The progression and stages of dementia

Alzheimer's Society
It will take a society to beat dementia

This factsheet describes the progression and stages of dementia. It gives people living with dementia, and their family, friends or carers, guidance on the changing symptoms and what to expect at each stage.

For more support on living with dementia, see booklet 872 **The dementia guide** (for people living with dementia) or booklet 600 **Caring for a person with dementia: A practical guide** (for carers).

For more information on the different types of dementia, see factsheets 401 **What is Alzheimer's disease?**, 402 **What is vascular dementia?**, 403 **What is dementia with Lewy bodies (DLB)?** and 404 **What is frontotemporal dementia (FTD)?**

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1 What does progression in ‘stages’ mean?

There are many different types of dementia and all of them are progressive. This means symptoms may be relatively mild at first but they get worse with time, usually over several years. These include problems with memory, thinking, problem-solving or language, and often changes in emotions, perception or behaviour.

As dementia progresses, a person will need more help and, at some point, will need a lot of support with daily living. However, dementia is different for everyone, so it will vary how soon this happens and the type of support needed.

It can be helpful to think of dementia progressing in three stages – early, middle and later. These are sometimes called mild, moderate and severe, because this describes how much the symptoms affect a person.

These stages can be used to understand how dementia is likely to change over time, and to help people prepare for the future. The stages also act as a guide to when certain treatments, such as medicines for Alzheimer’s disease, are likely to work best.

How important are the stages?

The stages of dementia are just a guide, and there is nothing significant about the number three. Equally, dementia doesn’t follow an exact or certain set of steps that happen in the same way for every person with dementia.

It can be difficult to tell when a person’s dementia has progressed from one stage to another because:

- some symptoms may appear in a different order to the stages described in this factsheet, or not at all
- the stages may overlap – the person may need help with some aspects of everyday life but manage other tasks and activities on their own
- some symptoms, particularly those linked to behaviours, may develop at one stage and then reduce or even disappear later on. Other symptoms, such as memory loss and problems with language and thinking, tend to stay and get worse with time.

It is natural to ask which stage a person is at or what might happen next. But it is more important to focus on the person in the present moment. This includes their needs and how they can live well, and how to help them with this.

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“**My mother is very poorly with dementia. I want some knowledge and comfort in knowing what to expect as she enters a different stage sadly.**

Family member of a person with dementia”

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2 Why is dementia progressive?

Dementia is not a single condition. It is caused by different physical diseases of the brain, for example, Alzheimer's disease, vascular dementia, dementia with Lewy bodies (DLB) and frontotemporal dementia (FTD).

In the **early stage** of all types of dementia, only a small part of the brain is damaged. In this stage, a person has fewer symptoms as only the abilities that depend on the damaged part of the brain are affected. These early symptoms are usually relatively minor. This is why 'mild dementia' is used as an alternative term for the early stage.

In the early stage, each type of dementia affects a different area of the brain. This is why symptoms vary between the different types. For example, memory loss is common in early-stage Alzheimer's but is very uncommon in early-stage FTD.

As dementia progresses into the **middle and later stages**, the symptoms of the different dementia types tend to become more similar. This is because more of the brain is affected as dementia progresses.

Over time, the disease causing the dementia spreads to other parts of the brain. This leads to more symptoms because more of the brain is unable to work properly. At the same time, already-damaged areas of the brain become even more affected, causing symptoms the person already has to get worse.

Eventually, most parts of the brain are badly damaged by the disease. This causes major changes in all aspects of memory, thinking, language, emotions and behaviour, as well as physical problems.

For more information about how damage to the brain affects certain skills and abilities, visit **alzheimers.org.uk/about-dementia/stages-and-symptoms/brain-changes-dementia**

3 What affects the speed of progression?

The speed at which dementia progresses varies a lot from person to person because of factors such as:

- **the type of dementia** – for example, Alzheimer's disease tends to progress more slowly than the other types
- **a person's age** – for example, Alzheimer's disease generally progresses more slowly in older people (over 65) than in younger people (under 65)
- **other long-term health problems** – dementia tends to progress more quickly if the person is living with other conditions, such as heart disease, diabetes or high blood pressure, particularly if these are not well-managed
- **delirium** – a medical condition that starts suddenly.

There is no way to be sure how quickly a person's dementia will progress. Some people with dementia will need support very soon after their diagnosis. In contrast, others will stay independent for several years.

Evidence shows that there are things a person with dementia can do to keep their abilities for longer. It can be helpful to:

- maintain a positive outlook
- accept support from other people
- eat and sleep well
- not smoke or drink too much alcohol
- take part in physical, mental and social activities (see factsheet 529 **Physical activity, movement and exercise**).

It is also important for the person to try to keep healthy by:

- managing any existing health conditions as well as possible
- having regular health check-ups, particularly eyes and ears
- asking their GP about jabs – for seasonal flu and pneumococcal infection (which can lead to bronchitis or pneumonia).

This is to prevent health problems developing which can make a person's dementia progress more quickly. For more information, see factsheet 425 **GP support after a dementia diagnosis**.

If the person's mental abilities or behaviour changes suddenly, they may have a separate health problem. This could be an infection that has led to delirium, or a stroke. A stroke is particularly common in some kinds of vascular dementia. Any sudden changes should be discussed with a doctor or nurse as soon as possible.

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“He is declining more rapidly now and is in the late stages of disease. I need to understand and be ready to care for him and meet his needs.”

Family member of a person with dementia

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4 Early stage

Dementia affects everyone differently, and early symptoms are often relatively mild and not always easy to notice. Many people at this stage stay largely independent and only need a bit of assistance with daily living.

It is important to focus on what the person can do, and not to take over and do things for them. Instead, family, friends or carers can try doing things with the person. For example, they can help the person develop a routine, reminder lists and prompts, and use technology.

For more information, see factsheet 526 **Supporting a person with memory loss** (for carers) and booklet 1506 **Keeping active and involved** (for people living with dementia).

The early stage of dementia is when many people choose to make plans for the future, while they still have the ability ('mental capacity') to do so. For more information, see factsheets 472 **Lasting power of attorney** and 463 **Advance decisions and advance statements**.

Symptoms of early-stage dementia

As a very rough guide, the early stage of dementia lasts on average about two years. This stage is when the following common symptoms start to affect the person's daily life:

- The most well-known early-stage symptom is memory problems. For example, a person may not recall recent events or may keep losing items (such as keys and glasses) around the house. Memory loss is often the first and main symptom in early-stage Alzheimer's disease. Although less often, it is also seen in early-stage vascular dementia and DLB. Memory loss is not common in early-stage FTD.
- Difficulties in thinking things through and planning are also common at this stage. A person may get confused more easily and find it harder to plan, make complex decisions (for example, about finances) or solve problems.
- Language and communication are often affected early on. A person may struggle to find the right word in a conversation, or they might not follow what is being said. Speech can also be affected when someone with vascular dementia has had a stroke. Specific types of FTD cause particular early problems with language – see factsheets 500 **Communicating with a person with dementia** and 404 **What is frontotemporal dementia (FTD)?** for more information.

- Poor orientation is another feature of early-stage dementia. A person may no longer recognise where they are and so get lost, even in a place that is familiar to them.
- People may also struggle with visual-perceptual difficulties. This can cause them problems judging distances, for example, when using stairs. Visual-perceptual difficulties are more common in early-stage Alzheimer's disease and DLB than in vascular dementia or FTD. They are different from the visual hallucinations (often of animals or people) that are a feature of early-stage DLB.
- Changes in mood or emotion are common at this stage. The person may be more anxious, frightened or sad, and so at risk of depression. It is also common to become more irritable – perhaps in frustration at lost abilities – or easily upset. A person can often be more withdrawn, lack self-confidence and lose interest in hobbies or people. For more information, see factsheet 444 **Supporting a person with dementia who has depression, anxiety or apathy**.

Changes in behaviour are not common in early-stage dementia, other than in FTD. A person with behavioural variant FTD may lose their inhibitions and behave in socially inappropriate ways. They may also act impulsively and lose empathy for others.

Significant physical changes at this stage tend to be limited to DLB, where problems with movement are similar to Parkinson's disease. If someone with vascular or mixed dementia has a stroke, this can lead to weak limbs on one side of the body.

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My dad has been diagnosed with vascular dementia yet his symptoms seem to have come on suddenly and severely. He is confused, agitated, combative, obsessive and compulsive and does not sleep.

Family member of a person with dementia

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5 Middle stage

In the middle stage of dementia, symptoms become more noticeable and the person will need more support in managing daily life. They may now need frequent reminders and some help to wash and dress (for example, having their clothes laid out for them).

Some people with dementia will benefit from a paid carer coming into their home. Other people may move into housing with dementia support on site (known as 'extra care housing' or 'assisted living').

Symptoms of middle-stage dementia

For many people with dementia, the middle stage is when symptoms will get worse. This is also when changes in behaviour generally start. This stage of dementia is often the longest. On average, it lasts about two to four years, during which time symptoms are likely to develop in the following ways:

- Existing problems with memory and thinking will worsen. Many people find it harder to recognise family or close friends. They may confuse them with strangers. Remembering new information will also get harder. This may cause the person to repeat the same question over and over.
- The way a person speaks or uses language is likely to get worse at this stage too. They may have problems finding the right word and they may forget what they are saying mid-sentence. It may get harder for them to follow what someone else is saying.
- Problems with orientation also become more severe. Someone may get confused about the time of day – for example, they may get up and dressed in the middle of the night. Or they might get confused about where they are, even at home.
- Symptoms of apathy, depression and anxiety tend to continue into the middle stage of dementia.
- In this stage, many people start to strongly believe things that aren't true (delusions). They often feel that other people are going to harm them or cannot be trusted (paranoia). It is very common for a person to believe that someone is stealing from them or that a partner is being unfaithful.
- A person at this stage may also start to see and hear things that aren't there (hallucinations). This is more common in the middle stage of Alzheimer's disease than in vascular dementia (visual hallucinations in DLB are a symptom in the early stage).

Changes like these partly explain why the person can struggle to control their emotions. Someone may get very easily upset, fearful or angry – and switch between these quite quickly. They might be reacting to a loss of independence, misinterpreting things around them or frustrated that they can't communicate their needs.

For more information, see factsheet 524 **Understanding and supporting a person with dementia**.

Physical and behavioural changes in the middle stage of dementia

Changes in behaviour tend to start from the middle stage of dementia. These changes are common, and individual symptoms may come and go. Changes in behaviour are some of the most challenging symptoms for people with dementia and for those who support them.

Common changes that are seen in all types of dementia at this stage can include:

- agitation and restlessness – for example, fidgeting or walking up and down
- screaming or shouting
- repetitive behaviour – for example, repeatedly pulling at clothes or asking the same question over and over
- following a carer around (trailing) or constantly checking that they are near
- disturbed sleep patterns – sleep is particularly disrupted, and in a different way, in a person with DLB
- losing inhibitions – for example, saying things that aren't appropriate or undressing in public (not just in FTD).

People may become more agitated, aggressive or confused in the late afternoon or early evening, a pattern known as 'sundowning'.

These behaviours are often because the person has a specific physical or emotional need (for example, hunger or boredom) that is not being met. For more information about these changes and how to deal with them, see factsheets 525 **Changes in behaviour**, 509 **Aggressive behaviour** and 501 **Walking and dementia**.

In all types of dementia, difficulties with using the toilet can start at this stage. In DLB, problems with movement are likely to get worse. A person's walking gets slower and less steady, leading to a higher risk of falls.

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6 Later stage

By the later stage, dementia will have a severe impact on most aspects of a person's life. They will eventually need full-time care and support with daily living and personal care, such as eating, washing and dressing. This support can be provided by care at home but is more often given in a care home setting.

Symptoms of later-stage dementia

Symptoms of all kinds are likely to cause the person considerable difficulties by this stage, but altered perception and physical problems are often the most noticeable. By the later stage, the symptoms of all types of dementia become very similar. This stage tends to be the shortest. On average, it lasts about one to two years.

For more information, see factsheet 417 **Supporting a person in the later stage of dementia**.

Memory and language difficulties in the later stage of dementia

Many people will struggle with memory of recent events, and they may often think they are at an earlier period of their life ('time-shifting'). This can cause challenging situations, for example, if they ask to see someone who is no longer alive.

People in the later stage may also stop recognising familiar places, objects and people. A person may not recognise themselves in a mirror, nor a close friend or family member. This is because they only remember how the person looked when they were much younger.

If a person speaks more than one language, they may lose the one they learnt later in life. Eventually, they may only understand the language of their childhood.

A person's spoken language in later-stage dementia may eventually be reduced to a few words or lost altogether. They may also understand fewer words. But a person may still be able to understand gestures, facial expressions and body language. They may also use non-verbal communication to express their feelings or needs.

Mood, emotions and perceptions in the later stage of dementia

Changes in mood remain in the later stage of dementia. Depression and apathy are particularly common.

Delusions and hallucinations (especially of sight and hearing) are most common in the later stage of dementia. They are not always distressing but they can explain some changes in behaviour, because the person's perception of reality is altered.

People with later-stage dementia often respond more to senses than to words. For example, they may like listening to songs or enjoy textures (such as the feel of different types of material).

Behavioural changes in the later stage of dementia

The changes in behaviour that can happen in the middle stage of dementia can also all happen in the later stage.

Aggression at this stage is often a reaction to personal care. Someone may hit or push away those trying to help them, or shout out to be left alone. The person with dementia may have felt scared, threatened or confused.

Restlessness is also very common. Sometimes, the person may seem to be searching for someone or something.

As in other stages, it is also important to consider whether the person has other needs that aren't being met. Someone with later-stage dementia will often be unable to tell others how they are feeling. A sudden change in behaviour can point to a medical problem (for example, pain, infection or delirium).

Physical difficulties in the later stage of dementia

The physical changes of later-stage dementia are partly why the person is likely to need much more support with daily living. At this stage, they may:

- walk more slowly, with a shuffle and less steadily – eventually they may spend more time in a chair or in bed
- be at increased risk of falls
- need a lot of help with eating – and so lose weight
- have difficulty swallowing
- be incontinent – losing control of their bladder and bowels.

The person's reduced mobility in particular raises their chances of blood clots and infections. These can be very serious or even fatal, so it is vital that the person is supported to be as mobile as they can.

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How long will a person with dementia live for?

Whatever kind of dementia a person has, their life expectancy is on average lower. This is why dementia is called a terminal condition.

This can be very upsetting to think about. However, it's important to remember that, no matter how a person's dementia changes over time, there are ways to live well with the condition. Good support can make a huge difference to the person's quality of life at all stages.

Dementia reduces life expectancy in two ways. First, some of the diseases that are closely linked to Alzheimer's disease and vascular dementia, such as diabetes and cardiovascular disease, lower life expectancy. For example, vascular dementia is closely linked to heart disease and stroke. A person with vascular dementia is at risk of dying from one of these at any stage of dementia.

The other way that dementia reduces life expectancy is through the effects of severe disease. By the later stage, a person is often very frail with a weakened immune response, likely to be spending a lot of time in bed and possibly having problems swallowing. These all make them much more likely to develop other medical problems that can lead to death, such as infections (like pneumonia) or cardiovascular problems (like a blood clot in the brain or lungs). This is why the later stage of dementia is often the shortest.

A person with dementia can also die at any stage from another condition not closely related to their dementia. Cancer and lung disease are common examples.

How long a person lives with dementia varies greatly from person to person. It depends on many factors, such as the ones listed on page 3. Other factors include:

- how far the dementia had progressed when the person was diagnosed
- what other serious health conditions the person has – such as diabetes, cancer or heart problems (and how long they have had these)
- how old the person was when their symptoms started – older people (over 65) are more likely than younger people (under 65) to have other health conditions that may lower their life expectancy. A person in their 90s who is diagnosed with dementia is more likely to die from other health problems before they reach the later stage than a person diagnosed in their 70s.

"I have been caring for my partner for the last five years. She has previously undiagnosed late stage dementia but finally lost all mobility and had to be admitted to hospital. I'm feeling desperately guilty."

Partner of a person with dementia

Does the type of dementia affect life expectancy?

The type of dementia a person has can also affect how long they live with dementia. These figures for the number of years a person may live after a diagnosis are just averages, and some people live longer. This information may be upsetting to read and think about but it is very important to remember that, with the right support, people with dementia can live well at all stages.

The average life expectancy figures for the most common types of dementia are as follows:

- **Alzheimer's disease** – around eight to 10 years. This is lower if the person is diagnosed in their 80s or 90s. A few people with Alzheimer's live for longer, sometimes for 15 or even 20 years.
- **Vascular dementia** – around five years. This is lower than the average for Alzheimer's, mostly because someone with vascular dementia is more likely to die from a stroke or heart attack than from the dementia itself.
- **Dementia with Lewy bodies (DLB)** – around six years. This is slightly lower than the average for Alzheimer's disease. The physical symptoms of DLB increase a person's risk of falls and infections.
- **Frontotemporal dementia (FTD)** – around six to eight years. If a person has FTD mixed with motor neurone disease (a movement disorder), their dementia tends to progress much quicker. Life expectancy for people who have both conditions is on average about two to three years after diagnosis.

To find out about the support available to someone at the end of their life, and to their carers, family and friends, see factsheet 531 **End of life care**.

You can also call our Dementia Support Line on **0333 150 3456** for personalised advice and support on living well with dementia, at any stage.

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My Dad has alzheimers and I need to know how long we have left.

Family member of a person with dementia

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Other useful organisations

Carers UK

0808 808 7777 (helpline, 9am–6pm Monday–Friday)
advice@carersuk.org
www.carersuk.org

Carers UK provides advice, information and support for carers.

The Lewy Body Society

01942 914000
info@lewybody.org
www.lewybody.org

The Lewy Body Society raises awareness of DLB among the general public, medical professionals and decision makers. It also provides information resources for people with DLB and carers.

Rare Dementia Support

020 3318 0243 (voicemail)
contact@raredementiasupport.org
www.raredementiasupport.org

Rare Dementia Support works to support people affected by seven rare dementia conditions: familial Alzheimer's disease (FAD), frontotemporal dementia (FTD), familial frontotemporal dementia (fFTD), Lewy body dementia (LBD), posterior cortical atrophy (PCA), primary progressive aphasia (PPA) and young-onset Alzheimer's disease (YOAD).

Stroke Association

0303 3033 100 (Stroke Helpline, 9am–5pm Monday–Friday; 10am–1pm Saturday)
helpline@stroke.org.uk
www.stroke.org.uk

The Stroke Association is the UK's leading stroke charity. They provide information and practical support to people concerned about or affected by stroke.



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This factsheet has been reviewed by people affected by dementia.

To give feedback on this factsheet, or for a list of sources, please email **publications@alzheimers.org.uk**

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We are reviewing this publication. If you would like to give us any feedback, you can email us at **publications@alzheimers.org.uk** or call us at **020 7423 7455**.

At Alzheimer's Society we're working towards a world where dementia no longer devastates lives. We do this by giving help to everyone who needs it today, and hope for everyone in the future.

We have more information **About dementia**.

For advice and support on this, or any other aspect of dementia, call us on **0333 150 3456** or visit **alzheimers.org.uk**

Thanks to your donations, we're able to be a vital source of support and a powerful force for change for everyone living with dementia. Help us do even more, call **0330 333 0804** or visit **alzheimers.org.uk/donate**

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Alzheimer's Society

It will take a society to beat dementia

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