

# Medication for people living with dementia



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Dementia is the umbrella term for a range of progressive conditions that affect the brain.

There are over 200 types of dementia. Each stops the brain cells working in specific areas that affect the person's ability to remember, think and speak.

Dementia always gets worse over time, and currently, there is no known cure.

However, for some types of dementia, medication may help to relieve some of the symptoms or even slow its progression.

## How do medications work for dementia?

Dementia medications can help to slow down the decline in a person's cognition (their ability to think, understand and remember). They may help with:

- anxiety
- concentration
- memory
- motivation
- daily living activities

Dementia medications are mainly used for Alzheimer's disease, which is the most common form of dementia.

Medications for dementia can be used in combination with non-medical treatments, such as occupational therapy, cognitive stimulation therapy, counselling and reminiscence/life story work (please see Sources of support on p10 for more information).

### Medications for Alzheimer's disease

The main types of medication for Alzheimer's disease are called 'cholinesterase inhibitors'.

It is thought that dementia may be caused in part by the decline in levels of a brain chemical called acetylcholine, which is needed for memory and learning. As levels of acetylcholine fall, symptoms get worse over time.

Cholinesterase inhibitors work by blocking the breakdown of acetylcholine in the brain. This can help to reduce some dementia symptoms, usually for a period of six to 12 months.



There are three types of cholinesterase inhibitor that may be used for Alzheimer's disease:

- donepezil (also known as Aricept)
- · rivastigmine (Exelon)
- galantamine (Gatalin XL, Reminyl, Galsya)

There is one other type of medication for Alzheimer's disease, called memantine (Ebixa, Nemdatine). This is a type of 'NDMA receptor antagonist'. It works by limiting excess levels of calcium in the brain, which can reduce the rate of damage to the brain cells.

## Who do these medications work for?

Donepezil, rivastigmine, galantamine and memantine are mainly prescribed for people with Alzheimer's disease. They can also be prescribed for dementia with Lewy bodies, Parkinson's disease dementia and mixed dementia, where a person has two or more types of dementia together – usually Alzheimer's disease and vascular dementia.

Donepezil, rivastigmine and galantamine are most beneficial for people with early to middle stage dementia (also known as mild to moderate).

Memantine may be used for people with middle stage (moderate) dementia who cannot take cholinesterase inhibitors, usually due to side effects. It may also be used alongside a cholinesterase inhibitor for late stage (severe) dementia.

It is important to note that dementia medicines are not effective for everyone. Some people may need to try several types to see which works best for them, and some may find there is no benefit at all.

# Medication for other forms of dementia

Dementia medications are not suitable for all forms of dementia. For example, the medicines used for Alzheimer's disease do not help with frontotemporal dementia and could even make the symptoms worse.

However, people with frontotemporal dementia may benefit from taking a type of antidepressant called selective serotonin reuptake inhibitors (SSRIs) which could help with uninhibited behaviour, overeating

and compulsive behaviours.

People living with vascular dementia – which is caused by problems with blood supply to the brain, for example as the result of a stroke or transient ischaemic attack (TIA, or 'mini stroke') – may be prescribed medicines to help with the underlying causes. These include medication for high blood pressure, high cholesterol and heart disease.

It is very important that a person with dementia takes any medications for other health conditions (such as diabetes, high blood pressure and depression) as prescribed to help them stay as physically and mentally healthy as possible.

# What to consider before deciding to try medication

Before starting medication for dementia, it is important to weigh up the pros and cons. The doctor will carefully consider:

 whether the medication is suitable for the person's type of dementia

- the likelihood of side effects (see p6 for more information), and whether they will be outweighed by the benefits
- any other pre-existing health conditions
- potential interactions with other medicines the person is already taking
- their ability to take the medication as prescribed

# How to tell if medication is working

The person living with dementia should have regular reviews of how well their medication is working with their GP, community pharmacist, or specialist memory clinic.

The healthcare professional will:

- see how well the person performs in cognitive tests (tests of memory and thinking)
- ask the person and their family carer how they think the medication is working
- assess the person's overall physical and mental health



If a dementia medication works for the person with the diagnosis, their symptoms will usually improve temporarily, for around six to 12 months, but then they will gradually get worse. However, the person may continue to take the medication to avoid a sudden 'rebound' worsening of or deterioration in symptoms.

It can be very disappointing for the person with dementia and their family if medication doesn't work, but there are other things they can do to look after their physical and mental health.

Please see Sources of support on p10 for information on things that may help, including staying healthy, good sleep habits, eating and drinking well, and making the home safe and comfortable.

#### Side effects

All medications come with some risk of side effects. For dementia medicines, common side effects include:

- diarrhoea, nausea and/ or vomiting
- headaches
- dizziness
- loss of appetite
- muscle cramps
- fatigue
- insomnia

To minimise the risk of unpleasant side effects, the doctor will often prescribe a low dose of medication at first, and gradually increase it until the person reaches the maximum dose that they can tolerate. This is known as 'titration'.

All prescribed medications come

with a patient information leaflet which lists possible side effects, and the person can ask their doctor for advice.

Community pharmacists can also be an excellent source of support and advice around side effects.

### **Stopping medication**

People may decide to stop taking dementia medicines for a variety of reasons. These might include:

- · unpleasant side effects
- · the medication not working
- · difficulty in taking the medication as prescribed, even with support, eg forgetting doses or taking too much

Stopping medication may be a personal choice or advised by the person's healthcare professional. Ideally, it should be a joint decision, and the doctor should ask the person and their caregiver for their opinions.

It is important that if a person wishes to stop taking their medication, they speak to their GP first. This ensures it is done in a safe and supervised way, often by

reducing it gradually. This will help to avoid complications such as a sudden worsening of symptoms.

#### Managing medications for a person living with dementia

Taking medications safely and as prescribed is essential if the person with dementia is to receive their full benefit. They may need support to do this.

Some medications need to be taken at set intervals or a specific time of day, with or after food, or on an empty stomach.

All of this information should be provided on the prescription label on the medication packaging and in the patient information leaflet inside, or you can seek advice from a pharmacist.

If the person with dementia forgets to take their medicines, there are a number of ways to help them remember:

 visual reminders like a wipeclean wall chart or a label stuck to the cabinet where medications are kept

- a pill organiser with separate compartments for times of day and days of the week
- alarms or alerts on the person's phone
- voice reminders, for example using an Amazon Alexa
- · smartphone apps
- linking taking the medication with an element of their daily routine, eg brushing their teeth: when something becomes a habit, it is easier to remember

In some cases, pharmacies can supply tablets in a dosette box – a pre-filled pill organiser that clearly shows the times and days when each medication needs to be taken. This can be especially helpful if the person needs to keep track of taking multiple medications. Please see Sources of support on p11 for more information on pharmacy services.

If a person living with dementia forgets a dose of their medicine, they should try to take it as soon as they remember. However, if it is within four to six hours of their next dose, they should skip the missed dose completely.

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Missing the occasional dose is unlikely to cause problems, but if the person misses their medication for several days back-to-back, they should contact their GP or prescriber. If it becomes a recurring problem, it is important to discuss why this is happening and whether it is still appropriate for them to take the medication.

Some people have difficulty swallowing tablets, especially as dementia progresses. If this is the case, speak to the person's GP, specialist or pharmacist about alternatives, for example a liquid medication, dissolvable tablets or a sticky patch worn on the skin.

If it is proving too challenging for the person to take their medicines – including if they are resisting taking it – make an appointment to discuss this with their GP. In some cases, 'covert administration' – for example, hiding the medication in food or drink – may be an option, or the decision may be made that medication is not proving useful.

### **Medication safety**

It is important that the person with dementia does not take more



medication than is prescribed.
This could happen if they forget
they have already taken their
medication or if they lose track of
how many doses they have taken.

To minimise the risk of overdose, community pharmacy teams can arrange for medication to be picked up or delivered to the person's home weekly. This will prevent a stockpile of medication building up at home.

If a person has taken too much medication – even if only a small amount – you should call NHS 111 for immediate advice, or call 999 or go directly to A&E if there are signs of severe overdose, eg delirium (a state of intense confusion), drooling, sweating or extreme nausea.

If the person has supplies of medication that they no longer take or are out of date, they should be taken to a pharmacy to be disposed of safely.

Medicines should be stored in a safe place at all times. If the person with dementia needs support with taking medications safely, it is advisable to keep them in a locked drawer, cupboard or safety box. It is also very important that medications are kept out of reach of any children who live in or visit the person's home.

### Help with prescription costs

In England, everyone over the age of 60 is entitled to free NHS prescriptions. In addition, prescriptions are free for people who have certain medical conditions (known as medical exemption or MedEx), receive some benefits, or are classed as being on a low income. For more information on eligibility for free prescriptions in England, please see Sources of support on p11.

If a person does not qualify for free prescriptions but requires two or more prescriptions a month, they can save money by buying a prescription prepayment certificate (PPC). This involves paying a set fee that covers all prescriptions issued during the month, no matter how many.

For more information on PPCs, please see Sources of support on p11.

In Wales, Scotland and Northern Ireland, prescriptions are free for everyone.



### **Sources of support**

To speak to a dementia specialist Admiral Nurse about medications for dementia, or any other aspect of dementia, please call our Helpline on **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25<sup>th</sup> December) or email helpline@dementiauk.org

To book a phone or video call appointment with an Admiral Nurse, please visit **dementiauk.org/book-a-clinic-appointment** 

#### **Dementia UK resources**

Types of dementia dementiauk.org/types-of-dementia

Getting the best out of GP and other health appointments dementiauk.org/practical-guide

Getting the most out of a remote consultation dementiauk.org/remote-consultation

Staying healthy with dementia dementiauk.org/ staying-healthy

Creating a 'life story' dementiauk.org/creating-a-life-story

Making the home safe and comfortable for a person with dementia dementiauk.org/safe-comfortable-home

Eating, drinking and dementia dementiauk.org/eating-and-drinking

Good hydration for a person with dementia dementiauk.org/hydration

Cognitive stimulation dementiauk.org/cognitive-stimulation

#### Other resources

NHS: who can get free prescriptions? nhs.uk/nhs-services/ prescriptions-and-pharmacies/who-can-get-free-prescriptions

NHS free prescriptions eligibility checker services.nhsbsa.nhs.uk/ check-for-help-paying-nhscosts/start



Prescription prepayment
certificates (PPC)
nhs.uk/nhs-services/
prescriptions-and-pharmacies/
save-money-with-aprescription-prepaymentcertificate-ppc

NHS: how your pharmacy can help nhs.uk/nhs-services/ prescriptions-and-pharmacies/ pharmacies/how-yourpharmacy-can-help/

Find a pharmacy nhs.uk/service-search/ pharmacy/find-a-pharmacy

NHS medicines tips for carers nhs.uk/conditions/social-careand-support-guide/practicaltips-if-you-care-for-someone/ medicines-tips-for-carers The information in this booklet is written and reviewed by dementia specialist Admiral Nurses.

We are always looking to improve our resources, to provide the most relevant support for families living with dementia. If you have feedback about any of our leaflets, please email feedback@dementiauk.org

We receive no government funding and rely on voluntary donations, including gifts in Wills.

For more information on how to support

Dementia UK, please visit

dementiauk.org/donate
or call 0300 365 5500.

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If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

#### Call **0800 888 6678** or email **helpline@dementiauk.org**

Open Monday-Friday, 9am-9pm Saturday and Sunday, 9am-5pm



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