

Treatments for dementia



**Alzheimer's
Research
UK**

Make breakthroughs possible



This information is for anyone who wants to know more about the treatments currently available for dementia. This might include people with dementia, their carers, friends and family.

Contents

Introduction	3	Non-drug treatments for dementia	10
What is dementia?	4	Availability of dementia treatments	11
Drug treatments for dementia	5	Treatments for other symptoms of dementia	12
Treatments for Alzheimer's	6	Depression	
Cholinesterase inhibitors		Agitation, anxiety and aggression	
Memantine		Caring for someone with dementia	16
Treatments for other types of dementia	8	Research	18
Vascular dementia		Taking part in research	
Dementia with Lewy bodies		The research we fund	
Frontotemporal dementia			

This booklet gives an overview of the treatments currently available for the different causes of dementia, including both drug and non-drug treatments. It covers treatments for Alzheimer's disease, vascular dementia, dementia with Lewy bodies (DLB) and frontotemporal dementia (FTD).

The information in this booklet does not replace the advice that doctors, pharmacists or nurses may provide, but gives you information that we hope you will find useful.

For advice about living with dementia or caring for someone with dementia you can contact one of the organisations listed on page 16.

Versions

If you would like a version of this information including references, please get in touch.

This booklet was updated in April 2020 and is due to be reviewed in April 2022.

What is dementia?

The word dementia is used to describe a group of symptoms – these include memory loss, confusion, mood changes and difficulty with day-to-day tasks.

Dementia is caused by different diseases, with Alzheimer's disease being the most common cause. Other causes of dementia include vascular dementia, dementia with Lewy bodies and frontotemporal dementia.

When people develop dementia, their brain cells become damaged and stop working properly. This happens inside specific areas of the brain, which can affect how you think, remember and communicate.

For more information about dementia, please ask for our free booklet '**All about dementia**'. Contact details are on the back page.

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

500,000
people in the UK

Drug treatments for dementia

If you have been diagnosed with dementia, there are several drugs that might help. These may differ depending on the type of dementia you have. You can find more information about the drugs, how they work and their effects, on the next few pages.

You can talk with your doctor about the treatments available and together you can decide which ones might be best for you. You might also like a carer or member of your family to be involved in these decisions.

If you are prescribed a drug for dementia, treatment is usually started by your own doctor following guidance from a specialist doctor. Specialist doctors who see people with dementia include psychiatrists, geriatricians and neurologists. Alternatively, your own doctor may start your treatment and it may be continued and monitored either by a specialist or by your doctor.

Throughout this booklet, the generic or common name of drugs is used, like donepezil. In brackets are the brand names, for example (Aricept).

The NHS 111 service can give you medical advice if you cannot reach your doctor.
Telephone: 111 - 24 hours a day.



Treatments for Alzheimer's

Alzheimer's disease is the leading cause of dementia and involves the build-up of two proteins in the brain, called amyloid and tau. This damages brain cells and leads to symptoms of memory loss, confusion and changes in mood.

People with Alzheimer's disease might benefit from taking a cholinesterase inhibitor. Cholinesterase inhibitors are not a cure but are used to treat some of the symptoms in Alzheimer's.

Cholinesterase inhibitors

There are three cholinesterase inhibitors available to treat Alzheimer's:

donepezil (Aricept)

rivastigmine (Exelon)

galantamine (Reminyl).

All of these drugs work in a similar way. So far, research has not found a difference in how effective each drug is, but some people may respond better to one drug than another or have fewer side-effects.

Cholinesterase inhibitors are given to people with mild to moderate Alzheimer's, and doctors will continue to prescribe one of these drugs as symptoms progress, so long as it is safe and suitable to do so.

How cholinesterase inhibitors work

In Alzheimer's disease, nerve cells become damaged and lose their ability to communicate. Cholinesterase inhibitors work by increasing the amount of a chemical called acetylcholine, that helps messages to travel around the brain. These messages are vital to the way we move, think and remember. Cholinesterase inhibitors can reduce the symptoms of Alzheimer's for a time.

These treatments are normally given as tablets or capsules, but they are available in a liquid form too. Donepezil is also available as a tablet that dissolves on the tongue, and Rivastigmine is available in patches, where the drug is absorbed through the skin. Your doctor will discuss the most suitable form for you.

Effects of cholinesterase inhibitors

People with Alzheimer's may find that their symptoms improve by taking a cholinesterase inhibitor. This could be improvement in thinking, memory, communication or with day-to-day activities. Others may find that their condition stays the same, or that their symptoms do not worsen as quickly as they would have expected. Some people may not notice any effect at all.

As these drugs don't stop the disease from progressing in the brain, symptoms will continue to get worse over time. However, they can help some people to function slightly better than they would do without the drug.

The most common side-effects of cholinesterase inhibitors are feeling or being sick, diarrhoea, having trouble sleeping, muscle cramps and tiredness. These effects are often mild and usually only temporary. Not everyone will experience side-effects. If you are worried about side-effects you can talk about this with your doctor.

Memantine

Memantine (Ebixa or Axura) is recommended as an option for people with moderate or severe Alzheimer's disease, and for people with moderate Alzheimer's if cholinesterase inhibitors are not suitable. Memantine is normally given as a tablet, but it is also available as a liquid. Your doctor will discuss the most suitable form for you. Like cholinesterase inhibitors, memantine is not a cure. However, it can help with some symptoms.

Memantine is currently only recommended for people with Alzheimer's disease, and people with dementia with Lewy bodies if cholinesterase inhibitors are not effective. Research is underway to learn more about whether it might be beneficial for people with other forms of dementia.

People with moderate or severe Alzheimer's disease are sometimes offered combination therapy, where a cholinesterase inhibitor is given in addition to memantine.

How memantine works

Memantine also helps nerve cells in the brain communicate with each other. It does this by regulating a chemical called glutamate in the brain. In Alzheimer's disease this can allow brain cells to work more effectively for longer, and it can help to reduce the symptoms of Alzheimer's disease for a while.

Effects of memantine

Some people taking memantine may not notice any effect at all. Others may find that their symptoms stay the same, when they would have expected them to get worse.

Some people experience side-effects when taking memantine. The most common side-effects of memantine are headaches, dizziness, drowsiness and constipation. These are usually only temporary, and if you are concerned about them you can talk to your doctor.



Treatments for other types of dementia

Vascular dementia

Vascular dementia occurs when blood vessels become damaged and blood flow to the brain is reduced. This type of dementia is linked to risk factors for cardiovascular disease. These include high cholesterol, high blood pressure, type 2 diabetes, stroke and heart problems. People with these conditions have an increased risk of developing vascular dementia.

While there are currently no specific treatments for vascular dementia, a doctor may prescribe medication to treat the risk factors like high blood pressure or diabetes. More research is needed to see if treating these conditions could slow the development of vascular dementia.

To help control these underlying conditions, your doctor may support you to stop smoking,

exercise regularly and to eat a healthy balanced diet. Research is still ongoing but has found that following this advice may help to reduce your risk of developing vascular dementia.

Vascular dementia is sometimes caused by a stroke, so a doctor may also recommend physiotherapy, occupational therapy or speech therapy if appropriate.

Cholinesterase inhibitors and memantine (details on p6) are not usually beneficial for people with vascular dementia. However, they may be helpful for people diagnosed with both Alzheimer's and vascular dementia, which is often called 'mixed dementia'.

Dementia with Lewy bodies (DLB)

Dementia with Lewy bodies is caused by small round clumps of protein that build up inside nerve cells in the brain. One of these proteins is called alpha-synuclein and the clumps it forms are called Lewy bodies. The protein clumps damage the way nerve cells work and communicate. In DLB, the affected areas of the brain control thinking, memory, vision and movement.

There is evidence that cholinesterase inhibitors (details on p6) may help to improve some of the symptoms of DLB, including thinking skills and visual hallucinations. So far memantine (p7) has only been shown to have small benefits for people with DLB, but it may be offered to those who can't be given donepezil or rivastigmine.

Lewy bodies are also responsible for the damage that causes movement problems in Parkinson's disease. Levodopa, a drug used to treat Parkinson's, may also be used to treat movement problems in DLB. There is a risk this drug may provoke or worsen visual hallucinations. If this occurs, inform your doctor. Physiotherapy could also help someone with DLB with their movement problems.

Frontotemporal dementia (FTD)

Frontotemporal dementia is a relatively rare form of dementia, accounting for less than 5% of all dementia cases. The disease is caused by damage to cells in areas of the brain called the frontal and temporal lobes. These areas regulate our personality, emotions and behaviour, as well as our speech and understanding of language.

At the moment there are no drugs specifically to treat frontotemporal dementia. Other drugs may help some symptoms of the disease; for example, an antidepressant drug may be considered. You can find more details in the next sections.

Physical symptoms such as problems swallowing or moving may need careful management in their own right. Someone with frontotemporal dementia may be offered speech therapy or physiotherapy to help with these symptoms.

Vascular dementia and dementia with Lewy bodies (DLB) are the second and third most common causes of dementia.

Non-drug treatments for dementia

There are several types of cognitive therapy that may benefit people with dementia. Cognitive skills can be described as thinking skills, and cognition is a word used to describe thought processes.

Cognitive stimulation activities are designed to stimulate thinking skills and engage people who have dementia. They are often group-based and include games, with an emphasis on enjoyment. Cognitive stimulation can be provided by health or social care staff with appropriate training.

The benefits of cognitive stimulation for people with dementia could include improvement in memory, thinking skills and quality of life.

Other types of cognitive therapy are currently being tested to see if they can benefit people with dementia. These include reminiscence therapy, where past activities and experiences are discussed, usually with photographs and other familiar objects from the past.

Cognitive rehabilitation is also being tested to find out if it can help people with dementia. This technique aims to improve how people manage everyday tasks by setting personal

goals and finding ways to achieve them. The focus is on developing the person's strengths and helping them to overcome their individual challenges.

It is best to be wary of 'herbal', 'alternative' or 'complementary' products that claim to benefit people with dementia, or to improve memory. There has been very little high-quality research into these products, and some may not be safe for people with dementia. For example, despite anecdotal reports, there is currently very little evidence from studies in people that coconut oil can benefit people with dementia.

The most important thing when considering taking a complementary therapy is to talk to your doctor. Some of these products interact with normal medication, so the doctor needs to know about anything being taken. These products should never be taken as a substitute for prescribed medicines.



Availability of dementia treatments

Cholinesterase inhibitors are currently available across the UK on NHS prescription, and are recommended for people with mild and moderate Alzheimer's disease. Memantine is available on NHS prescription for people with moderate or severe Alzheimer's, and for people with Alzheimer's if cholinesterase inhibitors don't help or are not suitable.

People with mild to moderate dementia may have the opportunity to participate in cognitive stimulation if it is available. It should be offered irrespective of any drug prescribed.

Treatments for other symptoms of dementia

Depression, anxiety, agitation and aggression are symptoms often related to dementia. Here you will find information about non-drug and drug treatments that can help people with dementia who experience these symptoms.

These symptoms are often experienced by people in the later stages of dementia, including those with Alzheimer's disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia.

Your doctor may advise a non-drug treatment to help with these symptoms first. Non-drug treatments could include exercise, cognitive therapy or group activities such as singing. For more details of these, see page 14.

You can discuss your treatment options with your doctor. Organisations on page 16 can give you advice about caring for someone with dementia and where to access local support and care services.

Depression

Depression is common in all forms of dementia. Your doctor may consider recommending cognitive behavioural therapy (CBT). CBT provides an opportunity for people to talk about their worries and concerns with a specialist practitioner. It aims to help people develop different ways of thinking and behaving.

There may also be other therapies offered in your local area that could help; these might include exercise or group activities such as music therapy.

You may be offered an antidepressant drug, either as an alternative to CBT or in combination with it. There are different types, or classes, of antidepressant; some are not suitable for people with dementia. Your doctor will be able to advise you if an antidepressant could help and which type would be best.

Agitation, anxiety and aggression

Some people with dementia experience agitation, aggression, delusions (negative or mistaken beliefs), severe anxiety, hallucinations, sleep disturbances and other behavioural symptoms. They are also known as neuropsychiatric symptoms or behavioural and psychological symptoms of dementia (BPSD).

While these symptoms can be difficult for the person living with dementia and their loved ones, there are simple things that might help. It may be possible to identify the cause or trigger of aggression or agitation. A person's physical health may affect their behaviour – for example pain, being constipated or needing the toilet. Someone's surroundings can also affect their behaviour, as well as their feelings towards certain situations.

Finding out if there are triggers that cause aggressive or agitated behaviour means it might be possible to remove, treat or avoid them. Mild behavioural symptoms can often

be helped with adjustments to physical surroundings, reassurance or changes to daily routine. Possible triggers could include:

undetected pain or discomfort

infection

depression

social situations

factors in the environment

disruption to routine.

For advice and support for coping with challenging behaviours and caring for someone with dementia, you can contact one of the organisations on p16. Your doctor or nurse will also be able to offer you advice.



Treatments for other symptoms of dementia

Non-drug treatments

To help someone with agitation, a non-drug therapy may be offered. The type of therapy will depend on local availability and the individual's preference, and might include:

aromatherapy

therapeutic use of music or dancing

animal-assisted therapy

massage

multi-sensory stimulation.

A person's response to these therapies should be carefully monitored and the approach changed if needed. These therapies can be provided by a healthcare professional with appropriate training and supervision.

Some people with dementia may find one of these therapies helpful and there is some research that suggests they may be beneficial. However, the studies done so far have been small, so more research is needed.

Antipsychotic drugs

If non-drug measures have not worked and someone is very distressed, they may be offered treatment with an antipsychotic drug.

These drugs should only be offered if there is severe distress or immediate risk of harm to the person themselves or others around them. While they can be helpful in certain circumstances, antipsychotics can also have serious side-effects so other methods to reduce agitation, anxiety and aggression should be tried first. Activities the person can engage with and enjoy might help. These could include reminiscence therapy, spending time outside, and listening to music or singing.

Anyone prescribed an antipsychotic drug should be closely and regularly monitored by a doctor. If you have any concerns about antipsychotics being used you can talk to your doctor.

To help with agitation or aggression, a doctor may suggest a

non-drug therapy

Effects of antipsychotic drugs

There are several different antipsychotic drugs. One, called risperidone (Risperdal), is licensed to treat severe agitation, aggression and behavioural changes in people with dementia. Short term treatment can help to reduce these symptoms.

On rare occasions, other antipsychotic drugs may be considered at a low dose if someone is extremely aggressive. Haloperidol (Haldol, Serenace) is another antipsychotic that might be considered for a very short period (one week). Lorazepam (Ativan, Temesta), a type of drug called a benzodiazepine, is not an antipsychotic drug but may also be used in a similar way for a short time to help reduce very aggressive behaviour.

All antipsychotics can have serious side-effects. Long term use of antipsychotic drugs is associated with an increased risk of stroke and

may worsen memory and thinking in people with Alzheimer's disease. For this reason, antipsychotics should not usually be used for longer than three months and the benefits of prescribing them need to be carefully weighed up against the risk of side-effects for each person.

Antipsychotics can be particularly dangerous for people with dementia with Lewy bodies and should only be prescribed in severe circumstances. They can cause symptoms to get worse.

Different antipsychotic drugs have been used in the past to treat dementia symptoms, but they are not recommended or licensed for this. You can, and should, talk with your doctor about what type of medication is being prescribed and why.



Caring for someone with dementia

Accessing services and support can make a real and positive difference to someone with dementia and their family.

Some services will be provided by local authorities and others can be arranged through your doctor. For advice, contact your local authority social services department to find out what support is available near you. Everyone with dementia is entitled to an assessment of their needs, and carers are also entitled to their own assessment.

The following organisations provide information, support and care services to people affected by dementia as well as their families and carers.

There are organisations that provide information and support to people affected by dementia.

The **Admiral Nurse Dementia Helpline** is supported by the charity Dementia UK. It offers practical advice and emotional support to people affected by dementia on **0800 888 6678**.

Age UK can provide information about help available through social services, as well as advice about issues faced by older people. Their helpline number is **0800 169 6565**.

Alzheimer Scotland provides the National Dementia Helpline on **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, Wales and Northern Ireland on **0333 150 3456**, offering information, support, guidance and signposting to other appropriate organisations.

Carers' Trust provides access to breaks for carers, information and advice, education, training and employment opportunities. Contact them on **0844 800 4361**.

Carers UK provides advice and information to carers through their website, publications and their Adviceline, **0808 808 7777**.

Guideposts provides services for people with long-term or degenerative conditions, including dementia. Their online and telephone resource, called HERE, can help people to find out about support and care services in their area. Call **0300 222 5709**.

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

The **Lewy Body Society**, provides support and advice to people with dementia with Lewy bodies, their families and carers. You can contact a helpline advisor on **01942 914000**.

Rare Dementia Support operates groups that provide support and information for people with frontotemporal dementia (FTD) and other less-common types of dementia, as well as their families and carers. Information can be found on the Rare Dementia Support website www.raredementiasupport.org or you can contact the support service on **020 3325 0828** or contact@raredementiasupport.org





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.

Join Dementia Research is a national service that allows you to register your interest in taking part in dementia research studies. It is operated by the National Institute for Health Research in partnership with Alzheimer's Research UK, Alzheimer's Society and Alzheimer Scotland.

Visit www.joindementiaresearch.nihr.ac.uk or call the Dementia Research Infoline on **0300 111 5 111**.



Research

Alzheimer's Research UK has funded over **£47.3 million** of pioneering research 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 them.

We are supporting research to improve the detection of dementia – aiming to help the right people get into the right clinical trials at the right time. This will mean potential new drugs can be tested in people when they are most likely to have the greatest benefit.

Backed by our passionate scientists and supporters, we're challenging the way people think about dementia, bringing together the people and organisations who can speed up progress, and investing in research to make breakthroughs possible.



Find out more

If you have questions about dementia, dementia 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 dementia research charity dedicated to making life-changing breakthroughs in diagnosis, prevention, treatment and cure.

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



Supporter care

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**

Make breakthroughs possible

Registered charity number 1077089 and SC042474



This booklet was printed with support from The Perfume Shop who had no input into the content of the booklet.