

What is young-onset dementia?

People with dementia whose symptoms started before they were 65 are often described as 'younger people with dementia' or as having young-onset dementia. The age of 65 is used because it is the age at which people traditionally retired. However, this is an artificial cut-off point as opposed to having any biological significance.

There are estimated to be at least 42,000 younger people with dementia in the UK, or more than 5 per cent of all those with dementia. Other terms used for dementia that started before age 65 include 'early-onset dementia' and 'working-age dementia'. This factsheet refers to young-onset dementia as this is the term preferred by many people with the condition.

The symptoms of dementia may be similar regardless of a person's age, but younger people often have different needs, and therefore require some different support. This factsheet looks at the types of dementia that younger people have, some of the difficulties they might experience and where the necessary support can be found. The main sections, in the following order, are:

Dementia in younger people

What are the main differences between young-onset dementia and dementia in older people? This section outlines the key facts.

What causes young-onset dementia?

There are many different types of dementia and other causes that relate to younger people. This section explains these in greater detail. It also covers the rarer forms of dementia, progression and other causes. These are explained in the following order:

- Alzheimer's disease
- Vascular dementia
- Frontotemporal dementia
- Dementia with Lewy bodies
- Alcohol-related brain damage
- Rarer forms of dementia
- Progression
- Other causes

Diagnosis

Recognising the symptoms is vital to getting a correct diagnosis. This section is about:

- Seeing a specialist
- Genetic testing

Particular issues faced by younger people

Younger people face different issues than those experienced by older people. This section outlines how younger people can cope with the challenges of a diagnosis and how they can continue with everyday life.

Treatment

Getting the right treatment is essential to helping a person live well with dementia. This section advises on what help and support is available.

Age-appropriate services

Keeping active and involved is important for younger people living with dementia. This section offers advice on:

- Services for younger people
- Finding age-appropriate services and support

Other useful organisations

There are many organisations that can be useful in offering further advice and support. The last section provides a list of such places that can help.

Dementia in younger people

Early-onset dementia is caused by broadly similar diseases to dementia in older people ('late-onset dementia'), but there are some important differences. There is a wider range of diseases that cause young-onset dementia and a younger person is much more likely to have a rarer form of dementia.

Young-onset dementia is also more likely to cause problems with movement, walking, co-ordination or balance. This is one reason why younger people with dementia may see a neurologist (a specialist in diseases of the brain and nervous system) rather than – or as well as – a psychiatrist (a specialist in mental health).

However, people under 65 do not generally have the co-existing long-term medical conditions of older people – especially diseases of the heart and circulation. They are usually physically fitter and dementia may be the only serious condition that a younger person is living with.

Early-onset dementia is more likely than late-onset dementia to be hereditary. In perhaps 10 per cent of all people with young-onset dementia the condition seems to have been inherited from a parent. If dementia has been inherited, the diagnosis may have implications for birth relatives of the person such as their siblings (brothers and sisters) or children.

What causes young-onset dementia?

The most common causes of young-onset dementia are the same progressive diseases that cause most cases of dementia in older people. Studies have produced a range of figures that show the causes of young-onset dementia. It is clear that the mix of causes of young-onset dementia is different from that in older people. The same disease in younger people can also have different symptoms. It is also sometimes thought that dementia progresses more rapidly in younger than in older people, but the evidence for this is not strong.

Early onset of common dementias

Alzheimer's disease

Alzheimer's disease develops when proteins build up in the brain to form structures called 'plaques' and 'tangles'. Alzheimer's is the most common type of dementia in younger people and may affect 30 to 35 per cent of younger people with dementia. However, this is a much smaller proportion than in older people with the condition, up to two thirds of whom have Alzheimer's disease.

Another difference is that younger people are much more likely to have an 'atypical' (ie unusual) form of Alzheimer's disease than older people. Atypical Alzheimer's disease is when the first symptoms are not memory loss, which is the most common symptom of late-onset Alzheimer's disease. Instead, the first symptoms are usually problems with vision (in posterior cortical atrophy), speech (in logopenic aphasia) or planning, decision-making and behaviour (in frontal variant Alzheimer's disease). These atypical forms of Alzheimer's disease account for up to one third of all Alzheimer's disease in

younger people but only 5 per cent of all Alzheimer's disease in older people. For more see factsheet 401, **What is Alzheimer's disease?**

In some people with early-onset Alzheimer's disease there is a very clear inheritance of the disease from one generation to the next. This genetic form of the dementia – familial Alzheimer's disease – is caused by rare mutations (defects) in three genes. These mutations are found in between 7 and 12 per cent of all people with early-onset Alzheimer's.

Symptoms of familial Alzheimer's disease usually start in someone's 30s, 40s or 50s; the earlier the symptoms start, the more likely the disease is to be genetic. However, familial Alzheimer's disease is extremely rare. It affects only about 500 known families worldwide and probably accounts for much less than 1 per cent of Alzheimer's disease when all ages, young or old, are considered.

People with Down's syndrome and other learning disabilities can also develop dementia at an early age (see factsheet 430, **Learning disabilities and dementia**). Alzheimer's disease is the most common type of dementia in people with Down's syndrome. This increased risk is thought to be associated with the extra copy of chromosome 21 which most people with Down's syndrome have. Chromosome 21 carries the gene for amyloid which forms the plaques in Alzheimer's disease.

Vascular dementia

Vascular dementia occurs when there are problems in the blood supply to the brain. It is closely linked to diabetes and to cardiovascular diseases such as stroke and heart disease. It is probably the second most common type of dementia in younger people – around 15 per cent of dementia in this age group may be vascular dementia.

Symptoms of vascular dementia vary. Early memory loss is less common than in Alzheimer's disease, whereas problems with thinking things through and slower speed of thought are more common. When vascular dementia follows a stroke, physical symptoms (eg limb weakness) are common. For more, see factsheet 402, **What is vascular dementia?**

There is a genetic form of vascular dementia known as CADASIL (cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy). CADASIL is rare and is most common in people aged 30 to 50. Symptoms include migraines, repeated strokes, fits, low mood and progressive loss of mental abilities. CADASIL is caused by defects in a gene called NOTCH3 and is inherited in a simple pattern similar to familial Alzheimer's disease.

Frontotemporal dementia

Frontotemporal dementia is caused by damage to the lobes at the front and/or sides of the brain. Around 10 to 15 per cent of younger people with dementia may have this form – much higher than in older people. Frontotemporal dementia is most often diagnosed between the ages of 45 and 65. This is in contrast to Alzheimer's disease, vascular dementia and dementia with Lewy bodies, all of which become more likely with age.

There are three different types of frontotemporal dementia – the behavioural variant, which causes changes in personality and behaviour first, and two types in which language is affected first. For more see factsheet 404, **What is frontotemporal dementia?**

In around 30 per cent of people with this type of dementia, there is good evidence that the disease is genetic. In this instance, genetic counselling and testing may be offered (see 'Genetic testing').

Dementia with Lewy bodies

This type of dementia is caused by the build-up of tiny protein deposits (Lewy bodies) in the brain. About 5 per cent of younger people with dementia may have dementia with Lewy bodies. Lewy bodies also cause Parkinson's disease and about one third of people with Parkinson's eventually develop dementia. Symptoms of dementia with Lewy bodies include varying levels of alertness, and people can also develop hallucinations and the features of Parkinson's disease (eg slower movement, stiffness, trembling of the limbs). For more see factsheet 403, **What is dementia with Lewy bodies?**

Alcohol-related brain damage

Alcohol-related brain damage includes Korsakoff's syndrome and alcoholic (or alcohol-related) dementia. It occurs in people, most often in their 50s, who regularly consumed excessive amounts of alcohol. Alcohol-related brain damage is caused by a lack of thiamine (vitamin B1), direct damage to nerve cells from alcohol, head injuries (eg falls, fights) and a poor diet.

At least 10 per cent of younger people with dementia may have alcohol-related brain damage. Symptoms overlap with those of Alzheimer's disease and vascular dementia. Alcohol-related brain damage differs from common dementias because it can be halted or even reversed in some people with treatment, abstinence and a good diet (see factsheet 438, **What is alcohol-related brain damage?**).

Rarer forms of dementia

Around 20 to 25 per cent of younger people with dementia are thought to have a rarer cause of the condition – a much higher proportion than in older people (see factsheet 442, **Rarer causes of dementia**). These causes include degenerative neurological conditions (where there is progressive damage to the nervous system) such as Huntington's disease, progressive supranuclear palsy, corticobasal degeneration and Creutzfeldt-Jakob disease (CJD).

In most cases these diseases cause problems with movement as well as dementia. Some of these rarer causes of dementia, such as CJD, can progress very rapidly over just a few months.

Progression

Everyone's experience of dementia is different, but for all the dementias mentioned above most people will become more frail as the condition progresses. This means that they will gradually become dependent on others for their care.

This may be very difficult for all those affected to think about. However, knowing this can enable the person with dementia to think ahead about the kind of treatment and care they might want. Many people decide to set up a Lasting power of attorney or make an advance decision before they reach this stage. This gives the person input into how they will be cared for. It also allows carers and family to think about these aspects too. For more on 'advance care planning' see factsheets 472, **Lasting power of attorney** and 463, **Advance decisions and advance statements**.

Other causes

A wide range of other diseases can cause symptoms of dementia, often along with other symptoms (eg spleen or liver problems) which can be very different.

These diseases include inherited metabolic disorders such as Gaucher's disease, Tay Sach's disease and Niemann-Pick's disease. These develop more often in childhood or adolescence and so their development in someone's 30s or 40s is much later than usual.

Other causes of dementia symptoms in younger people include hormone disorders (eg thyroid problems, Addison's disease), vitamin (eg B12) deficiencies, inflammatory conditions (eg multiple sclerosis) and infections (eg HIV). Memory problems can also be caused by sleep apnoea, where breathing stops for a few seconds or minutes during sleep.

These conditions are not discussed further here but it is important that they are diagnosed because some (eg vitamin deficiency, thyroid problems, sleep apnoea) can be treated.

Diagnosis

Getting an accurate diagnosis is important but can take longer for a younger person. This delay is due in part to a lack of awareness that dementia can affect younger people. Medical professionals such as GPs often misdiagnose younger people as being depressed or

anxious, experiencing relationship difficulties or suffering from the effects of stress. For women, symptoms may also be put down to the start of the menopause.

The delay in diagnosis is also partly because the symptoms of young-onset dementia are so varied. Young-onset dementia less often appears as memory loss, which is the most common symptom of dementia in older people. Instead, it more often appears as changes in behaviour (eg apathy, irritability) or personality (eg loss of empathy).

The contribution of family members and carers is often very important in helping to reach a correct diagnosis. Many friends and relatives say that – when they look back – the first sign was that the person did not seem quite themselves. For many, the person started to make mistakes and struggle at work even if their job had not changed. For others, problems with close relationships were the first signs. Keeping a symptom diary may be useful if you suspect something is not right.

The process of assessment and diagnosis for suspected young-onset dementia is broadly similar to that in an older person and usually starts with the GP (see factsheet 426, **Assessment and diagnosis**). However, there is a wider range of possible causes of symptoms in a younger person and so a particularly thorough assessment is needed. If young-onset dementia is suspected, the GP will generally refer the person to a specialist.

Seeing a specialist

The type of consultant the person will be referred to may vary; there are no standard pathways for assessment and the route to diagnosis can be complicated. Older people with suspected dementia are often referred to a memory assessment service and seen by an old age psychiatrist. Assessment and diagnosis in a younger person may follow this route but they are more likely than an older person to see a consultant neurologist or general adult psychiatrist. It is not unusual for a younger person to see several different specialists before getting a diagnosis.

In a few areas there are specialist diagnostic services for younger people with suspected dementia. These tend to be led by professionals – old age psychiatrists, neurologists, sometimes clinical psychologists – who have a special interest in cognitive problems (to do with memory or thinking) and dementia. A specialist diagnostic service should help younger people get faster and easier access to care. However, there is recent evidence that such services are becoming less common because of changes to the way NHS services are being delivered.

Assessment will often include extensive tests of mental abilities, behaviour and daily functioning, a full physical exam and at least one brain scan – often including more specialist scans. A lumbar puncture, a procedure to collect and analyse fluid around the spine, may be useful. It will also be better tolerated by a physically fit younger person than by a potentially frail older person.

Genetic testing

A person who is suspected of having frontotemporal dementia or early-onset Alzheimer's disease and who has a strong family history of that form of dementia may be offered genetic testing. This is to see whether they have a mutation that has caused the dementia. In some cases such 'diagnostic genetic testing' will confirm the dementia type and show that the dementia is genetic.

Genetic testing needs careful consideration because if a mutation is found this has implications for the person's birth relatives. Each child or sibling (brother or sister) will have a 50 per cent chance of carrying any mutation that is found. The strong inheritance of genetic frontotemporal dementia and the much rarer familial Alzheimer's disease means that anyone who has a mutation will almost certainly develop the dementia. For more about genetic testing see factsheet 405, **Genetics of dementia**.

Particular issues faced by younger people

One major issue facing a person with young-onset dementia is that their symptoms may be very different from the memory loss usually

associated with dementia in older people. They could have, for example, problems with behaviour, vision or language.

The other main issue is often the stage of life at which the person develops the condition. Many younger people with dementia report that the diagnosis was harder to accept because it was completely unexpected and had come 'at the wrong time' in their lives. As well as fear about the future, the diagnosis can cause feelings of loss, guilt or anger. The whole family finds it has to adjust to a wide range of changes.

In general, younger people with dementia are more likely to:

- be in work at the time of diagnosis
- have a partner who still works
- have dependent children
- have older parents to care for
- have heavy financial commitments, such as a mortgage
- be more physically fit and active
- have a rarer and genetic form of dementia.

Some people with dementia may want to continue working for some time after their diagnosis, or feel they have to because they need the money. It is natural to feel anxious about telling your employer about your diagnosis, but doing so will help give protection under the law if you want to keep working. Some people decide to take early retirement and maybe start voluntary work as a way to maintain a sense of purpose. Carers may want or need to continue working – possibly with changed working patterns to fit round a supporting role. They may also be concerned about giving up work to care full time.

Alzheimer's Society can advise on some issues relating to work and finances, but people with dementia and carers might require specialist advice. This may be available from a disability employment adviser at the local Jobcentre Plus, or from the local Citizens Advice Bureau (see 'Other useful organisations'). People should ask for a benefits check to make sure that they are receiving the benefits to which they are entitled (see factsheet 413, **Benefits**).

Seeking advice about pension rights is also important, particularly as the rules on pensions are changing.

For people with children, it is important that they understand – in an age-appropriate way – what dementia is, how it affects their parent and what changes to expect. Every child is different and will react in their own way. (For more see factsheet 515, **Explaining dementia to children and young people.**)

Driving may also be more problematic for younger people with dementia. Some people with dementia are able to drive safely for some time after diagnosis, but there will be a point at which the person will have to stop. For many people with dementia, the decision to stop driving can be a difficult one (see factsheet 439, **Driving and dementia**).

Some people with an inherited dementia (eg familial Alzheimer's disease, genetic frontotemporal dementia) will be found by diagnostic genetic testing to have a mutation which has caused the dementia. This raises the possibility of genetic testing of adult birth relatives who do not have any symptoms to see if they too have the mutation. Regional clinical genetics services will offer counselling to see whether such testing – called predictive genetic testing – is the right decision for that person. For more on this sensitive topic (including genetic testing for couples planning to have a baby) see factsheet 405, **Genetics of dementia**.

Treatment

Dementia cannot be cured but there are treatments and support that can help someone live well with the condition. This involves drug and non-drug treatment, support, activities, information and advice. Common drug treatments help with symptoms of dementia, such as donepezil for Alzheimer's disease or certain antidepressants for frontotemporal dementia. For vascular dementia, drugs will be offered to help to treat the underlying conditions.

Non-drug treatments are also available, usually through the GP. Counselling may help the person adjust to the diagnosis or with relationship issues. Talking therapies may help if the person (or anyone supporting them) becomes depressed or anxious. For more information see factsheets 444, **Depression and anxiety**, and 445, **Talking therapies (including counselling, psychotherapy and CBT)**.

Ask a professional about sessions of cognitive stimulation or life story work because these can also help. Non-drug approaches should also be tried first for behavioural changes (see factsheet 525, **Changes in behaviour**).

Dementia progresses more quickly if someone is physically unwell, so it is important that the person looks after themselves. This includes regular physical exercise, not smoking, drinking alcohol only in moderation, eating a healthy diet and keeping to a healthy weight.

Age-appropriate services

Services for all people with dementia should try to help them maintain their day-to-day skills, friendships and hobbies, as well as to develop new interests if they wish to. Where possible, they should also support people to continue to live an active life as a member of their local community. Local authorities can allocate a personal budget (only applicable in England) that can help in managing costs for such services. This is dependent, however, on whether the person qualifies for funding. For more information see factsheet 473, **Personal budgets**.

Services for younger people

Younger people with dementia require dedicated age-appropriate services that are able to meet their specific needs. This could be in the form of a dementia café, activity group, adventure holiday, help at home, day care or residential care. If the person has a very rare dementia then their needs may be very specific.

In practice, such age-appropriate services may not often be available, or not available within a reasonable distance. This is particularly true of supported housing or residential care for people with young-onset dementia. However, some larger care homes now have age-appropriate provision within a dedicated part of the building.

This general lack of age-appropriate services is partly caused by low levels of awareness of the distinct needs of younger people with dementia. Another factor is that young-onset dementia is relatively uncommon, so services tend to be thinly spread.

The result is that younger people with dementia may find that they are referred to a service designed around the needs of older people. Such a service set up for people of a different generation is unlikely to meet the needs of a younger person. For example, activities planned for older people may be less physically demanding and therefore unsuitable for a more active younger person. Or they may draw on experiences or music from a period which has no meaning to a younger person.

Alternatively, a younger person with dementia may find that they are excluded from an older peoples' service because of their age. This can mean that younger people find themselves in the 'gaps' between services, none of which will accept responsibility for their care. People with young-onset dementia and their families understandably say that they find this very frustrating.

Finding age-appropriate services and support

A good starting point to finding out about appropriate support is where the dementia was diagnosed. There may be a dementia adviser

or nurse – such as an Admiral Nurse – present who has specialised in young-onset dementia. Such a person can offer individualised advice and support as well as information about age-appropriate services that are available.

It is also a good idea to ask the GP or social services about a needs assessment, also called a community care assessment. This aims to find ways to help maintain independence and quality of life. If the local authority is paying for some of the person's care and support, they should offer them a personal budget. This could be in the form of a direct payment, which can be used flexibly to help meet the person's needs. For example, this could go towards sports or leisure activities or – as the dementia progresses – to pay a care worker to give personal care at home. For more information see factsheet 473, **Personal budgets**.

Local Alzheimer's Society staff can also advise on what is available in the area. They should be able to offer information and advice, and will run (or know about) dementia cafés and support groups, which are often led by such voluntary sector organisations. In addition, they can advise on befriending, advocacy, or information and support sessions for people with dementia or carers. They may additionally be able to offer a dementia adviser who can provide tailored information and advice.

In some parts of the country there are regional support groups for younger people or those living with specific dementias (eg frontotemporal dementia, familial Alzheimer's disease). These can put younger people with dementia, their families or carers in contact with others in similar circumstances. They offer the opportunity for people to share experiences and strategies for living well. See 'Other useful organisations' for more about these, including websites and newsletters about specific dementias.

Finally, people with dementia increasingly keep in touch through the internet. Alzheimer's Society hosts an online discussion group called Talking Point, which has a dedicated group for younger people. To join the discussion, go to **[alzheimers.org.uk/talkingpoint](https://www.alzheimers.org.uk/talkingpoint)**

Other useful organisations

British Institute of Learning Disabilities (BILD)

Birmingham Research Park
97 Vincent Drive
Edgbaston
Birmingham B15 2SQ

T 0121 415 6960
E enquiries@bild.org.uk
W www.bild.org.uk

Organisation that works to improve the lives of people with disabilities. Provides a range of information in print and online.

Citizens Advice Bureau

Various locations

W www.citizensadvice.org.uk

Your local Citizens Advice Bureau (CAB) can provide information and advice in confidence or point you in the right direction. To find your nearest CAB, look in the phone book, ask at your local library or look on the Citizens Advice website (above). Opening times vary.

CJD Support Network

PO Box 346
Market Drayton TF9 4WN

T 01630 673973 (helpline)
E info@cjdsupport.net
W www.cjdsupport.net

Supports people with prion diseases, including forms of Creutzfeldt-Jakob disease (CJD). Provides a range of information on the various forms of prion disease, and works with professionals to improve the level of care provided for people with these conditions.

Disability Benefits Helpline

For Disability living allowance

T 0345 712 3456 (free helpline open 8am to 6pm weekdays)
0345 722 4433 (textphone)

For Attendance allowance

T 0345 605 6055 (free helpline open 8am to 6pm weekdays)
0345 604 5312 (textphone)

For Personal independence payment

T 0345 850 3322 (free helpline open 8am to 6pm weekdays)
0345 601 6677 (textphone)

Helpline for advice or information about claims for Disability Living Allowance, Attendance Allowance or Personal Independence Payment.

Rare Dementia Support

T 07592 540555
W www.ucl.ac.uk/drc/support-groups

Runs specialist support group services for individuals living with, or affected by, one of five rare forms of dementia: frontotemporal dementia, posterior cortical atrophy, primary progressive aphasia, familial Alzheimer's disease and familial frontotemporal dementia.

The Lewy Body Society

Hudson House
8 Albany St
Edinburgh EH1 3QB

T 0131 473 2385
E info@lewybody.org
W www.lewybody.org (includes contact form)

Charity that aims to raise awareness of DLB for the general public and educate those in the medical profession and decision-making positions about all aspects of the disease. They also support research into the disease.

Young Dementia UK

PO Box 315
Witney
Oxfordshire OX28 1ZN

T 01993 776295
E mail@youngdementiauk.org
W www.youngdementiauk.org

National information and support charity focusing specifically on young-onset dementia. Created with and for younger people, families, friends and supporters.

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This factsheet has also been reviewed by people affected by dementia. A list of sources is available on request.



Alzheimer's Society National Dementia Helpline

England, Wales and Northern Ireland:
0300 222 11 22

9am–8pm Monday–Wednesday
9am–5pm Thursday–Friday
10am–4pm Saturday–Sunday

alzheimers.org.uk

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers.



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