

All about dementia



**Alzheimer's
Research
UK**

**The Power
to Defeat
Dementia**

Contents

Introduction	03
What is dementia?	04
I keep forgetting things. Have I got Alzheimer's?	06
Symptoms	07
Alzheimer's disease	
Vascular dementia	
Dementia with Lewy bodies	
Frontotemporal dementia	
Diagnosing dementia	10
How dementia progresses	11
What treatments and drugs are available?	11
What causes Alzheimer's and other dementias?	12
Alzheimer's disease	
Vascular dementia	
Dementia with Lewy bodies	
Frontotemporal dementia	
Does dementia run in the family?	13
Caring for someone with dementia	14
All about risk	16
Research	18



About Alzheimer's Research UK

Alzheimer's Research UK is the UK's leading dementia research charity. As research experts, we fund world-class pioneering scientists to find preventions, treatments and a cure for dementia. Our findings improve the lives of everyone affected by dementia now and in the future. We help people to understand dementia and the progress we are making. Read more about our work and achievements at www.alzheimersresearchuk.org

How you can help

You can help us in our mission to defeat dementia by donating today. To donate, call us on **0300 111 5555**, write to us at the address on the back cover or visit our website.

We rely on donations from individuals, companies and charitable trusts, money raised by individuals and gifts in people's Wills to fund our vital research.

Information in this booklet is for anyone who wants to know more about Alzheimer's and dementia. This includes people living with dementia, their carers, friends and families.

Introduction

This booklet gives an introduction to Alzheimer's disease, dementia with Lewy bodies, vascular dementia and frontotemporal dementia. It covers:

what they are

typical symptoms

causes

diagnosis.

There is also information about how you can help lower your risk of developing dementia.

The information here does not replace any advice that doctors, pharmacists or nurses may give you but provides some background information which we hope you will find helpful.

If you would like more detailed information about different forms of dementia, treatments for dementia or information about caring for someone with dementia, we have separate leaflets that could help. Please contact us for your free copy.

Sources

Please contact us using the details shown on the back cover if you would like a version of this booklet including references.

Review dates

This booklet was updated in November 2014 and is due to be reviewed in November 2016.

What is dementia?

Dementia is not a disease in itself. It is a word used to describe a group of symptoms that occur when brain cells stop working properly. This happens inside specific areas of the brain, which can affect how you think, remember and communicate.

Common symptoms of dementia include the gradual loss of memory, decline in communication skills and difficulty with thinking and reasoning.

Alzheimer's is a disease that causes dementia. It is probably the best-known cause of dementia, accounting for about two-thirds of cases in the elderly. About 500,000 people in the UK have Alzheimer's.

Other diseases can cause dementia. After Alzheimer's, the most common causes of dementia are vascular dementia, dementia with Lewy bodies and frontotemporal dementia.

It is possible to have more than one of these diseases at the same time. Alzheimer's is sometimes seen with vascular dementia or dementia with Lewy bodies. You might hear this called 'mixed dementia'.

Rarer causes of dementia include Creutzfeldt-Jakob Disease (CJD), HIV/AIDS and alcohol-related dementia.

The latest figures show that dementia affects around 850,000 people in the UK today. Most people with dementia are over 65, but it's estimated that over 40,000 under-65s have dementia. Dementia in people under 65 is often called early-onset dementia and the most common causes are early-onset Alzheimer's disease and frontotemporal dementia. A range of other rare conditions may also be responsible for early-onset dementia.



Alzheimer's disease is the most common cause of dementia, affecting about

500,000
people in the UK

It is estimated that over

40,000
under-65s have dementia



I keep forgetting things. Have I got Alzheimer's?

Most of us forget things every day, like people's names or where we put our keys, but this is not necessarily a sign of Alzheimer's or another dementia.

In dementia, memory loss is more serious than forgetting things occasionally.

There are many reasons why people become forgetful. Some medicines and drugs can affect memory, for example. Depression, anxiety, vitamin deficiency and thyroid problems can also cause forgetfulness, so it's important to get the right diagnosis.

If you are worried about your memory, if it's getting worse, or interfering with everyday life, you should talk to your GP.

Dementia often develops slowly and is not always obvious in the early stages. Symptoms similar to dementia can be seen in other illnesses. Sometimes it can be difficult to tell apart dementia from the usual mild forgetfulness seen in normal ageing.

Symptoms

You should see your GP if you or your family and friends are worried about any changes in:

memory

general mental functioning

ability to carry out daily tasks

personality

behaviour.

Your GP will be able to either reassure you or, if necessary, refer you to a specialist.

Diagnosing dementia early is important to allow you to get the right help and treatments and to plan for the future.

Everyone with dementia will experience symptoms in their own way. Different diseases that cause dementia can have different early symptoms but many overlap.

Symptoms *(continued)*

Alzheimer's disease

Typical symptoms of early Alzheimer's include:

Regularly forgetting recent events, names and faces.

Becoming increasingly repetitive, e.g. repeating questions after a very short interval.

Regularly misplacing items or putting them in odd places.

Confusion about the date or time of day.

Disorientation, especially away from normal surroundings.

Getting lost.

Problems finding the right words.

Mood or behaviour problems such as apathy, irritability, or losing confidence.

Vascular dementia

The early symptoms may be similar to those of Alzheimer's. But vascular dementia can have many different symptoms, depending on which area of the brain is affected.

The first symptoms of vascular dementia usually appear gradually but can develop suddenly depending on the cause.

Symptoms of vascular dementia can include:

Memory problems.

Disorientation.

Communication problems.

Becoming slower in thinking.

Personality changes including depression and apathy.

Becoming more emotional.

Difficulty with walking.

Frequent urge to urinate or other bladder symptoms.



Dementia with Lewy bodies

Dementia with Lewy bodies (also known as DLB or Lewy body disease) affects about 125,000 people in the UK.

Symptoms of dementia with Lewy bodies can include:

Variation in attention, alertness and confusion. These fluctuations can be very noticeable from day-to-day or even hour-to-hour.

Parkinson's-type symptoms, like slowing or difficulty walking, stiffness in the limbs and sometimes tremor.

Fainting and falls.

Visual hallucinations. These can often involve seeing people or animals that aren't really there.

Movements during sleep and vivid dreams.

Symptoms similar to Alzheimer's, including memory loss and disorientation.

The diseases that cause dementia can have different early symptoms, but many overlap.

Frontotemporal dementia

Frontotemporal dementia (FTD) can also be called frontotemporal lobar degeneration (FTLD) and the term describes a number of different conditions. These include behavioural variant FTD, progressive non-fluent aphasia and semantic dementia. In the past 'Pick's disease' was used to describe some of these diseases. FTD is quite rare and tends to affect people aged 30-60.

Symptoms of FTD can include:

Personality changes. These may include a change in how people express their feelings towards others or a lack of understanding of other people's feelings.

Lack of personal awareness, such as personal hygiene and grooming.

Lack of social awareness, such as making inappropriate jokes or showing a lack of tact.

Over-eating or changes in dietary preference.

Behaviour changes, including developing unusual beliefs, interests or obsessions.

Difficulty with simple plans and decisions.

Lack of awareness of any personality or behaviour changes.

Decline in language abilities. This might include difficulty understanding words, repeating commonly-used words and phrases or forgetting the meaning of words.

Difficulty recognising people or knowing what objects are for.

Diagnosing dementia, and which form of dementia someone has, is important. It will ensure that people can get the right support and treatments and can plan for the future.

Diagnosing dementia



Your GP is the first person to contact if you have any worries about your health. If your GP suspects dementia, you are likely to be referred to a memory clinic or specialist. Specialists who see dementia patients include old age psychiatrists, geriatricians, neurologists, clinical psychologists and memory nurses.



When you see a doctor or nurse with concerns about your memory or thinking, they will ask you about your symptoms and medical history. They may also speak with your partner or someone close to you about your symptoms. You may be asked some questions relating to your memory and have a physical check-up.



There is a range of memory tests available, and you might take one or more of these during your assessment. Because dementia usually gets worse over time, the tests may be repeated, perhaps every six to 12 months, to see if there have been any changes.



Other tests, including blood tests and brain scans, could be arranged. Very occasionally, your doctor may arrange an EEG (brain wave test) or a lumbar puncture (spinal tap) if they suspect a rare form of dementia.

Together all of these things will help a doctor find out about any problems in memory or thinking and the likely cause.

If you are assessed for the possibility of having Alzheimer's or another form of dementia, you can choose not to know the diagnosis. You can also choose who else can know about your diagnosis.

If you, or someone close to you, are given a diagnosis of dementia, you may have many questions about what to do next. It is important to ask your doctor about local services that can help you and your family. You might be entitled to benefits and other sources of support.

How dementia progresses

Alzheimer's, dementia with Lewy bodies and frontotemporal dementia are all neurodegenerative diseases. This means that the symptoms get worse over time. This is usually the case with vascular dementia too. The speed of change varies between people and also between different diseases, but in most dementias, symptoms progress slowly over several years.

Everybody is unique and is affected in their own way.

As dementia progresses:



Memory and thinking skills

People may find that their ability to remember, think and make decisions worsens.



Communication

Communication and language often become more difficult.



Behaviour

A person's behaviour may change and some people can become sad or demoralised.



Anxieties

Anxieties or phobias are quite common.



Restlessness

Changes in time perception may cause problems with sleeping and restlessness at night.



Anger

Anger or agitation is common in the later stages of dementia.



Unsteadiness

It is common for people to be unsteady on their feet and fall more often.



Extra help

Gradually people require more help with daily activities like dressing, toileting and eating.

Across the UK there are local services and support groups for people living with dementia and their carers. You can contact the organisations and charities on page 14 to find out about support in your area.

What treatments and drugs are available?

There are several treatments available to help with the symptoms of Alzheimer's. There are also treatments that may be able to help with the symptoms of other dementias. You can speak to your doctor for more information or request our booklet '**Treatments for dementia**'.

Call us on **0300 111 5555**, or download a copy from our website, **www.alzheimersresearchuk.org**

What causes Alzheimer's and other dementias?

The causes of dementia are not yet fully understood but research is making progress. Understanding the causes of dementia is essential to developing new treatments.

Alzheimer's disease

Scientists know that during Alzheimer's two proteins build up abnormally in the brain. They are called amyloid and tau and form clumps called 'plaques' and 'tangles'. These plaques and tangles interfere with how brain cells work and communicate with each other. The plaques are usually first seen in the area of the brain that makes new memories. A lot of research is focused on finding ways to stop the build-up of these proteins and protect brain cells from harm.

Vascular dementia

Vascular dementia is caused by blood flow to the brain being reduced. Blood carries essential oxygen and nutrients to the brain and without them brain cells die. The network of blood vessels that carries blood around the body is called the vascular system.

Stroke-related dementia happens after a stroke. A stroke occurs when blood supply to a part of the brain is suddenly cut off. This may cause difficulties in moving, problems with co-ordination, speech and sight. If a stroke causes memory loss and problems with attention, then a person may be diagnosed with post-stroke dementia. Multi-infarct dementia is vascular dementia caused by a series of small strokes in the brain, which a person might not notice.

Subcortical vascular dementia is caused by a series of small injuries to blood vessels deep inside the brain. A person usually does not notice these changes and their cause is not yet known. Over time, they gradually damage parts of the brain that are important for attention, memory and language.



Dementia with Lewy bodies

Dementia with Lewy bodies is caused by small, round clumps of protein that build up inside nerve cells in the brain. These are named Lewy bodies after Dr Frederic Lewy, who first identified them.

The protein clumps damage the way brain cells work and communicate with each other. The nerve cells affected by Lewy bodies control thinking and movement. Researchers do not yet know what causes the protein to build up, but work is underway to try to find out why it happens and discover ways to stop it.

Frontotemporal dementia

Frontotemporal dementia (FTD) is caused by a variety of abnormal proteins building up in the brain. The nerve cells affected are in areas of the brain called the frontal and temporal lobes. The frontal lobes are involved in regulating our personality, emotions and behaviour, as well as reasoning, planning and decision-making. The temporal lobes are involved in memory and the understanding and production of language. As the disease progresses, other parts of the brain become affected.

Does dementia run in the family?

The simple answer is most of the time, no. If you have several close relatives who have developed dementia under the age of 65, then it's possible that the disease could be an inherited form of dementia. Certain forms of early-onset Alzheimer's and frontotemporal dementia can run in families and often start in the 30s, 40s or 50s. These types of dementia are very rare.

In most cases, our risk of developing dementia is determined by a complex mix of our age, lifestyle and whether we carry any risk genes. Some research has suggested that if you have a parent or grandparent who developed Alzheimer's disease over the age of 65 then your risk of developing the disease may be slightly higher than someone with no family history. Researchers have found around twenty different versions of genes associated with an altered risk of Alzheimer's, but many only have a small effect on risk. There is still a lot to be understood about the genetic risk factors for dementia.

Dementia has a huge impact on someone's life, as well as on their family and carers. Accessing services and support can make a positive difference to those affected.

Caring for someone with dementia

Some services will be provided by local authorities and others can be arranged through GPs. For advice, contact your local authority social services department. The number will be in the phone book. Everyone with dementia is entitled to an assessment that establishes their needs and suggests how those needs can be met.

The following organisations provide information, support and care services to people affected by dementia as well as their families and carers. For more information ask for our booklet, '**Caring for someone with dementia: organisations that can help**'.

Admiral Nursing DIRECT is a telephone helpline, provided by Admiral Nurses and supported by the charity Dementia UK. It offers practical advice and emotional support to people affected by dementia on **0845 257 9406**.

The **Age UK** advice line, **0800 169 6565**, can give you information about help available through social services, as well as advice about issues faced by older people.

Alzheimer Scotland provides the National Dementia Helpline **0808 808 3000** in Scotland as well as local services all over Scotland for people with dementia and their carers.

Alzheimer's Society runs the National Dementia Helpline in England and Wales on **0300 222 1122** which can give you information, support, guidance and signposting to other appropriate organisations. In Northern Ireland call **028 9066 4100**.



The **Carers Trust** works to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member. Contact them on **0844 800 4361**.

Carers UK offers advice and information to carers through booklets, factsheets and its website. Their Adviceline can be contacted on **0808 808 7777**.

Guideposts Trust runs the Dementia Information Service for Carers. Call them on **0845 120 4048** for information, advice and support.

The **Lewy Body Society**, in partnership with Parkinson's UK, provides support and advice to people with dementia with Lewy bodies, their families and carers. You can contact a helpline advisor on **0808 800 0303**.

The **NHS** provides free, confidential information and advice for carers through Carers Direct on **0300 123 1053**.

There are also support groups for people with rarer forms of dementia: To find out more, visit the following websites or contact Jill Walton on **07592 540 555**.

The **Frontotemporal Dementia Support Group** (formerly The Pick's Disease Support Group) is directed towards carers who are coping with behavioural changes in a partner, family member or friend as a result of frontotemporal dementia. **www.ftdsg.org**

The **Posterior Cortical Atrophy Support Group** aims to provide information and support to people with PCA, their families, friends and healthcare professionals. **www.pcasupport.ucl.ac.uk**

The **FAD Support Group** is for families affected by autosomal dominantly inherited Familial Alzheimer's Disease (FAD). The group offers information, advice and social opportunities for people with FAD and their families. **www.fadsupportgroup.org.uk**

Alzheimer's and other dementias are complex diseases. We are making considerable progress in understanding how they develop and it's clear that they don't have one single cause.

All about risk

It is likely that a mixture of our age, genes and lifestyle could contribute to whether we develop dementia.

The risk of developing most dementias increases with age. That means as we get older, we are more likely to develop the condition. About two in 100 people aged 65 to 69 years have dementia, but this figure rises to one in five for those aged 85 to 89.

Dementia is not a normal part of getting older or an acceleration of ageing. It is caused by different diseases, most commonly Alzheimer's.

We can't change our age and there is currently no way we can completely prevent dementia but there may be some simple things we can all do that might help lower our risk.

A risk factor is anything that can increase your likelihood of developing dementia. Risk factors for cardiovascular disease (like heart disease and stroke) are also risk factors for all dementias.

So it's a good idea to keep healthy by:

not smoking

controlling high blood pressure

reducing your cholesterol level

controlling your blood glucose if you have diabetes

exercising regularly

achieving and maintaining a healthy weight

eating a healthy, balanced diet with lots of fruit and vegetables and low amounts of saturated fat

only drinking alcohol within the recommended limits.



Some studies suggest that enjoying an active life, with lots of interests and hobbies, might be beneficial. Other researchers have found that spending more time in education is associated with a lower risk.

There is currently not enough evidence to suggest that omega-3 fish oil or vitamin supplements could reduce the risk of dementia. It is not advised to take NSAIDs (non-steroidal anti-inflammatory drugs like aspirin or ibuprofen), HRT (hormone replacement therapy) or statins to protect against dementia, as research is continuing in this area. You should talk to your doctor before taking any supplements or drugs that claim to prevent dementia, as most are unproven and they can have serious side effects.

You might read or hear about other risk factors for dementia. Despite occasional publicity, research has not shown that eating meat, exposure to aluminium and living close to power lines are risk factors for dementia. There is also no firm evidence that turmeric, ginkgo, ginseng or coffee can protect against dementia.

Some studies suggest
that enjoying an
active life,
with lots of interests and
hobbies, might be beneficial

Volunteers, both with and without dementia, who take part in research studies or clinical trials play an essential role in helping scientists to understand dementia and test potential new treatments.

Taking part in research

Clinical Research Networks operate across the UK and can help you to get involved in dementia research in your area.

‘Join dementia research’ is a national service that allows you to register your interest in taking part in dementia research studies in England and Scotland. It is funded by the National Institute of Health Research in partnership with Alzheimer’s Research UK, Alzheimer’s Society and Alzheimer Scotland.

Visit **www.joindementia_research.nihr.ac.uk** or call the **Dementia Research Infoline** on **0300 111 5 111**. If you live in Wales or Northern Ireland, our Infoline staff can put you in touch with Clinical Research Networks in your area.





The research we fund

Alzheimer's Research UK has funded over £55m of pioneering research across the UK into the causes, diagnosis, prevention and treatment of dementia.

Through the work we fund into the causes of dementia, our scientists are building a detailed picture of what happens in the brain in these diseases – essential for developing new approaches to stop it.

We believe that dementia can only be defeated through research. Thanks to the generosity of our supporters, we will continue to nurture and support the ideas of scientists who will take us one step closer to a cure.



Find out more

If you have questions about research or want to get involved, contact the **Dementia Research Infoline** on **0300 111 5 111** or email **infoline@alzheimersresearchuk.org**

You can also write to us at the address on the back of this booklet.

The Infoline operates 9.00-5.00pm Monday to Friday. Calls cost no more than national rate calls to 01 or 02 numbers and should be included in any free call packages. Interpreter services are available.

We are the UK's leading research charity aiming to defeat dementia.

We welcome your comments to help us produce the best information for you. You can let us know what you think about this booklet by contacting us using the details below.



Contact us

Alzheimer's Research UK
3 Riverside, Granta Park, Cambridge CB21 6AD



General enquiries

T: 0300 111 5555
E: enquiries@alzheimersresearchuk.org



Dementia Research Infoline

T: 0300 111 5 111
E: infoline@alzheimersresearchuk.org

www.alzheimersresearchuk.org



**Alzheimer's
Research
UK**

**The Power
to Defeat
Dementia**

Registered charity number 1077089 and SC042474

