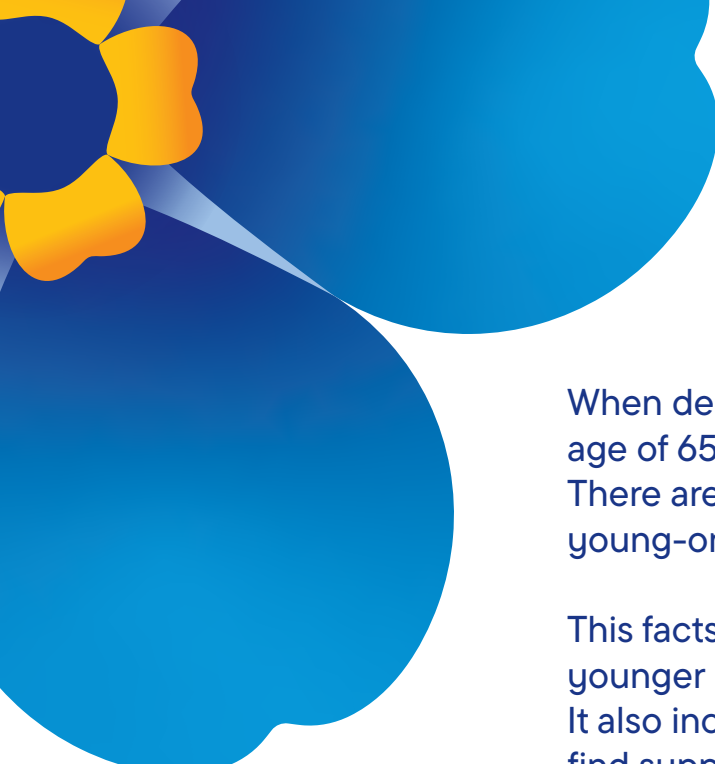


# What is young-onset dementia?



**Alzheimer's  
Society**

Together we are help & hope  
for everyone living with dementia



When dementia develops in a person before the age of 65, it is known as ‘young-onset dementia’. There are over 42,000 people in the UK with young-onset dementia.

This factsheet looks at the types of dementia that younger people can have and the effect of these. It also includes information on where people can find support.

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# 1 Dementia in younger people

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People whose symptoms started when they were under the age of 65 are often known as 'younger people with dementia' or as having young-onset dementia. This is not for a biological reason, but is based on the fact that 65 was the usual age of retirement for many people.

People sometimes use the terms 'early-onset dementia' or 'working-age dementia'. This factsheet uses the term 'young-onset dementia'.

Dementia is caused by a wide range of different diseases. This is similar for younger and older people ('late-onset dementia'), but there are important differences in how dementia affects younger people. These include the following:

- A wider range of diseases cause young-onset dementia.
- A younger person is much more likely to have a rarer form of dementia.
- Younger people with dementia are less likely to have memory loss as one of their first symptoms.
- Young-onset dementia is more likely to cause problems with movement, walking, co-ordination or balance.
- Young-onset dementia is more likely to be inherited (passed on through genes) – this affects up to 10% of younger people with dementia.
- Many younger people with dementia don't have any other serious or long-term health conditions.

Someone who is diagnosed under the age of 65 needs to adjust to living with a long-term condition as a younger person. They might be concerned about the effects this will have on their family, relationships, finances and daily life. They may also be worried that any children or siblings will have a higher risk of developing dementia.

There is more information about these issues throughout this factsheet.

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# 2 What causes young-onset dementia?

The causes of young-onset dementia are similar to the diseases that usually cause dementia in older people. However, some causes, such as frontotemporal dementia (FTD), are more common in younger people. Dementia in younger people often has different symptoms, even when it's caused by the same diseases as in older people.

There is more information about some common causes of dementia, and how they can affect younger people, on the next few pages.

## Alzheimer's disease

Alzheimer's is the most common type of young-onset dementia and may affect around 1 in 3 younger people with dementia. However, up to 2 in 3 older people with dementia have Alzheimer's disease. Alzheimer's disease develops when proteins build up in the brain to form structures called 'plaques' and 'tangles'. This causes brain cells to die and so affects functions controlled by the brain.

For most older people with Alzheimer's disease, the first symptom they notice is likely to be memory loss. However, in younger people with Alzheimer's disease, memory loss is less likely to be the first symptom.

For more information see factsheet 401, **What is Alzheimer's disease?**

## Atypical Alzheimer's disease

Younger people are much more likely to have an 'atypical' (unusual) form of Alzheimer's disease. The symptoms depend on the specific form a person has:

- In **posterior cortical atrophy (PCA)** the first symptoms are usually problems with understanding visual information, such as struggling to read or judge distances.
- In **logopenic aphasia** the first symptoms are usually difficulties with language, such as problems finding the right word, or taking long pauses while they speak.
- In **behavioural/dysexecutive Alzheimer's disease** the first symptoms are usually difficulties with planning and decision making, and behaving in socially inappropriate ways.

Up to 1 in 3 younger people with Alzheimer's disease have one of these forms, but only 1 in 20 older people with Alzheimer's disease have an atypical form. For more information see factsheet 442, **Rarer causes of dementia**.

### Familial Alzheimer's disease

Familial Alzheimer's disease is a very rare form of Alzheimer's disease. It is caused by genetic mutations (changes in genes) that run in families. Three genes have been found to have these rare mutations – PSEN1 (presenilin 1), PSEN2 (presenilin 2) and APP (amyloid precursor protein).

There is a 50% risk of a parent passing on the familial Alzheimer's disease mutation to their children. People with the condition usually have a strong family history of the disease and will know a range of family members who were affected at a similar age, along with one of their parents.

Symptoms of familial Alzheimer's disease usually start in someone's 30s, 40s or 50s. The earlier the symptoms start, the more likely it is that the disease is genetic. Familial Alzheimer's disease is very rare and probably accounts for fewer than 1 in 100 people with Alzheimer's disease. For more information see 'Genetic testing' on page 6 and factsheet 405, **Genetics of dementia**.

### Learning disabilities and dementia

People with Down's syndrome and other learning disabilities are more likely to develop dementia when they are younger. Dementia in people with Down's syndrome is usually caused by Alzheimer's disease, but not always.

The reasons why people with Down's syndrome are at increased risk of Alzheimer's disease are not well understood. It is thought to be due to chromosome 21, which most people with Down's syndrome have an extra copy of. This leads to an overdevelopment of a protein (amyloid precursor protein) which forms plaques on the brain. These plaques are a feature of Alzheimer's disease. By the age of about 40, almost all people with Down's syndrome have changes in the frontal lobe of their brain. However, not everyone will develop the symptoms of dementia.

For more information see factsheet 430, **Learning disabilities and dementia**.

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### Vascular dementia

Vascular dementia is caused by problems in the blood supply to the brain. It is closely linked to diabetes and to cardiovascular diseases such as stroke and heart disease.

Symptoms of vascular dementia vary from person to person. Early memory loss is less common. However, other symptoms are more common in vascular dementia, including slower speed of thought and problems with:

- planning
- organising
- making decisions
- solving problems
- following a series of steps
- concentrating.

Physical symptoms (such as limb weakness) are common in vascular dementia when a person develops it after a stroke. For more, see factsheet 402, **What is vascular dementia?**

### CADASIL

CADASIL (cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy) is a rare genetic form of vascular dementia. It is a disease of the blood vessels in the brain. Symptoms include migraines and repeated strokes, loss of mental abilities, seizures, apathy and depression. They usually start when a person is in their mid 30s.

CADASIL is caused by a genetic mutation in the NOTCH3 gene. It is usually inherited from a parent who has a 50% chance of passing on the mutated copy of the gene.

For more information see factsheet 442, **Rarer causes of dementia.**

### Frontotemporal dementia (FTD)

Frontotemporal dementia is caused by damage to the lobes at the front and/or sides of the brain. It is much more common in younger people with dementia than in older people. FTD is most often diagnosed in people between the ages of 45 and 65. This is different to Alzheimer's disease, vascular dementia and dementia with Lewy bodies, which all become more likely as people get older. There are three different types of FTD which cause different changes as the first symptoms.

## Behavioural variant FTD

This type can affect personality and behaviour first, such as:

- losing inhibitions
- becoming apathetic (losing interest in people or things)
- compulsive behaviours – such as repeated use of phrases or gestures.

## Progressive non-fluent aphasia

This type often changes language production first, for example:

- slow, hesitant speech
- mistakes in grammar
- problems understanding complex sentences.

## Semantic dementia

This type can change language comprehension first, including:

- asking the meaning of familiar words – for instance, ‘what is a “fork”?’
- problems recognising familiar people or objects
- trouble finding the right word.

For more information see factsheet 404, **What is frontotemporal dementia (FTD)?**

## Is FTD inherited?

About 20–40% of people with FTD have a family history of dementia. About 10% of people with FTD have a strong family history, with several close relatives from different generations affected.

The three main mutations causing FTD are in the progranulin (GRN), microtubule-associated protein tau (MAPT) and chromosome 9 open reading frame 72 (C9ORF72) genes.

The children or siblings of someone with a genetic mutation known to cause FTD have a 50% chance of carrying the same mutation. Families with a known mutation should be offered genetic counselling.

For more information see factsheet 405, **Genetics of dementia.**

## Dementia with Lewy bodies (DLB)

Dementia with Lewy bodies is caused by the build-up of tiny protein deposits (Lewy bodies) in the brain. DLB is less common in younger people with dementia than in older people. Lewy bodies also cause Parkinson’s disease and about one-third of people with Parkinson’s eventually develop dementia.

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Symptoms of dementia with Lewy bodies can include hallucinations and varying levels of alertness. People can also develop the features of Parkinson's disease (such as slower movement, stiffness and trembling limbs).

For more see factsheet 403, **What is dementia with Lewy bodies (DLB)?**

### Alcohol-related brain damage (ARBD)

Alcohol-related brain damage is caused by regularly drinking too much alcohol over several years. It covers a range of conditions including alcohol-related dementia and Wernicke–Korsakoff syndrome. People diagnosed with ARBD tend to be in their 40s and 50s, and it is more common in men.

ARBD is caused by a lack of thiamine (vitamin B1), direct damage to nerve cells from alcohol, head injuries (caused for instance by falls or fights) and a poor diet.

At least 1 in 10 younger people with dementia may have ARBD. Symptoms will depend on the cause of the ARBD. They can include problems with planning, organising, problem solving, attention and controlling emotions. They can also include changes in personality, difficulties learning new skills and disorientation.

Many people diagnosed with ARBD who stop drinking alcohol and receive good support (including treatment and a good diet) can see improvement in their symptoms. Sometimes they can make a partial, if not full, recovery.

For more information see factsheet 438, **What is alcohol-related brain damage?**

### Rarer causes of dementia

Rarer causes of dementia are more common in younger people than in older people. There are also a range of conditions that can cause symptoms similar to dementia in younger people.

For more information on these types of dementia see factsheet 442, **Rarer causes of dementia.**

### Genetic testing

People who are at increased risk of a genetic mutation that causes dementia should be offered genetic testing.

There are two types of genetic testing:

- **diagnostic genetic testing** – for people with a diagnosis and a strong family history of dementia
- **predictive genetic testing** – for people without symptoms but who have a high risk of inheriting dementia.



Before the genetic testing, the person and their family should be offered genetic counselling. This should explain the process and how it could affect them, and should be offered for several months before and after the genetic testing. The person and their family will be asked if they want to know the outcome or have it kept on file for a later date. It's important that the person and their family agree together as the decision will affect the whole family. Many people choose not to go ahead with the genetic testing after counselling, but it is up to each person to make the right decision for them.

A person should consider carefully whether they want genetic testing. There are both advantages and disadvantages to knowing whether they have a genetic mutation. Some people want to find out because it means they know they are carrying a mutation and it can remove the uncertainty. It can also mean they can take it into account when planning their future – for instance, if they're considering having children. For some people it leads to taking part in research into dementia too.

However, there are disadvantages as well. It can lead to feelings of guilt, especially related to other family members. Knowing there is a genetic mutation can cause depression, grief and anger for some people, as they are living with the knowledge that they will almost certainly develop dementia. It can also cause a lot of stress if people spend a lot of time 'looking' for symptoms.

Deciding whether or not to go ahead with genetic testing is a very personal decision and it is important that people receive support from trained professionals to help them with the process.

For more about genetic testing see factsheet 405, **Genetics of dementia**.

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### 3 The progression of young-onset dementia

Whatever the cause of young-onset dementia, it is a progressive condition, which means it will get worse over time. How quickly this happens will depend on a range of things. Everyone's experience of dementia is different, but there are some common experiences. Whatever type of dementia a person has, they will gradually need more support and become more dependent on others as their condition progresses. This can be hard to think about, but it's helpful to know so that people can plan ahead – see 'Planning ahead' on page 17.

Evidence suggests that young-onset dementia may progress faster than dementia in older people – however, the rate of progression varies a lot from person to person.

For more information about the progression of dementia see factsheet 458, **The progression and stages of dementia**.

## 4 Getting a diagnosis

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Getting an accurate and timely diagnosis of dementia is important. However, for younger people it can often take much longer. There can be specific reasons for this, including:

- Young-onset dementia is relatively rare and health professionals may not have much experience of associating the symptoms in a younger person.
- Early symptoms can be hard to recognise or not obvious. They might be put down to other factors such as stress, difficulties with relationships or work, or the menopause.
- This may be because early symptoms are less likely to be memory loss, and are more likely to be changes in behaviour, language, vision or personality.

If the younger person with dementia or other people dismiss early and mild symptoms or blame them on other causes, this can mean the person doesn't get the support they need. It's often only after someone receives a diagnosis that they and those around them can look back and notice when things first started to change.

### The assessment process

The process of assessment and diagnosis for someone who may have any type of dementia, including young-onset dementia, usually starts with the GP. For more information see booklet 78DD, **Diagnosing dementia: A practical guide to assessment**. However, there is a wider range of possible causes of dementia in younger people, and so a more comprehensive assessment may be necessary.

In some areas there are specialist services for diagnosing younger people with dementia. They can help to make sure the person gets the information and support they need as a younger person. However, these services are only available in some areas. The GP should refer a person to this service if it is available locally.

If a specialist service isn't available, people are often referred to services for older people. There should still be a named lead in young-onset dementia who should be able to offer appropriate information and support. However, not all services have this. Sometimes people are referred to more than one specialist if their symptoms are complex.

The assessment process often includes:

- taking a full history of the person's symptoms, any changes they've experienced and the impact of these on day-to-day activities

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- tests of a person's mental abilities, behaviour and ability to do daily tasks
- a full physical exam
- at least one brain scan (often with more specialist scans)
- looking at other health conditions and how these can be managed effectively.

The process might include a lumbar puncture, to collect and analyse fluid around the spine.

## 5 Living with dementia as a younger person

Younger people with dementia experience a range of challenges, which are often different to those that older people face. Younger people are less likely to experience memory loss as one of their early symptoms and may experience problems with behaviour, vision or language first.

They are also likely to have varied aspects to their lives that will be affected in different ways by dementia. This includes:

- their relationships, including with their children (if they have them)
- their finances
- employment (if they're working) and daily activities
- driving (if they drive)
- their hobbies and interests.

All of these can make it hard for a younger person to adjust to a diagnosis. Dementia can also be harder for younger people because it usually comes at a time in their life when it is least expected. However, there is support available and planning ahead can make a big difference.

If you've recently been diagnosed with young-onset dementia and want to know more about how it can affect you, read booklet 688, **Young-onset dementia: Understanding your diagnosis**.

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## Relationships

Dementia at any age can have a big impact on relationships. However, for younger people there are particular challenges that can affect their relationships with partners, family, friends and work colleagues.

Dementia can mean lots of changes to a younger person's plans for the future as they adapt to living with the condition. This can be difficult to come to terms with for both the person and their family.

Dementia at any age can lead to questions about how roles in relationships will change. For younger people with dementia, this can be more challenging due to their commitments. For example, they may have a mortgage, young children and household duties they share with a partner or friend.

After their diagnosis, younger people with dementia and their families may find that friends and other family members don't stay in touch or provide the support they need. This can be for different reasons. Dementia in a younger person is unexpected, so friends and family may not understand what the person and those close to them are going through. Giving people information, such as this factsheet, can help them to understand and come to terms with things.

A partner or children of the person with dementia may end up providing more and more care for the person over time. This can be difficult to adapt to and can lead to a big change in the relationship.

For more information for people with dementia, see our booklet 1507, **Your relationships**.

## Partnerships and sexual relationships

Partnerships and sexual relationships often change when one partner has dementia. Coping with and adjusting to these changes can be very difficult for younger people with dementia.

For more information on this see factsheet 514, **Sex, intimacy and dementia**.

Some couples may find that their relationship has changed during the time it has taken to get a diagnosis. Issues with their relationship may have been what led them to the doctor in the first place. When one partner receives a diagnosis of dementia it means the couple will need to review how things currently work in their relationship and what changes are needed. As the person's dementia progresses, more changes and adaptations will be necessary.

## Children

Younger people with dementia are more likely to have dependent children, and dementia can have a huge impact on them and their family relationships. It can be hard to explain to children what the diagnosis means and how it might impact the family. It's important to try and be honest with children, listen to their concerns and feelings and make time to answer any questions they have.

Children can find it difficult to come to terms with a parent having dementia. The person with dementia may feel guilty about the impact their diagnosis has on their children. It can also affect the relationships between other members of the family. There can be difficulties balancing the needs of the person with dementia, their children and other family members. For example, it can be a challenge to support children emotionally and help them cope with the changes in a parent. It can be particularly hard for the parent without dementia or other family members who will need to provide more support for the family, while also trying to meet the needs of the person with dementia.

For information and advice see factsheet 515, **Supporting children and young people when a person has dementia.**

If the person has (or thinks they have) a genetic form of dementia, that can have a huge impact on their relationship with their children. They and their children may have questions about genetic testing and whether they should have it. The person may feel guilty about putting their children at risk. Children may be angry or unsure how to process this information. It's really important that the family have access to appropriate support and counselling to deal with this. For more information see page 6.

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## Employment

Many younger people say that their first symptoms of dementia appeared while they were at work. For instance, they might have started to have problems with remembering appointments or how to do something they'd been doing for a long time. They may also find it difficult to concentrate or follow conversations.

Some people continue working for many years after a diagnosis of dementia. Others decide to stop, either because they no longer want to work, or the type of work they do means they're not able to carry on. Making this decision can be very difficult – work is important to people for lots of reasons aside from earning money. For many people their work is also part of their identity and gives them a community and sense of purpose. Where possible, staying in some form of employment can have a number of benefits for people with dementia.

Younger people diagnosed with dementia should tell their employers about their diagnosis. In some jobs this is required by their contract. Their employer may be able to support them, for instance by enabling them to take extra breaks or to work from home. Under the Equality Act 2010 an employer must make 'reasonable adjustments' to support the person with dementia to do their job. For example, they might agree a change to working hours or move to a quieter part of the workplace. People have a right to ask for the support they need.

Some people with dementia report being unfairly dismissed either before they received a diagnosis or because of their diagnosis. If a person feels they have been unfairly dismissed they may be able to make a complaint against their employer. There are organisations that can provide advice and support such as the Advisory, Conciliation and Arbitration Service (ACAS), the Equality Advisory and Support Service or the Equality Commission for Northern Ireland. For their contact details see 'Other useful organisations' on page 23.



People who are supporting a younger person with dementia can also find this affects their work situation. Some people find that, as dementia progresses, they need to change their hours or give up work altogether. As younger people are more likely to be still working this can be particularly challenging – both emotionally and financially. Carers do have rights when it comes to work, such as the right to request flexible working. They may want to discuss their options with their employer. They may also want to seek professional advice on what their rights are and what financial support they may be entitled to. For more information on ACAS, the Equality Advisory and Support Service, and the Equality Commission for Northern Ireland see ‘Other useful organisations’ on page 23.

For more information a person with dementia may want to read booklet 1509, **Employment**.

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## Finances

Younger people with dementia often have a range of financial commitments that may be impacted by their diagnosis. For example, they may still be repaying their mortgage or other loans, or supporting dependent children. Dementia can cause worry and uncertainty about how they will manage financially in the future. If the person has to give up work this can have a financial impact, not just on them but on the rest of their family.

There is financial support available for people with dementia and their carers, including a range of possible benefits. It's a good idea to arrange a benefits check with a benefits adviser so they can let the person and those supporting them know what they are entitled to. Contact Citizens Advice to do this (see 'Other useful organisations' on page 23).

For more information see factsheet 413, **Benefits for people affected by dementia**.

## Planning ahead

When someone has young-onset dementia it can be helpful to put things in place for the future, especially if they haven't thought about this before.

People in England and Wales may want to set up a Lasting power of attorney (LPA) so that someone they trust can make decisions for them if they reach the stage where they are no longer able to. There are two types of LPA – one covering property and financial affairs (such as bank accounts, bills and selling property) and one covering health and welfare (such as day-to-day care decisions).

In Northern Ireland a person can set up an Enduring power of attorney (EPA) so someone else can manage their finances and property if they are unable to.

For more information see factsheet 472, **Lasting power of attorney**, or NI472, **Enduring power of attorney and controllership**.

Other things that a younger person with dementia may want to consider include:

- making or amending a will
- setting up an advance statement (England and Wales) or living will (Northern Ireland) which documents their wishes and preferences for the future
- creating an advance decision (England and Wales) or advance directive (Northern Ireland) to set out treatments the person may not want in the future (for example a blood transfusion). For more information see factsheet 463, **Advance decisions and advance statements** (in England and Wales) or in Northern Ireland see factsheet NI467, **Financial and legal tips**.

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### Driving

If a person has been driving and is diagnosed with dementia, they must inform Driver and Vehicle Licensing Agency (DVLA) if they are in England and Wales, or Driver & Vehicle Agency (DVA) if they are in Northern Ireland. They should also inform their insurance company.

DVLA or DVA will ask for a doctor's report and may ask the person to take a driving assessment. The driving assessment can help with any final decision. It is important for the person to follow medical advice when it comes to driving, even if they are waiting on a decision from DVLA or DVA. Some people with dementia decide to give up driving voluntarily. For younger people with dementia this can be a very difficult change to adjust to. They are more likely than older people to have commitments that rely on them driving, such as children or work. This can have an impact on how a younger person with dementia feels about themselves and on their relationships with others.

However, it can help a person to consider some of the benefits of not driving, such as saving money on insurance, tax and parking, and having more opportunities to walk. For more information see factsheet 439, **Driving and dementia**.

## Staying involved and active

Dementia can have a big impact on a younger person's ability to do their daily activities and things they enjoy. This can impact their sense of identity and how they feel about themselves. It is important for people to maintain their independence and carry on doing things that matter to them. If the person has had to give up work or interests because of their diagnosis, finding new or different activities can help them to stay engaged and feeling useful.

Staying active and involved through different activities can be good for the health and wellbeing of people with young-onset dementia. This includes physical activities such as swimming or gardening, or taking opportunities to get involved in community events, research and campaigning. Some younger people with dementia find that their diagnosis means they can try new things they haven't done before – for example, becoming an ambassador for other people with young-onset dementia.

Younger people with dementia may need support to continue doing activities. Some people stop doing things after their diagnosis, or find they lose opportunities for doing things if their friends are unsure how to act around them or stop inviting them. However, it's important to continue doing things they enjoy.

Over time the person may need more support or the activities may need to be adapted to support them. Some younger people with dementia find it helps to do activities with other people living with young-onset dementia. There is more information about this under 'Finding the right support' on page 21.

There is a range of technology available that can help younger people with dementia with day-to-day activities. If the person is used to using a tablet or smartphone there are lots of apps that can help with remembering appointments, taking medication or even continuing hobbies. For more information a person with dementia may want to read booklet 1506, **Keeping active and involved**, and factsheet 437, **Using technology to help with everyday life**.

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# 6 Treatment

There is currently no cure for dementia. However, there are treatments and support services that can help someone with the condition. These include medicines and treatment without medicines, support, activities, information and advice.

Treatments with medicines are available to help with symptoms of some types of dementia. For more information, see factsheet 407, **Medicines to help memory and thinking**.

Treatments that don't involve medicines are also available. These may include talking therapies to help with depression or anxiety, and different forms of treatment (such as cognitive stimulation therapy) to help with some of the symptoms the person has. Some younger people with dementia may find counselling helps them to come to terms with their diagnosis. The British Association for Counselling and Psychotherapy can help with finding a suitable counsellor (see 'Other useful organisations' on page 23).

Treatments without medicines may also help with changes in a person's behaviour – see factsheet 525, **Changes in behaviour**.

Staying healthy and active can help a person to live well with dementia. This includes keeping physically active, eating a balanced diet, drinking alcohol within the recommended limits and not smoking.

## 7 Services and support for younger people

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There are a number of services available to support people with dementia. However, not all dementia services meet the needs of younger people. Services for younger people with dementia should understand the issues that come from receiving a diagnosis as a younger person. They should also be able to provide appropriate information and support to help with the issues younger people with dementia face. Having access to age-appropriate information and support can make a big difference to people with young-onset dementia and those supporting them.

Younger people with dementia may find they are offered services that are designed for older people and so aren't able to give the support they need. There are some services specifically for younger people with dementia, but they aren't available everywhere. Some dementia services are able to provide appropriate support for younger people with dementia as well as older people with dementia. For example, some activity groups may run groups just for younger people with dementia.

It's really important for younger people with dementia to have access to the right support, including services designed for them and meeting other people in a similar situation.

### Finding the right support

To find the right services, it may be useful to start by asking for support from the service where a person was diagnosed with dementia. They may be able to speak to a dementia adviser or specialist nurse who knows about young-onset dementia.

To find out if there are services for younger people with dementia in an area, people can visit or get in touch with their local Alzheimer's Society or search at [alzheimers.org.uk/dementiadirectory](https://www.alzheimers.org.uk/dementiadirectory)

In some areas there are local support groups for younger people or those living with certain types of dementia (such as FTD or familial Alzheimer's disease). These can enable younger people with dementia and those close to them to meet or get in touch with other younger people affected by dementia. See 'Other useful organisations' on page 23 for more information.

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Some people also find online support helpful, especially if they are unable to find specific services for younger people with dementia in their area. They could consider joining our online community for people affected by dementia. It has a dedicated section for people affected by young-onset dementia. To find out more go to **[forum.alzheimers.org.uk](https://forum.alzheimers.org.uk)**

### Paying for care and support

While many services for people with dementia are free, some may be charged for. People with dementia are also entitled to a needs assessment to work out what their needs are and to help them find the right care and support.

A person can contact their local authority or health and social care trust to arrange a needs assessment. Carers are also entitled to assessments of their own needs. For more information see factsheets 418 **Assessment for paying for care and support** (for England), W418 (for Wales), and NI418 (for Northern Ireland).



## Other useful organisations

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**Advisory, Conciliation and Arbitration Service (ACAS)**  
**0300 123 1100 (Helpline, 8am–6pm Monday–Friday)**  
**[www.acas.org.uk](http://www.acas.org.uk)**

ACAS can give you advice about workplace situations. Its website has guidance and publications or you can phone the helpline for information and advice.

**British Association for Counselling and Psychotherapy (BACP)**  
**01455 883300 (10am–4pm Monday–Friday)**  
**[bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)**  
**[www.bacp.co.uk](http://www.bacp.co.uk)**

BACP is the professional association for members of the counselling professions in the UK. You can search for accredited therapists in your area.

**Citizens Advice**  
**0800 144 8848 (Adviceline England, 9am–5pm Monday–Friday)**  
**0800 702 2020 (Advicelink Wales, 9am–5pm Monday–Friday)**  
**[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)**

Citizens Advice provides free, independent, confidential and impartial advice to everyone on their rights and responsibilities.

**Dementia UK**  
**0800 888 6678 (Admiral Nurse Dementia Helpline, 9am–9pm Monday–Friday, 9am–5pm Saturday and Sunday)**  
**[helpline@dementiauk.org](mailto:helpline@dementiauk.org)**  
**[www.dementiauk.org](http://www.dementiauk.org)**

Dementia UK is committed to improving quality of life for all people affected by dementia, including people affected by young-onset dementia. It provides Admiral nurses who are mental health nurses specialising in dementia care. YoungDementia UK is now part of Dementia UK.

**Equality Advisory and Support Service**  
**0808 800 0082 (Helpline, 9am–7pm Monday–Friday, 10am–2pm Saturday)**  
**[www.equalityadvisoryservice.com](http://www.equalityadvisoryservice.com)**

The EASS helpline can give you free advice and support.

## Space for your notes

**Equality Commission for Northern Ireland**  
**028 90 500 600**  
**information@equalityni.org**  
**www.equalityni.org**

The Equality Commission for Northern Ireland has a helpline where you can get free advice and support.

**GOV.UK**  
**www.gov.uk**

The UK government website, which includes information about benefits and how to contact Driver and Vehicle Licensing Agency (DVLA) and Driver and Vehicle Agency (DVA).

**NI Direct**  
**www.nidirect.gov.uk**

The website of the Northern Ireland government, which includes information about benefits available in Northern Ireland and how to contact Driver and Vehicle Agency (DVA).

**Rare Dementia Support (RDS)**  
**020 3325 0828**  
**contact@raredementiasupport.org**  
**www.raredementiasupport.org**

RDS works to support people affected by five rare dementia conditions: familial Alzheimer's disease (FAD), frontotemporal dementia (FTD), familial frontotemporal dementia (fFTD), posterior cortical atrophy (PCA) and primary progressive aphasia (PPA).

**The Lewy Body Society**  
**01942 914 000**  
**info@lewybody.org**  
**www.lewybody.org**

The Lewy Body Society aims to fund research into dementia with Lewy bodies and to raise awareness of the condition.



Factsheet 440  
Last reviewed: January 2020  
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Reviewed by: Professor Sebastian Crutch, Professor of Neuropsychology, Dementia Research Centre, University College London

To give feedback on this factsheet, or for a list of sources, please email [publications@alzheimers.org.uk](mailto: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](mailto: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.

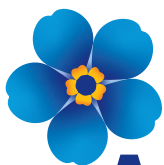
We have more information **About dementia.**

For advice and support on this, or any other aspect of dementia, call us on **0333 150 3456** or visit **[alzheimers.org.uk](http://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](http://alzheimers.org.uk/donate)**



*Patient Information Forum*



**Alzheimer's  
Society**

Together we are help & hope  
for everyone living with dementia

Alzheimer's Society  
43-44 Crutched Friars  
London EC3N 2AE

**0330 333 0804**  
**[enquiries@alzheimers.org.uk](mailto:enquiries@alzheimers.org.uk)**  
**[alzheimers.org.uk](http://alzheimers.org.uk)**

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