

Alzheimer's
Research UK
Defeating Dementia



All about dementia

Information on Alzheimer's disease, vascular dementia,
dementia with Lewy bodies and frontotemporal dementia.

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 www.alzheimersresearchuk.org/donate

We do not receive any Government funding and rely on donations from individuals, companies and charitable trusts, money raised by individuals and gifts in people's Wills to fund our vital research.

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Alzheimer's Research UK latest figures show that dementia affects **820,000** people in the UK at the moment.

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.

This booklet gives an overview of Alzheimer's disease, dementia with Lewy bodies, vascular dementia and frontotemporal dementias. 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.

For information about the current treatments available for dementia, please see our separate leaflet, 'Treatments for dementia', or speak to your doctor.

For advice about living with dementia or caring for someone with dementia you can contact one of the organisations listed on page 14.

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 2012 and is due to be reviewed again in November 2014.



What is Dementia? Alzheimer's?

Dementia is not a disease in itself.

Dementia is a word used to describe a group of symptoms. These can include the gradual loss of memory, communication skills and the ability to think and reason clearly.

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 that cause dementia at the same time. Alzheimer's is commonly seen with vascular dementia and 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. Severe depression, thyroid deficiencies and vitamin deficiencies can produce similar symptoms to dementia.

In dementia, brain cells stop working properly. This happens inside specific areas of the brain, which can affect how you think, remember and communicate.

Alzheimer's Research UK's latest figures show that dementia affects 820,000 people in the UK today. Most people with dementia are over 65, but it's estimated that over 64,000 under-65s have dementia. Dementia in people under 65 is often called early-onset dementia. Early-onset dementia can be caused by diseases similar to ones that affect older people, including Alzheimer's and frontotemporal dementia. A range of other rare conditions may be responsible for early-onset dementia.



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

Probably not. 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 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, then you should talk to your GP or doctor.

Symptoms

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.

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

memory

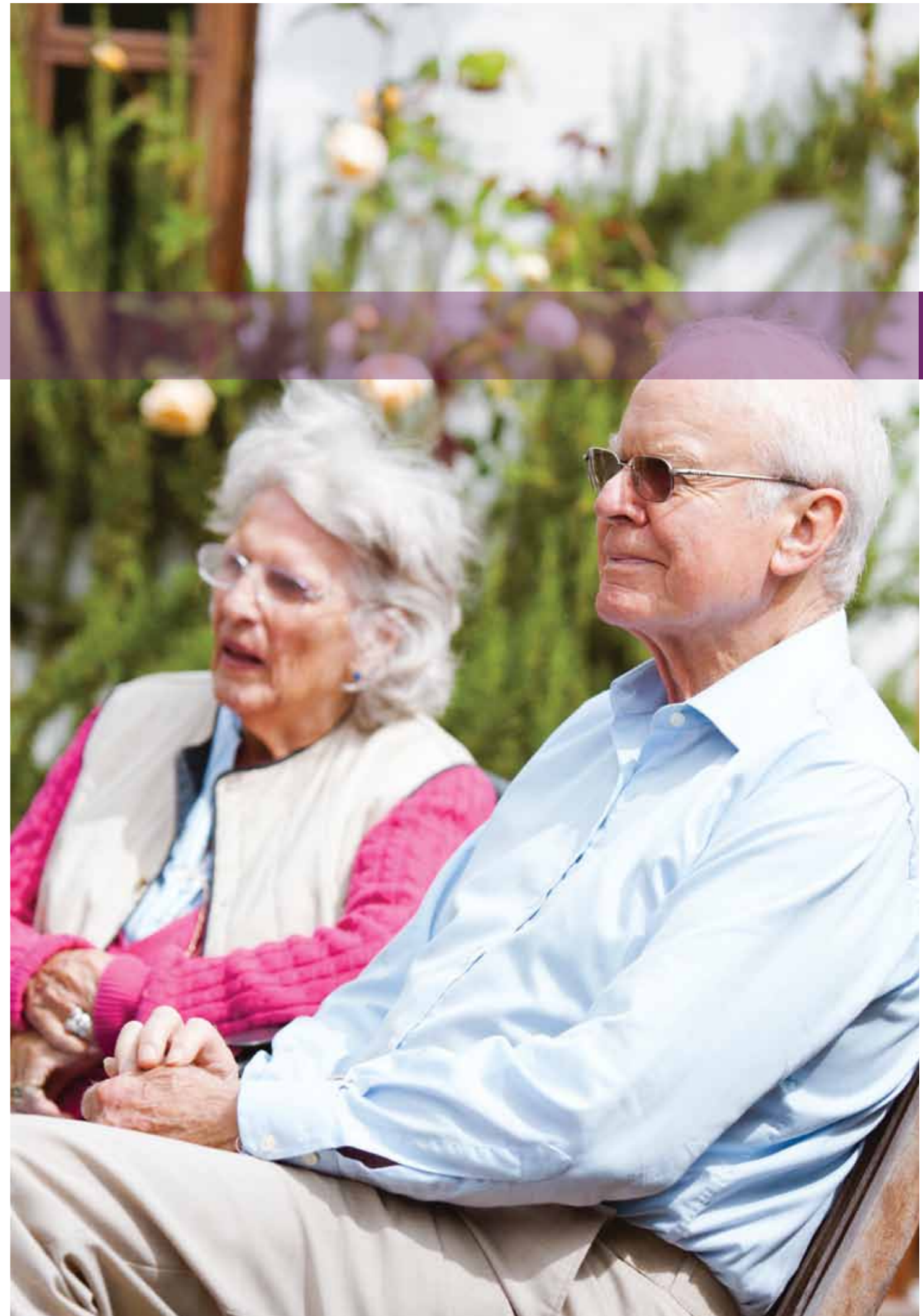
general mental functioning

ability to carry out daily tasks

personality

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 have different early symptoms and many overlap.



Symptoms con. Alzheimer's disease

Typical symptoms of early Alzheimer's include:

Regularly forgetting recent events, names and faces.

Regularly misplacing items or putting them in odd places.

Confusion about the time of day.

Disorientation, especially away from your normal surroundings.

Getting lost.

Problems finding the right words.

Reduced judgement, for example, being unaware of danger.

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 show suddenly depending on the cause.

Symptoms of vascular dementia can include:

Becoming slower in thinking.

Disorientation, especially away from your normal surroundings.

Difficulty finding words or using inappropriate words.

Memory problems like regularly misplacing items or putting them in odd places.

Becoming more emotional.

Difficulty walking or a change in the way a person walks.



Dementia with Lewy bodies

(also known as DLB or Lewy body disease) affects about 100,000 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 hour-to-hour or day-to-day.

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

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

Movements during sleep and vivid dreams.

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



Frontotemporal dementia

Frontotemporal dementia (FTD) can also be called frontotemporal lobar degeneration (FTLD) and is a term used to describe a number of different conditions. These include frontotemporal dementias, progressive aphasia (aphasia is a language disorder where people have problems speaking and writing) and semantic dementia. In the past "Pick's disease" was used to describe some of these diseases. FTD is quite rare, it affects about 11,000 people in the UK. It usually affects people aged 30-60. Symptoms can include:

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Personality changes, such as loss of inhibition, rudeness, apathy, impatience or inappropriate behaviour, of which the person is often unaware.

Loss of emotional warmth and empathy for others. The person may seem selfish and unfeeling.

Decline in language abilities – including difficulty getting words out or problems with understanding less common words and people's names.

Over-eating or changes in dietary preference, particularly cravings for sweet food.

Changes in sexual behaviour.

Day-to-day memory remains intact in the early stages, but the decline in ability to communicate may give the impression of memory problems.

Diagnosing Dementia

Diagnosing dementia, and which type of dementia someone has, is important. It will ensure that people can get the right support, treatments and plan for the future. 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. Specialist doctors who see dementia patients include old age psychiatrists, geriatricians, neurologists and clinical psychologists.

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

The most commonly used memory test is called the MMSE (mini mental state examination), although there is a range of other tests available.

Because dementia usually gets worse over time, these may be repeated, perhaps every six to 12 months, to see if there are any changes in memory.

Other tests, including brain scans and blood tests 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 given a diagnosis of dementia, you may be prescribed drugs or other treatments that can help with the symptoms or improve your quality of life.

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. For further advice and support you can contact the organisations on page 14.



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:

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

Communication and language often become more difficult.

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

Anxieties or phobias are quite common.

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

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

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

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 to find out more.

For more information, please see our separate booklet 'Treatments for dementia'. You can get a copy by calling us on 0300 111 5555 or from our website www.alzheimersresearchuk.org

What causes Alzheimer's and related diseases-

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 abnormal proteins build in the brain. They form clumps called either 'plaques' or '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 these proteins in their tracks 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 nourishment to the brain and without it brain cells die. The network of blood vessels that carry 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 caused by a series of small strokes in the brain, which a person might not notice.

Subcortical vascular dementia or vascular cognitive impairment is caused by a series of small injuries to blood vessels deep inside the brain. A person usually does not notice these injuries and their cause is not yet known. Many of these injuries over time 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 Frederich 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 and find out why it happens and 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 a parent or grandparent with dementia over the age of 65 then your risk of developing dementia is only marginally higher than someone with no family history of the condition.

If you have a close relative (parent or sibling) who has 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 30's 40's or 50's. These types of dementia are very rare.

For more information about the rare, inherited forms of dementia you can speak to your doctor or contact one of the organisations listed on page 14.

Caring for someone with dementia

Dementia has a huge impact on someone's life, as well as on their families and carers. There is practical and emotional support available to help. Accessing services and support can make a big positive difference to someone with dementia and their family. 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 should be 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.

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 2579406.

Age UK can give you information about help available through social services, as well as advice about issues faced by older people. Their helpline is 0800 1696565.

Alzheimer Scotland provides the National Dementia Helpline 0808 8083000 in Scotland as well as local services all over Scotland for people with dementia and their carers.


Alzheimer's Society provides the National Dementia Helpline in England and Wales on 0300 2221122 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 or friend who is ill, frail, disabled or has mental health or addiction problems. www.carers.org

Guideposts Trust run the Dementia Information Service for Carers. Their National Information Line is 0845 1204048, which can provide information, advice and support to carers.

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 8000303.

The NHS provides free, confidential information and advice for carers through Carers Direct on 0808 8020202.



Dementia has a huge impact on someone's life, as well as on their families and carers.

There are also support groups for people with rarer forms of dementia: To find your local contact, visit these websites:

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, and 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. For more information please visit www.dementia.ion.ucl.ac.uk or contact jill.walton@ftdsg.org.uk

All about risk

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. It is likely that a mixture of our age, genes, environment 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 dementia. About one in 20 people over the age of 60 have dementia, but this rises to about one in five people over the age of 80.

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

We can't change our age and there is currently no way we can completely prevent dementia but research suggests 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 chance 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:

Exercising regularly

Not smoking

Achieving and maintaining a healthy weight

Controlling high blood pressure

Reducing your cholesterol level

Controlling your blood glucose if you have diabetes

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.

It's not yet known whether eating oily fish or taking B vitamins can reduce the risk of dementia as studies so far have had mixed results. It is not advised to take NSAIDs (non-steroidal anti-inflammatory drugs like aspirin or ibuprofen) or HRT (hormone replacement therapy) 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 shown that meat, aluminium or living close to power lines are not risk factors for dementia. There is also no evidence that turmeric, ginkgo, ginseng, statins or coffee can protect against dementia.

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



Research

Taking part in research

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. If you are interested in taking part in research, there are organisations that can help. You can also ask your doctor if they know of any studies or clinical trials taking place in your area.

Clinical Research Networks are in place across the UK and can help you get involved in dementia research in your area:

DeNDRoN (Dementias & Neurodegenerative Diseases Research Network) promotes involvement in dementia research in England. Visit their website at www.dendron.org.uk or ring 020 3206 4960.

NeuroDem Cymru (The Wales Dementias and Neurodegenerative Disease Research Network) can be contacted on 01248 382226/382328 or at www.neurodemcymru.org

Scottish Dementia Clinical Research Network allows patients and carers in Scotland to register their interest for research. Contact them on 01738 562322 or visit www.sdcrn.org.uk

Northern Ireland Clinical Research Network can provide information about current dementia research in Northern Ireland. Contact them on 028 9063 6360 or at www.nicrn.hscni.net

UK Clinical Trials Gateway (www.ukctg.nihr.ac.uk) is a website designed to help you and your doctor find clinical trials that may be appropriate. If you are interested in joining a trial, you should discuss this with your doctor as you may need a referral.

People in Research is a database listing research projects and organisations that are looking for members of the public to get involved in their work. This could include advising on ethics, peer reviewing research proposals, assisting with studies

The research we fund

Alzheimer's Research UK has funded tens of millions of pounds of pioneering research across the UK to promote the development of new treatments for 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 treatments to stop it.

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

Defeating dementia

Alzheimer's Research UK is the UK's leading dementia research charity.

We fund world-class pioneering scientists to find preventions, treatments and a cure for dementia. Keep up to date with the latest dementia research news by signing up to our newsletter at www.alzheimersresearchuk.org or writing to us.

Read more about our work and achievements at www.alzheimersresearchuk.org



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All our reviewers for their help.

If you're interested in helping us by reviewing our information booklets, please get in contact using the details on the back cover.

Have your say

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.

About us

Alzheimer's Research UK is the UK's leading dementia research charity. Help us to defeat dementia by donating today www.alzheimersresearchuk.org/donate

Contact us

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