about any aspect of dementia:

Contact our Helpline: **0800 888 6678** or **> helpline@dementiauk.org** 

> Book a virtual appointment: • dementiauk.org/book

Our charity relies entirely on donations to fund our life-changing work. If you would like to donate to help us support more families:

- Call **0300 365 5500**
- Visit O dementiauk.org/donate
- Scan the QR code

Thank you.





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