The progression of Alzheimer’s disease and other dementias

Each person experiences dementia in their own way, but the way the condition progresses can be seen as a series of stages. This factsheet outlines the characteristics of the early, middle and late stages of Alzheimer’s disease and briefly looks at how other forms of dementia progress.

While it can be helpful for planning ahead to have some awareness of the likely progression of a person’s dementia, it is important to realise that everyone’s experience will be different. It is much more important to focus on trying to live well with dementia, meeting the needs of the person at that time, than to focus only on which stage they are in.

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The progression of Alzheimer’s disease and other dementias

Dementia as a progressive condition

The most common types of dementia – Alzheimer's disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia – are all progressive. This means that the structure and chemistry of the brain become increasingly damaged over time. The person's ability to remember, understand, reason and communicate will gradually decline. As dementia worsens, the person will need more and more support with daily living. Their behaviour and mood will also change.

Health professionals often use scales to measure these changes. At different times they may assess a person’s mental ability (in a Mini Mental State Examination for example), daily living skills (such as dressing or managing medication), behaviours, overall functioning or quality of life. Some of these scales were developed specifically for Alzheimer’s disease and work better for that than for other types of dementia. Assessment of the extent of someone’s dementia should take account of these scales but should also take a broader view of the person, including their capabilities and needs.

Looking at dementia as a series of three stages – early, middle and late – can be a useful way of understanding the changes that occur over time. However, it is important to realise that this view of dementia can only provide a rough guide to the course of the illness.

This is because:

- some symptoms may appear earlier or later than indicated here, in a different order, or not at all
- the stages may overlap – the person may need help with one task, but may be able to manage another activity on their own
- some symptoms, such as irritability, may appear at one stage and then vanish, while others, such as memory loss, will worsen over time.
The way that a person experiences dementia will depend on many factors. These include their physical make-up, other illnesses they may have, their emotional resilience, the medication they take and the support they can rely on.

**Before dementia develops**

There is good evidence that, by the time most people develop any symptoms of dementia, the underlying disease has been causing damage to their brain for years. Researchers are very interested in this ‘pre-symptomatic’ period and have developed tests to look at the brain chemistry, function and structure at this time. It is likely that any medication designed to slow down or prevent the diseases that cause dementia would work in this early phase, before the disease is fully established.

Over time, the changes in the brain will begin to cause mild symptoms, but which are initially not bad enough to count as dementia. Subtle problems in areas such as memory, reasoning, planning or judgement may cause difficulties with more demanding tasks (such as preparing a meal) but they will not yet significantly affect daily life. A person at this stage may be given a diagnosis of mild cognitive impairment (MCI). About 10–15% of people with this diagnosis will go on to develop dementia each year. For more information see factsheet 470, *What is mild cognitive impairment (MCI)?*.

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**Rate of progression**

The speed at which dementia worsens varies widely. There are some differences between the different dementias – Alzheimer’s disease, for example, seems to have the slowest progression on average – but much of the variation is from person to person. A wide range of factors influence how quickly someone’s dementia will progress. These include age – people who develop symptoms before 65 often have a faster
progression. Evidence also suggests that a person's genes play a role, as does someone's overall physical health. People with poorly controlled heart conditions or diabetes, those who have had several strokes or those who have repeated infections are all likely to have a faster deterioration.

On the positive side, there is some evidence that keeping active and involved can help a person with dementia retain abilities for longer. Regular physical exercise in particular seems to slow the rate of decline. For more information see factsheet 529, *Exercise and physical activity*.

Some of these factors affect the underlying disease processes in the brain, while others do not but still help with dementia symptoms. Those supporting someone with dementia should help them to stay active – physically, mentally and socially. The person with dementia should also try to eat healthily, get enough sleep, take medications as advised and not smoke or drink too much alcohol. It is also important for the person to have regular check-ups (for eyes, ears, teeth and feet) and vaccinations, and to keep a careful eye on underlying health conditions. A sudden change in the person’s abilities or behaviour could indicate a physical or psychological health problem or an infection.

**Alzheimer’s disease**

Alzheimer’s is the most common type of dementia and the most studied. Its progression can be summarised in three stages. Progression of the other common dementias can then be compared with Alzheimer’s disease.

Each type of dementia tends to have particular early symptoms, because different parts of the brain are affected first. Later on, as damage spreads to more areas of the brain, the symptoms of different types of dementia tend to become more similar. By the late stage, the person will need a high level of care, whatever type of dementia they have.

**Early (‘mild’) stage**

Alzheimer’s disease usually begins with very minor changes in the person’s abilities or behaviour. At the time, such signs can often be mistakenly attributed to stress or bereavement or, in older people, to the normal process of ageing. It is often only when looking back that it is realised that these signs were probably the beginnings of dementia.
Loss of memory of recent events is a common early symptom. The person will have difficulty recalling things that happened recently and also with learning new information. Someone with Alzheimer’s may:

- mislay items around the house
- forget recent conversations or events
- struggle to find the right word in conversation or lose the thread of what is being said
- become slower at grasping new ideas and unwilling to try out new things
- become confused or lose track of the day or date
- show poor judgement, or find it harder to plan or make decisions
- have problems judging distance or seeing objects in three dimensions (for example, when navigating stairs or parking the car)
- lose interest in other people or activities.

If you are caring for someone with Alzheimer’s disease, there’s a lot you can do in the early stages to help them maintain their independence. It may be tempting to do things for them, but they are more likely to retain their sense of self-worth and independence if they are given the chance to do things for themselves, with support if necessary. Focus on what the person can do, rather than what they cannot. Explore how things can be achieved in a different way.

The person may also become anxious, irritable or depressed. They may experience distress over their failure to manage tasks and may need some reassurance. If this is the case, talk to them and give them as much emotional support as you can. For more information see factsheet 444, Apathy, depression and anxiety.

Middle (‘moderate’) stage
As Alzheimer’s disease progresses, the changes become more marked. The person will need more support to help them manage their day-to-day life. They may need frequent reminders or help to eat, wash, dress and use the toilet. They are likely to become increasingly forgetful – particularly of names – and may sometimes repeat the same question or sentence over and over. They may also fail to recognise people or confuse them
with others. At this stage, the person might put themselves or others at risk through their forgetfulness, for example by not lighting the gas on the cooker or forgetting to take medication.

Some people at this stage become very easily upset, angry or aggressive – perhaps because they are feeling frustrated or because they misinterpret what is happening – or they may lose their confidence and need a lot more support or reassurance. Other symptoms may include:

- becoming confused about where they are, or walking off and becoming lost
- muddling up time and getting up at night because they are mixing up night and day
- behaving in ways that may seem unusual, such as going outside in their nightclothes, becoming very agitated or unknowingly behaving in socially inappropriate ways
- experiencing difficulty with perception and, in some cases, having delusions (strongly believing things that are not true) or, less often, hallucinations (usually, seeing things that are not really there).

Changes in behaviour tend to be most common from the middle stage of dementia onwards and are one of the most challenging aspects of dementia for carers. For more information about these symptoms and how to deal with them see factsheets 525, Changes in behaviour, 509, Dementia and aggressive behaviour, 501, Walking about, and 527, Sight, perception and hallucinations in dementia.

**Late (‘severe’) stage**

At this stage, the person with Alzheimer’s will need even more help and will gradually become totally dependent on others for nursing care. Loss of memory may become very pronounced, with the person unable to recognise familiar objects, surroundings or even those closest to them, although there may be sudden flashes of recognition.

The person may also become increasingly weak. They may start to shuffle or walk unsteadily, eventually spending more time in bed or a wheelchair.
Other symptoms may include:

- difficulty eating and, sometimes, swallowing
- considerable weight loss, although some people eat too much and put on weight
- incontinence – losing control of their bladder and sometimes their bowels as well
- gradual loss of speech, though the person may repeat a few words or cry out from time to time.

The person may become restless, sometimes seeming to be searching for someone or something. They may become distressed or aggressive, especially if they feel threatened in some way. Angry outbursts may occur during close personal care, usually because the person does not understand what is happening. Those caring for the person should try not to take this personally – the person is not being deliberately aggressive. It is also important to consider that the person may be experiencing pain which they cannot express verbally. Painkillers can often help.

Although the person may seem to have little understanding of speech, and may not recognise those around them, they may still respond to affection and to being talked to in a calm, soothing voice. They may also enjoy scents, music or stroking a pet.

On average, people with Alzheimer’s disease live for eight to ten years after their symptoms begin. However, life expectancy does vary considerably depending on how old the person is and other factors as mentioned above. For example, people whose symptoms started in their 60s or early 70s can expect to live for around seven to ten years, whereas someone whose symptoms started in their 90s will, on average, live for about three years. The length of time that someone with Alzheimer’s can expect to live for also depends on whether they were diagnosed early on or later in the course of the disease.

For more information about this stage of Alzheimer’s disease see factsheet 417, The later stages of dementia. For more detailed information about Alzheimer’s disease in general see factsheet 401, What is Alzheimer’s disease?
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Vascular dementia

Vascular dementia develops when brain cells are deprived of oxygen and die. This happens either because of diseases of the very small blood vessels deep in the brain (known as subcortical vascular dementia), or after a major stroke or a series of smaller strokes (both known as stroke-related dementia).

It is sometimes difficult to tell whether a person has Alzheimer’s disease or vascular dementia. It is also not unusual to have a mixed form of dementia, meaning the person has both vascular dementia and Alzheimer’s disease together.

Subcortical and stroke-related vascular dementia share some symptoms but have others that differ. They also tend to progress in different ways. Subcortical vascular dementia usually develops gradually and progresses slowly, like Alzheimer’s disease. In contrast, when vascular dementia follows a large stroke, symptoms usually develop suddenly. Stroke-related dementia often then follows a ‘stepped’ progression, with long periods when symptoms remain the same and short periods when they suddenly worsen. (This pattern is seen because each stroke further damages the brain.)

The symptoms of vascular dementia are overall broadly similar to those of Alzheimer’s disease – and become more similar as the dementia progresses – but with some important differences. The main early symptoms of vascular dementia are often not forgetfulness but rather:

- difficulties with planning or organising, following steps (for example, cooking a meal) or making decisions
- slower speed of thought
- problems concentrating, including short periods of confusion.
You can help someone with vascular dementia by breaking tasks down into smaller steps and giving them plenty of time to think and speak.

A person with early stage vascular dementia is prone to apathy, mood swings and being unusually emotional. They are also particularly likely to have anxiety and depression, partly because they are more aware of the problems their dementia is causing.

Vascular dementia after a major stroke is often accompanied by physical symptoms, such as weakness of a limb, or problems with vision or speech. These early symptoms arise when the stroke has damaged a particular part of the brain. With rehabilitation the symptoms might get a little better or stabilise for a time.

As vascular dementia progresses, the symptoms become closer to those of middle and eventually later stage Alzheimer’s disease. Problems with memory loss, confusion, disorientation, reasoning and communication all become worse. The behavioural changes seen as vascular dementia progresses, such as irritability and agitation, are also similar to those of Alzheimer’s disease. Delusions, and less often hallucinations, are also seen. The late stage of vascular dementia is largely as described above for Alzheimer’s disease.

Each person will experience dementia differently. On average, people with vascular dementia live for around five years after symptoms begin, less than the average for Alzheimer’s disease. In many cases, the person’s death will be caused by a stroke or heart attack. For more information see factsheet 402, What is vascular dementia?

**Dementia with Lewy bodies**

Dementia with Lewy bodies gets its name from microscopic deposits that are found in the brains of people with the condition. These deposits cause damage to, and the eventual death of, nerve cells in the brain. Dementia with Lewy bodies develops slowly and tends to progress gradually, like Alzheimer’s disease.
Parkinson's disease is also caused by Lewy bodies and some symptoms of this disease are shared with dementia with Lewy bodies. Early symptoms of this type of dementia may also overlap with those of Alzheimer’s disease, but there are several important differences.

Unlike Alzheimer’s disease, in the early stages of dementia with Lewy bodies the person’s attention and alertness often vary widely from day to day, or even during the course of a single day. This can often be puzzling for those around them.

It is sometimes difficult to tell whether a person has Alzheimer’s disease or vascular dementia. It is also not unusual to have a mixed form of dementia, meaning the person has both vascular dementia and Alzheimer’s disease together.

Most people with dementia with Lewy bodies also have recurrent visual hallucinations. These are much more common than in early Alzheimer’s disease and are very detailed, often of animals or people. Misperceptions and auditory hallucinations (hearing sounds that are not real) are also very common. These symptoms may explain why people with this dementia often falsely believe that they are being persecuted.

Half or more of those affected by dementia with Lewy bodies have movement problems when the dementia is diagnosed, and this proportion increases as dementia progresses. These symptoms are like those of Parkinson’s disease, such as slowness of movement, stiffness and sometimes tremor. The person may also have difficulty judging distances and be prone to problems with balance, falls and fainting.

As dementia with Lewy bodies progresses, some of the symptoms become more like those of middle or late stage Alzheimer’s disease, including greater problems with day-to-day memory and behaviours that challenge, such as agitation, restlessness or shouting out. Worsening of Parkinson-type symptoms means that walking gets slower and less steady. The risk of falls remains high. The combination of symptoms in a person with dementia with Lewy bodies can be particularly stressful for family and carers.
After the symptoms of dementia with Lewy bodies begin, people live on average for six to twelve years. However, each person will experience dementia with Lewy bodies differently. For more information see factsheet 403, *What is dementia with Lewy bodies (DLB)?*

**Frontotemporal dementia (including Pick’s disease)**

This type of dementia is caused by damage to the frontal and/or temporal lobes at the front and sides of the brain by the ears. These are the areas responsible for our behaviour, our emotional responses and our language skills. There are three different types of frontotemporal dementia – one type that affects behaviour first, and two that affect language first.

During the early stages of frontotemporal dementia, memory of recent events may be unaffected. However, there will be other changes.

A person with behavioural variant frontotemporal dementia may appear uncharacteristically selfish and unfeeling. They may behave rudely, or may seem more easily distracted. Other early symptoms may include loss of inhibition, ritualised behaviour (such as tapping or repeatedly walking the same route) or compulsions and a liking for sweet foods. It is much more likely for those around the person to be aware of these changes than the person is themselves.

In a small number of people with frontotemporal dementia, the first symptoms are problems with recalling the names of objects and understanding words (semantic dementia) or with producing fluent speech (progressive non-fluent aphasia).

As frontotemporal dementia progresses, differences between these types lessen: people with the behavioural variant develop language problems and those with language problems develop behaviour changes. In the later stages, the symptoms of frontotemporal dementia become more similar to those of Alzheimer’s disease. There are some differences – for example, day-to-day memory loss and problems judging distance or seeing objects in three dimensions develop later in frontotemporal dementia, whereas changes in behaviour, such as agitation or aggression, develop earlier. Supporting a person with frontotemporal dementia can be a
challenge as they may be younger and will have changes in behaviour and communication.

Each person’s experience of frontotemporal dementia will be different, but on average people live for six to eight years after symptoms begin. For more information see factsheet 404, *What is frontotemporal dementia (FTD)*?