

My Choice



**The information you need to help
you to Live Well with Dementia**

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We suggest you make your way through the booklet section by section, at your own pace. If you are accessing this digitally you can click on the relevant section in the contents page to be taken straight to that section.

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Why 'my choice'?

A diagnosis of dementia can be worrying and have a big impact on you and those close to you. It can take time to adjust to your diagnosis and process all the information you have been given. Sometimes people can feel overwhelmed by too much information, while others can feel they are given too little information.

It is important that you understand what can help you manage your symptoms, how to live well with Dementia, and how to prepare for the future. This includes what you and those around you can do, as well as how to access activities and services that are available to support you.





The aim of 'my choice' is to give you accurate and accessible information in a way that helps you make informed choices to support your health and wellbeing now and for the future.

What you choose to do, and how you do that is your choice. It is very important that you feel comfortable and enjoy the things you do. But don't be afraid to try new things, or to do things differently. This can feel overwhelming at first, and you might need some support when trying new things, but it is often worth it in the longer term.

What information is included in 'my choice'?

'My choice' includes information based on the most up-to-date evidence available on treatments, interventions and activities that aim to help people to live well with dementia.

We have only used research that has been published in recognised and trusted medical and health-related journals. The thumb signs show you the level of evidence available at the current time, and the blue star means this advice is relevant to everyone as they age. There is a lot of dementia research underway, so recommendations may change in the future, and as that happens, this booklet will be updated.

The green thumbs up sign means there is a good level of evidence that a treatment, intervention or activity works to support health and wellbeing in dementia.	
The yellow sideways thumb means there is currently not enough evidence to know if the treatment, intervention or activity works to support health and wellbeing in dementia.	
The red downward thumb sign means there is enough evidence to suggest that the treatment, intervention or activity doesn't work to support health and wellbeing in dementia.	
The blue star means the interventions and activities can help protect people against dementia as they age, and are also helpful for people with mild cognitive impairment.	

Where it is relevant, we have also included National Institute of Health and Care Excellence (NICE) recommendations. NICE provides evidence-based guidance, advice, quality standards

and information to health and care services in the UK, and makes several recommendations for dementia care.

The topics and recommendations included in this booklet all have the same aim: to help you to live well with dementia, to support your cognition (brain function), and to help you feel mentally and physically well.

The effects of dementia change over time, and we are all different, so some things may work better at different stages, and you might need to try a few different things to find the ones that work best for you.

Where can I find more information?

In each section we have provided details on where to find more detailed information from trusted organisations that support people living with dementia.

For any questions about your health and medications, your GP surgery is your first point of contact. You do not need to wait for your annual reviews to get in touch with them.

For most other activities, different locations have different services available, so it is worth asking your dementia or health and care support worker for local contacts. It's also worth getting in contact with local groups and charities that support people in your community.

At the back of this booklet, we have added additional information we think you may find helpful, including about benefits you may be entitled to.

Glossary of terms:

Cognition: this includes thinking skills, processing, understanding, responding to, and remembering information.

Dementia support worker: this is someone allocated to support you after your diagnosis. This is set up differently depending on where you live and may be called dementia navigator, support worker or coordinator.

Intervention: an action taken to help improve a situation. E.g. doing puzzles to stimulate your brain.



This section also includes advice on keeping hydrated, alcohol, and food supplements.

Why is eating well important for people living with dementia?

Eating well (healthy nutritious food) helps maintain general health and wellbeing and in addition eating certain foods may help slow and manage cognitive decline in dementia.

Some foods are proven to be more likely to cause inflammation and toxin build-up in the brain that can contribute to dementia symptoms. Some foods can also increase the risk of heart and blood vessel disease and diabetes, which can also contribute to dementia symptoms.

What works?



There is some evidence that the following diets may help people living with dementia:

- The Mediterranean diet: mainly plant-based foods, fish, and olive oil.
- MIND (Mediterranean and DASH for Neurodegenerative Delay): vegetables, berries, 'good' carbohydrates, nuts, and olive oil.
- Omega-3 rich diet: eating fresh and oily fish, nuts and seeds, and oils
- A healthy, balanced diet: eating a wide variety of foods in the right proportions.



These diets currently do not have enough evidence that they help people living with dementia:

- Paleo diet: fruits, vegetables, lean meats, seafood, eggs, nuts and seeds, and avoiding grains, beans and dairy products.
- Ketogenic diet: high fats, moderate proteins and minimal carbohydrates such as bread and pasta.

National Institute of Health and Care Excellence recommendation:

NICE recommends healthy eating to support health and wellbeing.

How can I eat well?

What you decide to eat is a personal choice and may be influenced by your culture, preferences, health and food tolerances. Before making big changes to your diet it is

important you seek advice from relevant healthcare professionals, especially if you have other medical conditions. You should see your GP if you have any unintentional weight loss.

Keeping hydrated



It is important to drink plenty of fluids, especially water, to keep hydrated and support general health and brain function. Keeping well hydrated also helps prevent problems such as infections and constipation, which can make people with dementia more confused and unwell.

Alcohol



It is best to avoid alcohol if you have been diagnosed with dementia. Even moderate drinking can negatively affect brain function and brain health, worsen your memory, and your general health and wellbeing. If you need support to reduce your alcohol intake, please speak to your GP so you do this safely.

Food supplements

Most vitamins, herbs and other food extracts are natural substances that can help improve nutrition and wellbeing, however, there is less evidence about the benefits of vitamins compared to prescribed medications. If you have a vitamin deficiency, your GP may arrange blood tests and prescribe certain vitamins for you.



Vitamins A, B12, C and D have mixed evidence that they may help with dementia. Your doctor could prescribe vitamins A, B12 and D if you have a deficiency.

Ginkgo Biloba and Turmeric also have mixed evidence that they may help brain function.



Vitamin E, Selenium, Coconut oil and Ginseng do not have enough evidence to support their use in dementia.

NICE does not recommend offering Ginseng, vitamin E or herbal supplements to treat dementia.

If you choose to try any over-the-counter supplements, speak to your pharmacist or GP first about doses and side effects, or potential interactions if you are taking other supplements or medications.

Additional information available online:

www.alzheimers.org.uk/get-support/daily-living/eating-drinking

www.dementiauk.org/get-support/health-issues-and-advice/eating-and-drinking/



Why is heart health important in dementia?

Controlling blood pressure and cholesterol levels is important and may reduce the risk of heart disease, stroke, and associated complications for people living with dementia.

Our hearts (including our vascular system) are essential to our general health and wellbeing. High blood pressure, high cholesterol, and high blood sugar levels (diabetes) can cause or worsen heart disease. There is evidence of links between heart disease, diabetes and dementia- which are still being researched. Certain populations and ethnicities are also more at risk of heart disease and diabetes, which also puts them at increased risk of dementia.

What works?



The following interventions support heart and diabetic health and can help people to live well with dementia:

- Keeping active, eating a healthy diet - particularly a diet like the Mediterranean diet, reducing your alcohol intake, stopping smoking, and maintaining a healthy weight.
- Regularly checking your blood pressure, cholesterol and blood sugar levels to ensure they stay within healthy levels.
- Taking prescribed medication if your blood pressure, cholesterol or blood sugar levels are too high- which will need monitoring to ensure you are on the right treatment.

National Institute of Health and Care Excellence recommendation:

NICE recommends lifestyle changes such as stopping smoking, keeping a balanced diet, physical activity, reducing alcohol intake, cholesterol management and lowering blood pressure to prevent risk of heart disease.

How do I look after my heart health?

Lifestyle changes can make a big difference.

Arrange regular blood pressure monitoring and cholesterol blood tests. If you are prescribed medication, take it as prescribed and have regular blood pressure and medication reviews.

Speak to your diabetes healthcare team about how to best manage and keep your diabetes under control.

Additional information available online:

www.bhf.org.uk/information-support/heart-matters-magazine/research/blood-pressure/blood-pressure-tips

www.diabetes.org.uk/guide-to-diabetes/managing-your-diabetes



Why is hearing and vision important for people living with dementia?

Monitoring for changes in hearing and sight is very important for people with dementia to support communication and reduce confusion.

Hearing and seeing well supports communication and interactions with other people and the world around us. Changes to hearing and vision can negatively affect our perception and ability to interact and communicate with others, and can increase misunderstanding and confusion for people living with dementia. There is some evidence that hearing loss may be a risk factor for some types of dementia.

Some people with dementia may also experience visual disturbances, noise sensitivity and visual and auditory hallucinations, which can be distressing and cause confusion. This is related to the brain's interpretation of vision or hearing rather than their actual vision or hearing. Additional information about reducing problems due to changes in visual perception is available in the box below.

What works?



These interventions all have evidence they help people living with dementia:

- Regular hearing and vision assessments. It is also important that you:
 - Wear prescribed hearing aids and make a routine for cleaning and battery replacement.
 - Wear prescribed (and clean) glasses.
- You can also do other things to help, including:
 - Minimise background noise and distraction when communicating.
 - When speaking with someone, ensure you can see their face clearly.
 - Reduce the number of people talking at any one time.
 - Don't shout and ask others not to shout as this can distort sound.
 - Use magnifying glasses to read and subtitles to support your hearing.
 - Use adjustable lights in your home to support your vision.
 - Talk to friends, family and carers about any changes they may notice to your hearing and vision.
 - Review surroundings and decorations, including patterns and colours, to reduce problems associated with visual perception.

Visual perception and dementia

Visual perception changes can result in difficulty judging space, distance, and objects. To reduce confusion, disorientation, and the risk of falls, the following may be helpful:

- Reduce glares and shadows that may cause confusion or disorientation with good lighting.
- Use different colours and patterns to improve the visibility of important objects. For example, use contrasting colours for toilet seats, handrails, doors, tables and plates; this will make things easier to distinguish from each other and more recognisable.
- Reduce visual clutter by removing unnecessary decorations, patterns on flooring or walls, and excess furniture, and arrange things in a neat and orderly manner. This will reduce visual confusion.
- Remove any trip hazards that may increase the risk of falling.

National Institute of Health and Care Excellence recommendation:

NICE recommends people with dementia have eye tests and hearing assessments every two years.

How can I manage my hearing and vision?

If you experience visual or hearing changes or disturbances, speak to your GP. Your GP can assess whether this is related to your dementia and also refer you for hearing and vision assessments, or you can go to an optician for an eyesight or hearing assessment. Always wear prescribed glasses and hearing aids. You can also make some changes around the home that may help with any difficulties as a result of changes to visual perception.

Additional information available online:

www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/sight-hearing-loss

www.scie.org.uk/dementia/living-with-dementia/sensory-loss/hearing-loss.asp

www.specsavers.co.uk/hearing/hearing-loss/dementia-and-hearing-loss

www.specsavers.co.uk/home-eye-tests/why-choose-specsavers-vision-care-at-home

You can do an online hearing test here: <https://rnid.org.uk/information-and-support/take-online-hearing-check/> and if you have any hearing changes you can use this to ask your GP for a referral for a hearing test.



Why is mental health important for people living with dementia?

Having hobbies and being socially and physically active can reduce depression and anxiety in dementia and improve quality of life.

Mental health conditions include depression, anxiety and agitation, and can result in feelings of sadness, increased tension, and loss of interest or enjoyment in the things you'd usually enjoy. Changes in mental health can happen at any time, including when adjusting to a dementia diagnosis, and it is important to tell someone and seek help as soon as possible if this happens to you.

Mental health conditions can negatively affect wellbeing and can also affect behaviour. People with dementia may not always be able to express that they are sad, depressed or anxious. Instead, this may be observed by others through changes in behaviour, distress, or lack of interest in things you'd normally enjoy. Unmanaged depression and anxiety can make dementia symptoms and outcomes worse.

What works?



Evidence shows that keeping socially and physically active, maintaining good quality sleep, and participating in enjoyable activities (such as group activities, music and reminiscence therapy, and talking to others) may help people improve and maintain their mood.

Activities work best if they are related to a person's interest and maintain a sense of belonging and self and could include singing, dancing, pottery, gardening, and other hobbies or activities that interest them. Others may benefit from complementary therapies, including massage, acupuncture and aromatherapy.



Evidence is mixed for psychological therapies and medication to treat depression, anxiety and agitation for people with dementia. In some people medications may cause harmful side effects. Speak to your GP or dementia specialist if you want more information about medication.

National Institute of Health and Care Excellence recommendation:

NICE recommends non-medicine interventions to reduce distress in people living with dementia. Medication is only recommended in more severe cases and only in combination with other interventions.

How can I get support for mental health?

If you are worried about changes in your mood or behaviour, please see your GP.

Try to keep involved in activities and groups that you already enjoy. Sometimes, you and others may need help to adapt how you do things to make activities easier to access. Even small changes like changing the 'rules' of an activity to make it more manageable, can make a big difference and can mean you can carry on enjoying the activities for longer.

You can also speak to your dementia support worker and local charities about activities available in your area, including dementia-friendly groups.

Additional information available online:

www.alzheimers.org.uk/about-dementia/treatments/dementia-drugs/non-drug-approaches-changes-mood-and-behaviour

www.nhs.uk/conditions/dementia/living-with-dementia/behaviour



Why is sleep important for people living with dementia?

Good quality sleep is important to maintain health and wellbeing, mood, daytime functioning, and cognition in dementia.

Poor-quality sleep can lead to the build-up of toxins in the brain and impact wellbeing and behaviour. People with dementia are more likely to experience poor-quality sleep.

What works?



The following interventions to help sleep are supported by some evidence they can help people living with dementia:

- Music therapy: listening to personalised playlists that support relaxation and sleep can improve sleep and reduce anxiety.
- Light therapy: using bright light in the daytime (including exposure to sunlight) can improve daytime functioning and sleep.
- Keeping lights low in the evening and minimising activity or disturbances in the evening could promote restful sleep during the night.
- 'Sleep hygiene', which means maintaining a consistent bedtime routine, and may include music and light therapy and reducing stimulus at bedtime.
- Being physically active during the day, including daylight exposure.
- Carer training to support people with dementia with good sleep habits.
- If you have persistent problems medications may be prescribed by specialists for people with specific sleep disorders. Their use should be closely monitored by the professionals who prescribe them and should be used for the shortest possible time.



These sleep interventions currently don't have enough evidence to show if they help people living with dementia.

- Using weighted blankets to promote sleep and reduce anxiety and depression.
- Mindfulness: a technique to improve relaxation and reduce stress and depressive symptoms.
- Lavender oil administered in an aroma stream may reduce agitation and may help improve sleep for people with dementia.

Medication:



Melatonin can be prescribed by your doctor, but there is mixed evidence that it is effective in improving sleep in dementia, especially when no sleep disorder has been diagnosed. If you feel medication to help you sleep may be needed, speak to your doctor first.



Nytol contains an over-the-counter drug called diphenhydramine, which has been shown to increase the risk of dementia, and as a result, the benefit for people with dementia is less clear.

National Institute of Health and Care Excellence recommendation:

NICE does not recommend Melatonin to manage insomnia for people with Alzheimer's Disease. NICE recommends a personalised multi-component sleep management approach that includes sleep hygiene education, exposure to daylight, exercise and personalised activities.

How can I support my sleep?

You can try most of these interventions, with support from family, friends, carers or your dementia support worker if needed. Supportive technology can help, for example, by setting a sleep schedule and by timing music and lighting (see Supportive technology section below).

Some medications to help you sleep will need to be prescribed by your GP. Sleep medications may have lingering side effects the following day, may cause dependency, lose some of their effectiveness with prolonged use, and may cause side effects.

Additional information available online:

www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/sleep



Why is physical activity important for people with dementia?

Physical activity improves and maintains health, wellbeing, and quality of life and what you do is down to your personal preferences and abilities

Physical activity involves movement and some physical effort, such as housework, gardening, walking, moving to music, chair yoga, or an exercise class.

Physical activity promotes heart health, supports your immune system, and can reduce the risk of falling and injury. It can improve mood, and reduce cognitive and behavioural changes. It can be combined with other benefits by doing activities with other people and going outside to get exposure to nature and sunlight

What works?



Physical activity has been shown to be an important part of living with dementia, and there is good evidence that it:

- It improves mood, whilst reducing depression and anxiety symptoms.
- It reduces the risk of heart and vascular disease, cancer, and diabetes.
- It reduces the risk of falls and fractures.
- It keeps your bones strong and reduces the risk of osteoporosis.
- It supports your brain health because it requires cognitive effort to be physically active.

National Institute of Health and Care Excellence recommendation:

NICE recommends people living with dementia are supported to undertake health-enhancing activities, including exercise, according to a person's preferences.

How can I be physically active?

You can do things to maintain your activity at home like keep doing housework and gardening. Overly strenuous activities may not be advised for specific medical conditions, so it's important to check with your GP before you commence more extensive training programmes.

Additional information available online:

www.nhs.uk/live-well/exercise/exercise-guidelines/physical-activity-guidelines-older-adults/



Why is social activity important for people with dementia?

Social activity is about being with other people to do things you enjoy, and it is important for maintaining wellbeing in dementia

Social activity is about keeping engaged and involved with your family, friends and communities, doing things that you enjoy. This could include gardening, cooking, walking, volunteering, being active in your place of worship, creative activities, going to events, visiting family and friends and anything else that involves interacting with other people.

What you do is entirely about your personal preference, and it needs to be interesting, enjoyable or meaningful to you. Different cultures will have different customs and activities that can provide a supportive environment for people with dementia. You can also be socially active online from the comfort of your own home using supportive technology, but it is important you also have in-person interaction in a meaningful way.

What works?



Keeping socially active has good evidence it can:

- Help people living with dementia enjoy life better, feel more connected to their community and have a sense of purpose.
- Help to stimulate the mind, leading to improved cognitive functioning.
- Help to reduce feelings of boredom, loneliness and depression.
- Help to increase physical activity, which can help improve physical health.
- Help to improve communication skills, which can help with maintaining relationships.
- Help to stimulate memory and cognition.

National Institute of Health and Care Excellence recommendation:

NICE recommends person-centred care for people living with dementia, and this includes recognising the importance of relationships and interactions with others and their potential for promoting wellbeing.

How can I be socially active?

You can keep engaging with friends, family, communities and activities you are already involved in, and find out about new opportunities from your dementia support worker and local dementia charities. Some people may find social engagement in larger groups

overwhelming, so it is really important you get involved in groups and activities that you find enjoyable.

Supportive technology may help you keep in contact with friends and family living further away.

Additional information available online:

www.alzheimers.org.uk/get-support/your-dementia-support-services/activity-groups

www.nhs.uk/conditions/dementia/activities/



What is cognitive activity, and why is it important for people living with dementia?

Cognitive stimulation activities improve cognition, memory, concentration, and mood, and can slow the rate of cognitive changes by keeping the brain active. Doing a mixture of different and new types of activities engages different parts of the brain.

Cognitive stimulation comes from any activity that stimulates thought, focus and memory by stimulating different parts of the brain. Activities include word and number puzzles (e.g. crosswords), jigsaws, board games and computer games. It also includes talking with others about new topics, such as current affairs and engaging in new and different social and physical activities.

Cognitive Stimulation Therapy (CST) is a structured course of therapy over a number of weeks. It involves participating in activities that aim to promote cognition and foster social interactions and a sense of belonging.

What works?



Evidence shows that participating in activities that provide cognitive stimulation and engage different parts of the brain improves cognition, helps social interaction and communication, improves quality of life and reduces symptoms of depression in people living with dementia.



Evidence also suggests that Cognitive Stimulation Therapy (CST) may potentially slow the rate of cognitive change in people with mild to moderate dementia.

National Institute of Health and Care Excellence recommendation:

NICE recommends group cognitive stimulation therapy for people living with mild to moderate dementia.

How can I access cognitive stimulation?

Cognitive Stimulation Therapy may be accessed by discussing with your dementia support worker or doctor. Other cognitive stimulation activities such as word and number puzzles, jigsaw puzzles, board games, computer games, and reading books and newspapers can be undertaken at home. You can also join organised social activities and classes (see the Physical Activity, Social Activity and Mood sections of this booklet).

Additional information available online: www.dementiauk.org/cognitive-stimulation/
www.alzheimers.org.uk/categories/treatments-and-therapies/cognitive-stimulation-therapy-cst



Why are helpful habits important for people living with dementia?

Helpful habits are strategies and routines that can help people with dementia manage day-to-day activities. It is helpful to get into the habit of doing activities and routines that can support you and your memory now and in the future.

What works?



There is evidence that adopting helpful habits and using memory aids can help people living with dementia live well and independently for longer. These include:

- Ensuring you see your GP for your annual health check, as well as for other health checks like medication reviews, blood pressure checks, hearing and vision tests, annual vaccinations, and testing for any other issues that may contribute to cognitive problems (for example, vitamin deficiencies).
- Making notes and lists about tasks and daily activities such as:
 - Shopping lists
 - What you are having for lunch and how to prepare it
- Using a calendar to write down meetings and appointments, and repeating this every time you make a new appointment.
 - You can do this on a paper calendar or use the calendars on a smartphone or computer (if you are comfortable using one).
- Setting alarms to remind you when you need to do something like make lunch or go for an appointment.
- Choosing a place to keep important things you use regularly and get into the habit of using that place. As an example, keep your keys safe and easy to access near your front door.
- Putting up signs in different parts of the house to remind you to do things, such as turning off the cooker or locking the door.
- Labelling food so you are reminded about how long it has been in the fridge and when it needs to be eaten.
- Get a medication organiser or ask your pharmacy to put your medication in weekly boxes to help you remember when to take it safely.
- Keep contact details of family, friends and your healthcare team in a safe and accessible place.
- Set up direct debits for your essential bills.

- Start to use and get used to technology that has been designed to support people living with dementia to live at home independently (we will cover this in more detail in the next section: supportive technology).

How can I adopt helpful habits?

You can ask your healthcare provider to refer you to an occupational therapist who specialises in dementia, and they can advise more on activities that will help you. You can also try some of these strategies on your own or with help from family and friends.

Additional information available online:

www.alzheimers.org.uk/get-support/staying-independent/memory-aids-and-tools

Supportive technology

What is supportive technology, and why is it important for people living with dementia?

Supportive technology is designed to help people live safely and independently at home for longer.

There are lots of different types of technology that can help enable people to live well, independently, and safely with dementia. Some of these are specifically designed for people with dementia, while some are already commonly found in people's homes.

Technology does not replace the importance of human interaction, but it can be used to support people with dementia and their carers.

Examples of supportive technology include:

- Communication and video devices that help family, friends and carers keep in contact
- Monitoring devices/sensors – like movement sensors around the home that can pick up on problems such as falls
- Location devices – that can locate you if you get lost
- Memory aids like calendars with reminders
- Medication dispensers and reminders
- Household aids like automatic light switches
- Games and tools that can support your social, physical and cognitive engagement

What works?



The right technology, used in the right way, has the potential to help people with dementia live independently for longer, and support carers too. Overall, there is good evidence supportive technology can be helpful for people living with dementia.

However, each type of supportive technology is designed differently and will have different levels of evidence to show whether it works or not. Technology is not always designed for people living with dementia, and you may need additional support from family and carers to use it.

How can I access supportive technology?

Care providers may provide some of this technology, such as home sensors, location devices and communication devices when you need it. You can also access this technology privately at an earlier stage, including with the support of family and friends.

There are many technologies to choose from, and not all will suit everyone- this is down to your preferences and needs. Some people may also be worried about management, security, losing independence and privacy. It is good to make your concerns and preferences known to family, friends and caregivers. As your condition changes, the opportunity for technology to support you may also change.

Additional information available online:

www.scie.org.uk/dementia/support/technology/stay-independent

www.alzheimers.org.uk/get-support/staying-independent/what-assistive-technology

www.scie.org.uk/dementia/support/housing/design



Why is planning for the future important for people living with dementia?

Planning for the future helps you maintain control and choice about what happens in the future. It also helps your loved ones and healthcare team ensure your wishes are known and respected.

Planning for the future is about making your preferences, choices, and wishes known before this becomes more difficult to do in the future. This involves talking to your loved ones and your healthcare team about what is important to you, such as what treatment you'd want, and where you want to live in the future.

You can also choose who you want to make decisions on your behalf, as an example to help manage your finances or to make decisions about your healthcare when you are less able to do this yourself. When thinking about this, some people also find it useful to think about where they live, including making plans to adapt their home before their health may start to change.

Three main documents help you record your wishes:

- A lasting power of attorney for health and welfare
- A lasting power of attorney for property and finances
- An advanced care plan

What works?



Lasting powers of attorney are legally recognised once they are registered. The link below tells you how to set up a power of attorney and register it online. You can also do this via a solicitor, which might be recommended if your dementia is more advanced.

An advanced care plan needs to be held by your healthcare providers. Your dementia support worker and other healthcare workers can help you do this. It is important to give your GP and loved ones a copy of your advanced care plan.

Lasting powers of attorney and advanced care plans are a well-evidenced way to ensure your wishes are considered when you may not be able to make them known or make decisions for yourself.

National Institute of Health and Care Excellence recommendation:

NICE recommends that everyone with conditions like dementia are supported to make advanced care plans and appoint powers of attorney.

How can I plan for the future?

The following government website allows you to make and register a power of attorney yourself: www.gov.uk/power-of-attorney. There are details of how to find a solicitor to support you, if that's needed, below. As your dementia progresses, you may need a solicitor to support this process.

Dementia charities and your healthcare workers can provide advice on advanced care planning and templates that you complete yourself.

Additional information available online:

www.gov.uk/power-of-attorney

www.lawsociety.org.uk/public/for-public-visitors/common-legal-issues/power-of-attorney

www.dementiauk.org/wp-content/uploads/2020/02/ACP-Booklet-A4-2018-online.pdf

Other useful information

Dementia Treatment and Research

There have been recent advances in dementia treatment; however, new treatments are likely to be limited to people at the very earliest stages of dementia, and the advice in this booklet still applies. It is best to speak to your dementia doctor or GP about medication for dementia that may help you.

Additional information about medication can be found online here:

www.nhs.uk/conditions/dementia/treatment/

www.alzheimers.org.uk/about-dementia/treatments/dementia-drugs/drug-treatments-and-medication-alzheimers-disease

There is also research underway to test new treatments and interventions to support people with dementia. Ask your healthcare team if you would like more information or would like to be involved in dementia research.

You can also register to be involved in dementia research here:

www.joindementiaresearch.nihr.ac.uk/

Financial support (benefits)

Most people diagnosed with dementia will be entitled to benefits, as will any carers who are undertaking caring activities over multiple hours a week.

If you are of state pension age and have a dementia diagnosis, depending on your current care needs, you may be entitled to an attendance allowance:

<https://www.gov.uk/attendance-allowance>

If you are below state pension age and have dementia, depending on your current care needs, you may be entitled to personal independence payments (PIP):

<https://www.gov.uk/pip>

If you are a carer of someone living with dementia and they are receiving PIP or attendance allowance, you may be entitled to carer's allowance: www.gov.uk/carers-allowance

If you receive an attendance allowance, PIP, or carer's allowance and meet other criteria, you may also be eligible for council tax discounts: www.alzheimers.org.uk/get-support/legal-financial/discounts-disregards-exemptions-council-tax#content-start

It is important to reapply for benefits if your situation changes to ensure you are receiving the right level of financial support for your changing circumstances.

If you need help applying for these benefits, you can ask someone from the Department for Work and Pensions to support you. See www.gov.uk/support-visit-benefit-claim

Age UK also provides a benefits support service via their advice line: 0800 678 1602.

If you are unwell

It is important you are seen as soon as possible by your GP or other health care worker if you start to feel unwell, if any of your symptoms become difficult to manage, or if you are struggling at home.

In people with dementia, acute confusion can be the first sign there is an underlying health problem like an infection. This type of confusion is called delirium, and its effects can continue long after the initial cause of the confusion is treated, so it is important to see your GP if you suddenly start getting very confused.

Try to prevent infections by:

- Washing your hands regularly
- If you know someone has an infection such as flu, it is advisable to avoid unnecessary contact with them while they are unwell.
- Get an annual flu vaccination from your GP.
- Drinking plenty of fluids and keeping well-hydrated
- Ensure you eat foods that are prepared well and are in-date

People with dementia are often admitted to the hospital as an emergency due to falls, medication, and infections, therefore, prevention is advisable:

- It is important to keep active at the same time as reducing your risk of falling (see physical activity, hearing and vision, and supportive technology sections).
- Your pharmacist should regularly review your medication. You can ask for medication dispensers such as weekly boxes to help ensure these are taken safely (see helpful habits and supportive technology sections).
- Reduce your risk of infections (as above).

If you need to have surgery or go to the hospital for a planned admission, speak to your medical team about how best to reduce the risk of complications due to your dementia. Medical procedures like general anaesthetics can make people with dementia more confused and unwell.

Travel

Visiting friends and family and keeping active and engaged in things you enjoy is important. However, when travelling, in particular overseas, unfamiliar environments and routines can be stressful; they may cause confusion which can worsen your symptoms. If you travel, plan this carefully to reduce the risk of associated health issues and make this as easy as possible. Ensure you take out travel insurance if you are travelling abroad.

Driving

Changes to memory and attention can affect your driving ability. After a diagnosis of dementia, you will need to report your condition to the DVLA and your car insurance provider. If you are able to continue driving, your doctor may advise you have on-road driving assessments every six months to assess if you are safe to continue driving.

Additional day to day support

You may find you, or your loved ones, need more support day to day in the future.

If you start to need help with social care (as an example for washing, dressing, cooking, shopping, help to access activities, or to take medications) you can request a social service needs assessment.

To get a needs assessment you will need to speak to your local council. This website: <https://www.gov.uk/apply-needs-assessment-social-services> will connect you to your local councils website.

Social workers will review your care needs and help make a plan based on your individual needs. Depending on your financial situation, this can either be provided and paid for by social services, or you may have to contribute to, or cover the costs yourself.

If you need to cover costs yourself, you may also need to find the support you need yourself and these websites may be helpful:

For care in your home: <https://www.nhs.uk/service-search/other-services/Care-at-home/LocationSearch/1833/>

For residential care: <https://www.alzheimers.org.uk/get-support/help-dementia-care/care-homes-who-decides-when>

All care providers are monitored by the Care Quality Commission, so it is worth looking at what rating each care provider has before making a decision.

It is also important that you get reassessed by social services if and when your needs or finances change, to ensure you continue to get the right support.

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