Alzheimer's Society

Leading the fight against dementia

The dementia guide

Living well after diagnosis

NHS

About this guide

This guide is for anyone who has recently been told they have dementia. This could be any type of dementia, such as Alzheimer's disease, vascular dementia or mixed dementia.

It will also be useful to close friends and family of someone with dementia, as it contains information for anyone taking on a caring role.

The booklet will help people to understand more about dementia and the treatments, support and services that are available. It includes information about living as well as possible with dementia and about making plans for the future.

You might choose to read the whole booklet, or, if you prefer, focus on the parts that seem most relevant to you. Each section starts with summarised key points. These have been included for people who may prefer to read an overview of the section rather than the whole thing.

You will find a checklist on page 118. It lists some of the things discussed throughout this guide that you can do to help you live well now and plan for the future.

This guide has been produced by Alzheimer's Society with support and funding from the Department of Health.

A diagnosis of dementia can cause a range of emotions. The news might come as a shock, or, for some people, it may bring a sense of relief as it provides an explanation for the problems they have been experiencing. It can also have a big impact on family and friends.

If you, or someone close to you, have recently been diagnosed with dementia, you might be feeling angry, frustrated, worried, fearful, sad, embarrassed, lonely, guilty or even relieved. Everyone is different, but all these reactions are possible at different times and they are all normal. How you feel will probably vary from one day to the next.

'We went out and celebrated when I was diagnosed, because I finally knew what was wrong with me. I could tell people "I have Pick's disease".'

Graham, East Sussex, living with Pick's disease (frontotemporal dementia)

'Even though we expected it, our first reaction was to be frightened and upset. I think [my husband] thought it diminished him as a person and felt ashamed. But time has changed that, because it hasn't diminished him in any way.'

Brenda, West Sussex, carer for a person with Alzheimer's disease

If you can, talk to friends and family about how you're feeling. Other people need to understand what you're going through. They might be finding things hard too, so talking can help both you and them. There are also specialist health and social care professionals you can talk to for support.

You will find a list of Alzheimer's Society services on page 106 and other useful organisations that may be able to provide information or support on page 110.

If you'd like to talk about the information in this guide, please phone Alzheimer's Society's National Dementia Helpline on **0300 222 1122** – calls are charged at a low-cost rate. The Helpline is for anyone affected by dementia and is open 9am–5pm Monday–Friday and 10am–4pm on Saturdays and Sundays. Trained helpline advisers can provide you with information, support, guidance and signposting to other appropriate organisations.

Throughout this booklet you will see suggestions for Alzheimer's Society factsheets. You can order these using the form on page 121 or see **alzheimers.org.uk/factsheets**
For factsheets specific to Northern Ireland, please contact your local Alzheimer's Society office.

It's important to know that you aren't alone – about 800,000 people in the UK have dementia. It's possible to live well with dementia and there is support available for you and your family.

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1 About dementia

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1 About dementia

Key points: About dementia

Dementia occurs when the brain is affected by a disease. It's not a normal part of ageing.

Dementia affects everyone differently and can cause a wide range of symptoms. These can include problems with memory, thinking, concentration and language. People may become confused or struggle with how they perceive things. Dementia can also cause changes in mood or emotions and affect how someone behaves.

Dementia is progressive, which means that symptoms get worse over time. However, many people with dementia lead active and fulfilling lives for many years.

There are many different types of dementia. The most common are Alzheimer's disease and vascular dementia, which are sometimes combined (called mixed dementia). Less common are dementia with Lewy bodies and frontotemporal dementia.

There are also some rarer conditions that cause dementia. Together, they account for only about five per cent of all people with dementia.

Various factors increase the risk of someone developing dementia. Ageing, genes, health and lifestyle all play a part.

Most people with dementia are over 65 years of age, but dementia does also affect younger people.

Some people are diagnosed with a condition called mild cognitive impairment (MCI). This causes symptoms that are similar to dementia, but aren't as serious. People with MCI have a higher risk of developing dementia, but not all of them will.

What is dementia?

The word dementia describes a group of symptoms that may include memory loss, difficulties with planning, problem-solving or language, and sometimes changes in mood or behaviour.

Dementia isn't a natural part of ageing. It occurs when the brain is affected by a disease.

There are many known causes of dementia – probably more than 100. The most common types are Alzheimer's disease and vascular dementia. Some people have a combination of these, known as mixed dementia. To find out more, see Types of dementia on page 14.

About dementia

- There are around 800,000 people in the UK who have dementia.
- The chance of developing dementia increases significantly with age. One in 14 people over 65 years of age, and one in six people over 80, has dementia. It is more common among women than men.
- Over 17,000 younger people (under the age of 65) in the UK have dementia. This is called early-onset or young-onset dementia.

What are the symptoms?

Everyone experiences dementia in their own way. Different types of dementia can also affect people differently. However, there are some common symptoms that are listed below.

Memory loss:
- problems recalling things that happened recently (although some people easily remember things from a long time ago)
- repeating themselves (such as asking the same question over and over).

Difficulty thinking things through and planning:
- problems concentrating, following a series of steps, grasping new ideas or solving problems
- struggling with familiar daily tasks, such as following a recipe or using a debit or credit card.

Problems communicating:
- difficulty finding the right word
- struggling to follow a conversation or misinterpreting things.

Being confused about time or place:
- losing track of what time, date or season it is
- not knowing where they are, even in a place they know well.

Sight and visual difficulties:
- difficulty judging distances (eg on stairs)
- misinterpreting patterns or reflections in mirrors.

Mood changes or difficulties controlling emotions:
- becoming unusually sad, frightened, angry or easily upset
- losing interest in things and becoming withdrawn
- lacking self-confidence.

Changes over time

Dementia is generally progressive, which means that symptoms gradually get worse over time. How quickly it progresses varies greatly from person to person. Many people with dementia maintain their independence for many years.

In the middle and later stages of dementia, people will need more and more support with daily activities like cooking or personal care such as washing and dressing. Dementia does shorten life expectancy, although some people live with it for many years.

At all stages there will be ways to make life better. To find out more, see sections Living well on page 39, Services for people with dementia on page 71 and Support for carers on page 85.

What are the causes?

Dementia is caused by physical changes in the brain. As dementia progresses, the structure and chemistry of the brain changes, leading to damage and gradual death of brain cells.

Damage to different parts of the brain will have different effects. For example, in one area it might affect short-term memory, while in another it might affect a person's ability to organise things. To find out more about changes to the brain, see Types of dementia on page 14.

Why do some people get dementia?

Scientists are still researching why some people get dementia while others don't. Most now believe it depends on a combination of age, genes, health and lifestyle.

For more information see factsheet 450,
Am I at risk of developing dementia?

Types of dementia

There are many known types of dementia. Around 95 per cent of people with a diagnosis will have one of the four main types – Alzheimer's disease, vascular dementia (or a mixture of these two, called mixed dementia), dementia with Lewy bodies or frontotemporal dementia – all described on the following pages.

Alzheimer's disease is the most common type, followed by vascular dementia. To find out about rarer causes of dementia, and a related condition known as mild cognitive impairment, see page 21.

For more information see factsheet 400,
What is dementia?

Alzheimer's disease

Inside the brain
Abnormal material called 'plaques' and 'tangles' builds up in the brain. This disrupts how nerve cells work and communicate with each other, and the affected nerve cells eventually die.

There is also a shortage of some important chemicals in the brain when someone has Alzheimer's disease. Reduced levels of these chemicals mean messages don't travel around the brain as well as they should.

Early symptoms
Alzheimer's disease usually begins gradually with mild memory loss. This is because the first changes in the brain are often in the part that controls memory and learning. A person with Alzheimer's disease might forget people's names or where they have put things. They might also have problems with language, such as finding the right word for something.

Other early symptoms include feeling confused or finding it hard to follow what is being said. Some everyday activities might seem challenging, for example, someone might get muddled checking change at the shops. Some people also become more withdrawn and experience mood swings.

For more information see factsheet 401,
What is Alzheimer's disease?

Vascular dementia

Inside the brain
The word 'vascular' relates to blood vessels. Vascular dementia results from problems with the blood supply to the brain – without enough blood, brain cells can die.

There are several types of vascular dementia. One type is caused by stroke (called stroke-related dementia). Another is caused by poor blood supply to deep parts of the brain (called subcortical vascular dementia).

Strokes happen when a blood clot blocks the flow of blood to part of the brain, or when a blood vessel bursts in the brain. Vascular dementia sometimes follows a large stroke. More often though, it comes after a number of small strokes (called multi-infarct dementia).

Subcortical vascular dementia – when there is poor blood flow to the deep parts of the brain – is often due to narrowing of the arteries supplying the brain.

Early symptoms
If someone has had a large stroke, symptoms of vascular dementia can begin suddenly. Symptoms can then remain stable or even get a little bit better over time in the early stages. If the person has another stroke, these symptoms might get worse again.

If someone has a series of small strokes, their symptoms may remain stable for a while and then get worse in stages (rather than have a gradual decline). With subcortical vascular dementia, symptoms may get worse gradually or in stages.

The symptoms of vascular dementia will depend on which part of the brain has been damaged. Some people might have physical weakness on one side due to a stroke. Other changes include difficulty thinking quickly or concentrating and there might be short periods when they get very confused. Some people might also become depressed or anxious. Memory loss isn't always a common early symptom.

For more information see factsheet 402, What is vascular dementia?

Mixed dementia

It's possible for someone to have more than one form of dementia – called mixed dementia. The most common combination is Alzheimer's disease with vascular dementia. It's also possible to have a combination of Alzheimer's disease and dementia with Lewy bodies.

Dementia with Lewy bodies

Inside the brain
This form of dementia gets its name from tiny abnormal structures called Lewy bodies that develop inside brain cells. Similar to the plaques and tangles of Alzheimer's disease, these structures disrupt the way the brain functions, reducing levels of chemical messengers and causing cells to die.

Lewy bodies are also found in people with Parkinson's disease. One third of people who have Parkinson's disease eventually develop dementia (called Parkinson's disease dementia).

Early symptoms
People who have dementia with Lewy bodies might find it hard to remain alert and have difficulties planning ahead, reasoning and solving problems. These symptoms typically vary a lot from one day to the next.

People might have problems with how they see things. For example, it might be hard to judge distances or they might mistake one object for another. Many people see things that aren't really there (visual hallucinations). Disturbed sleep patterns are also common.

However, if someone has dementia with Lewy bodies, their memory will often be affected less than someone with Alzheimer's disease.

Many people with dementia with Lewy bodies also develop symptoms like those in Parkinson's disease, including shaking (especially in the hands), stiffness and difficulty moving around.

For more information see factsheet 403,
What is dementia with Lewy bodies (DLB)?

Frontotemporal dementia

Inside the brain

The term frontotemporal dementia covers a range of conditions. It was originally called Pick's disease and this term is sometimes still used. Frontotemporal dementia mostly affects people in their 40s, 50s and 60s (younger than most people who get Alzheimer's disease or vascular dementia). It's caused by damage to areas of the brain called the frontal and temporal lobes. These areas control behaviour, emotional responses and language skills.

In most cases, abnormal proteins collect within brain cells in these lobes and cause the cells to die. Important chemicals that carry messages around the brain are also affected.

Early symptoms

There are three different forms of frontotemporal dementia – behavioural variant, semantic dementia and progressive non-fluent aphasia.

With behavioural variant frontotemporal dementia, changes in personality or behaviour are often noticed first. The person might seem withdrawn or not to care as much about other people. They might make socially inappropriate remarks. They may also become obsessive or impulsive, for example developing fads for unusual foods.

When someone has semantic dementia their speech is usually fluent but they lose the meaning or understanding of some words. Language is also affected in progressive non-fluent aphasia. Speech is often slow and requires a lot of effort.

People in the early stages of frontotemporal dementia often don't experience day-to-day memory loss.

For more information see factsheet 404,
What is frontotemporal dementia?

Dementia in younger people (early-onset dementia)

More than 17,000 people in the UK now living with dementia were diagnosed before they reached the age of 65. The terms 'early-onset dementia', 'young-onset dementia' and 'working age dementia' are used to describe their diagnosis.

People under 65 can develop any type of dementia. However, they are more likely than older people to have a less common type, such as frontotemporal dementia or another dementia with a genetic cause. Only a third of younger people with dementia have Alzheimer's disease.

While many of the symptoms are similar, younger people with dementia may have different support needs from older people, as they may have younger families and still be working. Younger people may also have different interests and expectations of how they can continue to live well with dementia.

For more information see factsheet 440,
Younger people with dementia

Rarer causes of dementia

A wide range of other conditions can lead to dementia. These are rare, and together account for only about five per cent of all people with dementia. However, they are more common in younger people with dementia.

These diseases include:

- corticobasal degeneration
- Creutzfeldt-Jakob disease
- HIV-related cognitive impairment
- Huntington's disease
- alcohol-related brain damage and Korsakoff's syndrome
- multiple sclerosis
- Niemann-Pick disease type C
- normal pressure hydrocephalus
- progressive supranuclear palsy.

For more information see factsheet 442,
Rarer causes of dementia

Mild cognitive impairment

Some people are diagnosed with mild cognitive impairment (MCI) if they have problems with their memory, thinking, language or the way they see and interpret things (visuospatial skills), but these aren't severe enough to be dementia. People with MCI have an increased risk of developing dementia, but some don't develop dementia and a few will even get better.

For more information see factsheet 470,
Mild cognitive impairment

2 Treatments

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2 Treatments

Key points: Treatments

There is no known cure for dementia, but there are drugs and other therapies that can help with some of the symptoms. With a combination of these, lots of people can live well with dementia for many years.

Four drugs have been developed to treat Alzheimer's disease. Donepezil (eg Aricept), rivastigmine (eg Exelon) and galantamine (eg Reminyl) are for people in the early and middle stages of the disease; memantine (Ebixa) is for those in the later stages. The names in brackets are common brands of these drugs.

These drugs lessen symptoms of Alzheimer's disease for a while in some people. They are sometimes given to people with mixed dementia or dementia with Lewy bodies.

These drugs aren't suitable for people with frontotemporal dementia, who may be given antidepressant drugs for some of their symptoms.

A person with vascular dementia will usually be prescribed drugs to treat any underlying conditions, such as high blood pressure or heart problems.

People with dementia can also benefit from approaches that don't involve drugs. One example is reminiscence therapy, which involves talking about things from the past, using prompts such as photos or music. Another example is cognitive stimulation, which might involve doing word puzzles or discussing current affairs.

People with dementia may experience depression or anxiety. They are often prescribed antidepressant drugs and may be offered talking therapies, such as counselling or cognitive behavioural therapy.

Drugs to treat dementia

Currently, there is no known cure for dementia. Scientists from around the world are involved in research to try to find one. However, there are drugs that can help to improve some of the symptoms or stop them progressing for a while, depending on the type of dementia. Non-drug treatments and support after diagnosis (such as information and advice) are also valuable.

Other physical illnesses need to be treated too – see Staying healthy on page 48.

Alzheimer's disease

Four drugs have been developed to tackle some of the physical changes in the brain that cause Alzheimer's disease.

Donepezil, rivastigmine and galantamine

People who have mild to moderate Alzheimer's disease may be prescribed donepezil (for example Aricept), rivastigmine (for example Exelon) or galantamine (for example Reminyl). The names in brackets are common brands of these drugs. People who have mixed dementia in which Alzheimer's disease is the main cause may also be prescribed these.

These drugs are initially prescribed by a specialist, such as a geriatrician (for older people) or neurologist (for diseases of the brain and nervous system) in a hospital or a psychiatrist at a memory clinic. The GP will generally then take over routine prescribing with a review by the specialist every six months.

The three drugs all work in a similar way and offer similar benefits. They work by increasing the amount of a chemical called acetylcholine which helps messages to travel around the brain. People with Alzheimer's disease have a shortage of this chemical.

Possible benefits

Some people find these drugs lessen their symptoms for a while. Possible benefits include improvements in motivation, anxiety levels, confidence, daily living, memory and thinking.

Possible side effects

Side effects are usually minor – often loss of appetite, nausea, vomiting and diarrhoea. If one of the drugs causes problematic side effects, it's possible to switch and try another.

Memantine

People who have moderate Alzheimer's disease but can't take any of the three drugs listed on page 26, for example because of the side effects, might be offered memantine (Ebixa). It is also becoming more common to be offered memantine in the later stages of Alzheimer's disease when symptoms become severe.

Memantine works by protecting brain cells from the harmful effects of a natural substance called glutamate. People with Alzheimer's disease often have harmfully high levels of glutamate in their brains.

Possible benefits

Memantine can temporarily slow down the progression of symptoms in people in the middle and later stages of Alzheimer's disease. It may also help with agitation or aggressive behaviour, both more common in later stages of dementia.

Possible side effects

Memantine usually has fewer side effects than the other three drugs, although it can still cause dizziness, headaches, tiredness, increased blood pressure and constipation.

For more information see factsheet 407, Drug treatments for Alzheimer's disease

Vascular dementia

The four drugs described in the previous section aren't recommended for vascular dementia unless this is part of mixed dementia with Alzheimer's disease.

It may be possible to slow down the progression of vascular dementia by taking drugs that treat the underlying conditions. The GP will often prescribe drugs for people with vascular dementia who are at risk of having a stroke or heart attack by treating high blood pressure, high cholesterol, diabetes or heart problems. (In many cases the person will already be taking some drugs to control these conditions.)

Other dementias

Dementia with Lewy bodies

Someone with dementia with Lewy bodies might be offered one of the three anti-Alzheimer's drugs (donepezil, rivastigmine or galantamine). In particular, they may benefit from one of these if they have distressing symptoms, such as seeing things that aren't there (hallucinations) or believing things that aren't true (delusions).

Frontotemporal dementia

The anti-Alzheimer's drugs haven't been shown to offer any benefits to people with frontotemporal dementia and may even be harmful. They are not approved for treating frontotemporal dementia and generally shouldn't be prescribed.

It's common for people with behavioural variant frontotemporal dementia to be prescribed antidepressant medication. This can reduce inappropriate and obsessive or compulsive behaviours.

Questions to ask the doctor about medications

- Are there any medications that can help me?
- Why are you offering me this medication?
- How do I take this medication?
  - What happens if I miss a dose?
  - Can I still take my other medication?
  - Can I drink alcohol?
- What are the pros and cons of this medication?
  - How will it help me?
  - How will it affect my symptoms?
  - How will it improve day-to-day life?
  - Might I suffer any side effects?
  - What changes should I tell you about?
- Are there other treatments I could try instead?
- Have you got any information I could take away?

Non-drug treatments

Drugs aren't the only way to treat or manage the symptoms of dementia. There are many other things that can help people to live well. These include a range of therapies such as talking therapies, reminiscence therapy, cognitive stimulation therapy and complementary therapies.

Talking therapies

Talking therapies, such as counselling (see below) or psychotherapy (see page 32), give people the chance to speak in confidence to a qualified professional about problems or issues that might be bothering them. They might help someone to come to terms with a diagnosis and identify ways to live well with dementia. Talking therapies may also help with symptoms of depression or anxiety (see page 36).

Talking therapies typically involve regular sessions with a therapist, either one-to-one or sometimes in a group. They can be face-to-face, over the phone or online. Some people will have just one session while others will have therapy that continues for many months.

Counselling

Counsellors listen to problems in a non-judgemental and supportive way. They support people to talk about their difficulties and identify solutions.

Psychotherapy

Psychotherapists help people to understand how their personalities and life experiences influence relationships, thoughts, feelings and behaviour. Understanding this can make it easier for people to deal with difficulties.

There are several different types of psychotherapy. One of the most common types is cognitive behavioural therapy (CBT) (see below). Family therapy can also be helpful to resolve problems arising due to changes in relationships.

Psychotherapy may help to treat depression, anxiety and problematic behaviour in people with dementia.

CBT aims to help people make changes to how they think (cognition) and what they do (behaviour). These changes can improve the way people feel. CBT suggests ways of making things easier by focusing on the here and now. It's widely used to treat depression and anxiety, and there is growing evidence that it can also help people with dementia and depression. CBT usually involves between five and 20 sessions. A carer might attend the sessions too so they can then help the person with dementia to use the techniques at home.

Finding a therapist for talking therapies

For therapy to be successful, people need to build a good relationship with a therapist they trust. A person with dementia will benefit from seeing a therapist who has experience and understanding of the condition.

The GP, memory service or local social services department should have details of local therapists. Ask about a referral. Some talking therapies are available free through the NHS while private therapists will charge.

When choosing a private therapist it's important to ask about what they can offer that will help, their approach, confidentiality and fees, and whether they are accredited by a professional organisation.

For more information see factsheet 445, Talking therapies (including counselling, psychotherapy and CBT)

'Before his diagnosis I thought it was me, that I was imagining things. It helped me to talk to a counsellor at the time. [My husband] went to see him a few times too. We both found it useful.'

Wendy, Powys, carer for a person with dementia

Other non-drug treatments

There are other non-drug treatments that may be helpful as dementia progresses. Some of the more common approaches are reminiscence therapy or life story work and cognitive stimulation. However, what is available and how to be referred can vary around the country. Ask your GP, memory service or local Alzheimer's Society for details.

Reminiscence therapy and life story work
Reminiscence therapy involves talking about things from the past, using prompts such as photos, familiar objects or music.

Life story work is usually shared between the person with dementia and a family member, friend, or support worker. A scrapbook or photo album is used to record details of the person's life experiences, values and beliefs.

Sometimes these approaches are combined using a memory box of favourite possessions or memorabilia. Techniques like this are popular because they draw on early memories, which people with dementia tend to retain best.

There is evidence that reminiscence therapy and life story work, particularly when done one-on-one, can improve mood, wellbeing and some mental abilities such as memory. By talking about who they are, people with dementia can help others focus on them, and not their dementia.

Cognitive stimulation therapy
Cognitive stimulation therapy (CST) is done in small groups and initially involves a programme of themed activity sessions over several weeks. It might involve doing word puzzles or discussing current affairs in one session and playing an instrument along to music in another. CST also includes elements of reminiscence therapy. There is evidence that cognitive stimulation approaches such as CST improve mental abilities and quality of life.

Complementary therapies
Complementary therapies are a broad range of treatments, which are outside of conventional medicine. They are used to treat or prevent illness and promote health and wellbeing.

Some complementary therapies that may help people with dementia are:
- aromatherapy – particularly with lemon balm and lavender
- massage
- bright light therapy (sitting in front of a light box)
- music therapy.

Complementary therapy should be used alongside (not instead of) conventional medicines. Anyone thinking about trying these therapies should tell their GP. The GP might be able to make a referral through the NHS or suggest practitioners in the local area.

For more information see factsheet 434,
Complementary and alternative therapies and dementia

Treating depression and anxiety

People with dementia – particularly vascular dementia or Parkinson's disease dementia – may experience depression or anxiety.

Depression and anxiety – mood disorders – are more common in the early stages of dementia. In later stages someone is more likely to develop behaviour that seems out of character.

Drug treatments
Drugs are just one approach to treating depression and anxiety. Antidepressant drugs work by correcting the level of some chemicals in the brain. However, research shows that common antidepressants don't work as well for depression in people with dementia as for those without dementia.

It can take several weeks for someone to notice the benefits of taking an antidepressant. Many people experience some side effects to begin with, but these usually lessen after a week or two. The GP might advise people to try different antidepressants, at different doses, to find what works best.

Benzodiazepines (another type of drug commonly used to treat anxiety) aren't generally suitable for people with dementia because they can cause severe drowsiness or increase confusion, and are addictive if used for more than two weeks. Alternative drugs for anxiety are available – speak to your GP.

Other treatments
There are other ways to treat depression and anxiety that don't involve taking drugs. These include talking therapies (such as CBT), reminiscence activities and life story work. To find out more, see Non-drug treatments on page 31.

Other simple things that can help with depression and anxiety include keeping active, doing enjoyable activities and talking to friends and family. Eating a healthy diet and not having too much alcohol or caffeine can also help.

3 Living well

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3 Living well

Key points: Living well

If you've been diagnosed with dementia, there are lots of things you can do that will help you to live as well as possible.

To help you cope with memory problems you could try using a large diary, and perhaps keeping it next to a calendar clock. Also try keeping important items, such as keys or glasses, together in the same place.

Try to make your home safer. Remove things that are easy to trip over and install carbon monoxide detectors and smoke alarms. You could also get automatic timers for plugs, lights and heating.

Try to stay active and social: it can help you retain skills and memory, as well as improve your self-esteem, sleep and wellbeing. Wherever possible, keep doing what you enjoy, even if you have to do it a little differently.

Ask an occupational therapist (a health professional who supports people to maintain everyday skills) for advice on activities.

Having dementia doesn't mean you should feel unwell or depressed. It's important to try and stay healthy. Regular exercise and eating a balanced diet can help. If you smoke, try to stop.

Arrange regular checkups with your GP, as well as regular dental, eye and hearing checks. Get the annual flu vaccine and see the doctor promptly if you feel unwell.

A positive outlook

Living with dementia is challenging and you may feel angry or frustrated about what's happening to you.

Your plans for the future might change, but dementia doesn't change who you are. A diagnosis of dementia doesn't mean that you need to stop doing the things that you enjoy, but you might have to do them in a different way.

There are some practical things that you can do to help you live as well as possible. Focus on the things you can and want to do, and try not to become isolated. Keeping busy with activities you enjoy may help you to feel more confident.

'You must carry on doing the things you enjoy, and not sideline yourself from your friends and family or clubs and groups. We've always led busy lives, going out and about – and we still do.'

Brenda, West Sussex, carer for a person with dementia

Coping with memory loss

Memory loss can be distressing and undermine your confidence. There are lots of practical things that can help. You might try some of the following:

- Keep a notebook or large 'week to view' diary. Write down things you want to remember, such as names or to-do lists. Keep the diary by the kettle or phone, so you get used to referring to it.
- Put labels or pictures on cupboards to help remind you where things are. Or you could keep frequently used items – a cup, plate and cutlery – out on a table.
- Place useful telephone numbers by the phone.
- If you find it helps, put a note on the door to remind yourself to lock up at night.
- Ask your pharmacist about putting your pills in a disposable dosette box which has the days of the week marked on it.

For more information see factsheet 526, Coping with memory loss

Technological aids that people can find useful include:

- Reminder messages – when you go in or out of the house, a recorded voice reminds you to pick up your keys or lock the front door.
- Calendar clocks – these show the date and the day of the week. Keeping the clock next to a diary or weekly planner can help you orientate yourself when checking appointments.
- Locator devices – these help you find frequently mislaid items such as keys. You attach a small electronic tag to the item. If you mislay it, you can click a button on the locator device to make the tag beep.

For more information see factsheet 437, Assistive technology – devices to help with everyday living

Making things easier

- Put a regular routine in place – you might find it reassuring to do things at the same time each day or week.
- Keep things straightforward – simplify your routine or daily tasks to make them more manageable.
- Take things one step at a time – try to focus on one thing at a time and break each task down into a step-by-step process.
- Don't be afraid to ask questions – there is nothing wrong with asking someone to repeat or explain something.
- Don't feel like you have to rush things – give yourself plenty of time and take things at a slower pace if you feel the need.

Keeping safe at home

Having dementia can make accidents at home more likely. There is a range of equipment available that can help you stay safe, from personal alarms to timers that switch off electrical items. It can be easier to get used to them if you do so early on, rather than introducing them if an emergency or crisis arises in the future.

You might want to consider these ideas:

- Prevent falls by making sure the house is well lit and removing trip hazards, such as rugs. Have handrails fitted on the stairs or in the bathroom.
- Use a personal alarm to alert people if you fall.
- Install carbon monoxide detectors and smoke alarms.
- Use timers for plugs, lights and heating systems to turn things on and off automatically.

Ask your local fire service about a free home fire safety visit. An occupational therapist can give advice on items that could improve your safety and help you stay independent. Ask your GP or staff at the memory clinic or social services to refer you to one.

For more information see factsheet 503, Safety in the home

Being active

Keeping as active as possible – physically, mentally and socially – will bring great benefits. It can help you meet people, retain skills and memory, boost your self-esteem, improve sleep and avoid depression. Some creative activities can be helpful too, such as painting, writing a diary or listening to music.

You may find that some of these things can help:

- taking regular physical exercise
- gardening
- looking back on good times by creating a scrapbook or photo album
- playing games or cards and doing word, number or jigsaw puzzles
- reading books, newspapers or magazines
- listening to audiobooks, the radio or music
- arts and crafts – new or old favourites
- day trips or holidays
- seeing friends and family
- spending time with a pet.

You might find that activities take you longer than they did before. You may need to make changes to the way you do things, or have some support to do them. It's important to adapt to these changes, rather than not doing the activity at all.

For more information see factsheet 521, Staying involved and active

Staying healthy

Having dementia doesn't mean you should feel ill, depressed or anxious. It's important that you check with the doctor if you're feeling unwell, because other illnesses and infections can make you more confused and forgetful.

You might find the following tips useful:

- Try to eat balanced meals and drink plenty of fluids.
- Take regular physical exercise if you can.
- If you enjoy the occasional alcoholic drink, you might want to keep doing this (unless your GP advises you not to).
- If you smoke, consider stopping.
- Keep warm.
- Get enough sleep.
- If you find yourself regularly feeling low, anxious or irritable, you may be depressed. This can be treated, so talk to someone close to you about it. See your GP if it continues or gets worse.
- Have the flu vaccine each year and ask about the pneumonia vaccine for over-65s if this applies.

'I don't in many ways think of myself as being ill. Most of the things I could do, I can still do, just not in the same way.'

Rusty, Wiltshire, living with Alzheimer's disease

Checkups

Visiting the doctor regularly means that any other health problems that could make your dementia appear worse should get picked up quickly. This is especially important if you also have diabetes, or heart or breathing problems.

In addition:

- have regular sight and hearing checks
- have regular dental checkups
- pay attention to foot care and make sure your shoes fit well.

For more information see factsheet 522, Staying healthy

4 Planning ahead

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Key points: Planning ahead

After you've had time to adjust to your diagnosis, make sure your financial and other affairs are in good order.

There are things you can do to make managing money easier. Talk to your bank about a 'third-party mandate' which will allow someone else to deal with your bank account. Consider getting a 'chip and signature' card, so you don't have to remember a PIN number.

You and your carer may be entitled to a range of benefits. If you have dementia you may be eligible for Attendance allowance, or (if under 65) Disability living allowance or the new Personal independence payment. Your carer may also be eligible for Carer's allowance. Ask social services, a Citizens Advice Bureau or Age UK for advice. You will find their contact details in the Other useful organisations section starting on page 110.

Now is the time to plan ahead and talk to others about the future. If you're able, try to do it as soon as you can.

4 Planning ahead

Make sure you have an up-to-date will. Consider setting up a Lasting Power of Attorney. This will allow someone you trust to make decisions on your behalf if you're no longer able.

To have a say in your future medical care, you can also set up an advance decision. Talk to your GP or solicitor about this.

If you drive, you must tell the Driver and Vehicle Licensing Agency (DVLA) in Great Britain or Driver and Vehicle Licensing Northern Ireland (DVLNI) about your diagnosis. You will find their contact details on page 114. You must also tell your car insurer.

If you're working when you're diagnosed with dementia, you may choose to carry on doing so. It's important to talk to your employer.

If you stop working or reduce your hours, you may be eligible for some further benefits.

Financial matters

Once you have had a chance to adjust to your diagnosis, take time to ensure your affairs are in order. It's important to make sure that all your essential documents can be found easily.

Things to think about include: details of your bank accounts, tax, benefits and pension, as well as mortgage or rent documents, insurance policies and your will.

It may become more difficult for you to make decisions or choices about financial or legal matters as time goes on. There are lots of things you can do to make sure you get to choose how you live now and in the future. Where possible, make these plans as early as you can with a trusted friend, family member or professional. (Choose someone who is likely to be able to support you as time goes on.)

Direct debits

If they aren't already in place, consider setting up direct debits for regular payments such as gas and electricity bills. That way they will get paid automatically and may also be cheaper.

Bank accounts

During the later stages of dementia, the bank might advise couples who have joint bank accounts to have separate accounts. This can make some things simpler. Benefits and pensions, for example, can be paid directly into your account. Any means-testing for benefits will be more straightforward too if the accounts are separate.

If you need or want someone else to deal with your account, you can arrange a 'third-party mandate' to allow this. You will need to fill in a form from the bank to set this up. The mandate will not apply in the future if you reach a point where you no longer have capacity (ability) to make decisions for yourself. See Lasting Power of Attorney on page 61 for information on how to arrange for someone you trust to make decisions on your behalf in the future.

Debit and credit cards

If you have memory problems, you may find it difficult to remember PIN numbers for debit or credit cards that have a 'chip and PIN' device. Talk to the bank about alternatives, such as a 'chip and signature' card or photocard.

Trusts

If you have property or savings, you might set up a trust. This will ensure things are managed the way you have chosen, now and in the future. Seek advice from a solicitor or financial adviser.

For more information see factsheet 467, Financial and legal affairs

Benefits

People with dementia and their carers may be entitled to a range of benefits. Some are means-tested so they depend on income or savings. Accessing them can seem complicated but there are people who can advise on what to claim for and help you to complete the forms (which can be long and detailed).

Try to get help from someone with experience of these forms to complete them with you. Help may be available from a social worker, a local welfare rights service, a Citizens Advice Bureau or Age UK, as well as the Benefit Enquiry Line and the Department for Social Development in Northern Ireland. The GOV.UK website also provides useful information. For some benefits, the Department for Work and Pensions (DWP) can arrange for someone to visit you at home (see Other useful organisations starting on page 110).

Types of benefits

Attendance allowance, Disability living allowance and Personal independence payment

These are the main benefits that people with dementia can claim. They are based on daily living, care and mobility needs, not on the dementia diagnosis. They aren't means-tested or based on National Insurance contributions. They are tax-free.

Attendance allowance is for people who are 65 or older. It's based on a person's need for help with personal care (for example with taking medication, or washing or dressing). There are two rates, depending on whether help is needed in the day or at night (lower rate), or both day and night (higher rate). You can request a claim form by calling the Benefit Enquiry Line or at www.gov.uk (see Other useful organisations for contact details).

Disability living allowance (DLA) is only available to people who claim before their 65th birthday. People who are awarded the benefit will continue to receive it after that age. There is more about DLA (and the new Personal independence payment – PIP – which is replacing it) in the section Benefits for people of working age with dementia on page 68.

Benefit claim forms include questions about which activities the person with dementia finds difficult or impossible to carry out. They also ask about care and supervision, such as whether the person needs help with bathing or cooking. A medical assessment isn't always required for Attendance allowance or DLA but will be for PIP.

These benefits can be claimed whether the person lives alone or with other people. If the person with dementia is admitted to hospital or residential care for a prolonged period, any Attendance allowance, DLA or PIP may be suspended temporarily.

Carer's allowance

If the person with dementia has someone who looks after them for at least 35 hours a week, that person may be entitled to Carer's allowance. They will only be eligible if the person with dementia receives Attendance allowance, the DLA care component at the highest or middle rate, or the daily living component of the new PIP at either rate.

The carer doesn't have to be related to the person with dementia or live with them, but they must be 16 or over and earning less than a set amount each week. If a carer of a person with dementia is claiming Carer's allowance, the person with dementia may lose some of their own benefits. Seek advice before deciding whether the carer should claim. You can get a claim form by calling the Benefit Enquiry Line or at www.gov.uk

Other benefits

There are other benefits available. For example:

- State pension or Pension credit – if the person with dementia or their carer is retired, check that they are getting all the State pension or Pension credit they are entitled to. Phone the Pension Service or go online to www.gov.uk
- Housing benefit or Council tax support – if the person is on a low income, they may also be entitled to means-tested Housing benefit (if renting) or Council tax support. The local council can advise. Many people with dementia also qualify for reductions on their Council tax bill, irrespective of their income or savings, through Council tax discounts.
- Winter fuel and Cold weather payments – when someone has reached the qualifying age they will usually be entitled to Winter fuel payments to help with heating bills. Some people may also qualify for Cold weather payments during very cold spells.

For information about benefits specifically for people of working age, see page 68.

For more information see factsheets 413, Benefits and 431, Benefit rates and income/savings thresholds

Putting someone else in charge of benefits

If you are living with dementia, you can contact the Department for Work and Pensions to appoint someone you trust – an 'appointee' – to receive, and manage, the money you get in benefits. The proposed appointee will have to prove that they are managing your money with your best interests in mind. DWP will monitor the situation.

Making decisions for the future

Everyone needs to make decisions from time to time about their health, care and finances. As dementia progresses, it will become harder for you to do this. If you're able to, think about your future, talk to others and plan ahead as soon as you can. You can make decisions and plans so that your future care and finances are handled in a way that reflects your wishes. These choices could range from how your money is managed to how you want to be cared for at the end of your life.

If you have dementia, the law protects your right to:

- make your own decisions and be involved in any decisions that affect you
- get support with making decisions about the future that you are finding difficult to make now
- put plans in place in case you are unable to make decisions in the future
- appoint someone you trust to make decisions in your best interests if you can't.

Wills

Everyone should make a will. It allows you to choose who inherits your money and your possessions. Talk to a solicitor about making or updating a will.

If you are living with dementia, you can still make a will or change it, as long as you understand the decision you're making and the implications of any changes. A solicitor can offer advice.

Lasting Power of Attorney

Many people with dementia choose to give someone they trust 'power of attorney'. This means that the 'attorney' – often a spouse or grown-up son or daughter – can make certain decisions on your behalf if you lose the capacity (ability) to do this. In all cases decisions must be made by the attorney in the best interests of the person with dementia.

The legal document to set this up is called a Lasting Power of Attorney (LPA). This isn't currently available in Northern Ireland because the law is different – see Enduring Power of Attorney on page 62. There are two types of LPA:

- **LPA for health and welfare** (a personal welfare LPA) – this allows the attorney to make decisions about the healthcare and welfare of the person with dementia. It can include decisions about whether to refuse or give consent to medical treatment. It can also cover where the person lives.
- **LPA for property and affairs** – this can give the attorney powers such as paying bills, collecting income and benefits, accessing bank accounts and selling a house on behalf of the person with dementia.

The forms needed to apply for an LPA are available for free from the Office of the Public Guardian (by phone or online) and to buy at some stationery shops. See Other useful organisations starting on page 110 for contact details. Many people pay a solicitor to help them complete the LPA forms, but you don't have to do this.

If someone with dementia decides to set up an LPA, they need to do this while they still have the mental capacity to do so. The LPA will need to be registered with the Office of the Public Guardian before it can be used. There is a fee for this.

There are some important differences between the two types of LPA. A personal welfare LPA can only be used if the person's dementia means they have lost the capacity to make such decisions. If an LPA for property and affairs is set up, a person with dementia can choose to hand over responsibility for financial affairs earlier, while they still have mental capacity.

Enduring Power of Attorney

To give someone power of attorney in Northern Ireland, you will need to make an Enduring Power of Attorney (EPA). Talk to your solicitor about setting this up.

In England and Wales EPA was replaced by LPA in October 2007 (see page 61). An EPA only covers property and affairs (not health and welfare). EPAs made before this date are still valid but you can no longer make a new EPA (unless you live in Northern Ireland).

Deputies and controllers

If someone with dementia no longer has the capacity to make a power of attorney, in England and Wales a family member or close friend can be appointed as a 'deputy'. They would be appointed by the Court of Protection following a legal process which is more expensive than setting up an LPA and can take several months.

Deputies must act in the person's best interests and the decisions they make can be checked annually by the Court of Protection.

In Northern Ireland a 'controller', similar to a deputy, can be appointed by the Office of Care and Protection to make property and financial decisions.

Getting legal advice

If you decide to pay for a solicitor, you may want to talk to a few different ones and compare prices and services. It's important to find a solicitor you are comfortable with and whose advice you trust and understand.

Your local Citizens Advice Bureau may be able to offer advice, or you can search the Solicitors for the Elderly website or phone them to find a solicitor in your area. You can also find a local solicitor on The Law Society website. (See Other useful organisations starting on page 110 for contact details.)

For more information see factsheet 472, Lasting Powers of Attorney

Other ways to plan for future care

If you have been diagnosed with dementia, you can choose to make decisions about your future care in a range of ways other than an LPA. Discussing views and preferences about the future with family and health or social care professionals is called advance care planning. This can cover one or more of:

- Lasting Powers of Attorney (see page 61)
- advance statement (see page 64)
- advance decision to refuse treatment (see page 64)
- 'do not resuscitate' order – a decision not to have your heart or breathing restarted if they stop.

Discussions about care at the end of life can be difficult for people with dementia and their families. There shouldn't be any pressure on you to have these discussions.

If you have dementia and you do want to plan ahead, you will need to have the capacity to do so. If you're thinking about advance care planning, it's important to do it as soon as you can.

Advance statement
If you want to, you can write down your priorities and preferences for the future. This is called an advance statement – it might cover where you would like to be cared for or how you like to do day-to-day things. It's used if you're in a position in the future where you cannot decide for yourself.

Unlike the other documents mentioned previously, an advance statement isn't legally binding. But it should be taken into account when deciding what is in your best interests. You will need to sign it, tell people about it, and keep it somewhere safe.

Advance decision to refuse treatment
If you would like to make sure you have a say in your future medical care, you can make an advance decision (in England and Wales) or an advance directive (in Northern Ireland). This legal document enables you to refuse, in advance, specific medical treatments or procedures in case you become unable to decide this for yourself. Decisions might include whether to be resuscitated if your heart stops, for example. You can't use an advance decision or advance directive to refuse basic care such as food, drink and pain relief.

If you're considering an advance decision, seek advice from your GP. They will advise about the advantages of choosing or refusing particular medical treatments. You may also want to talk to a solicitor to make sure the content and wording of the advance decision is correct. Speak to your close friends or relatives about your advance decision as involving them will help them understand your wishes.

For more information see factsheet 463,
Advance decisions and advance statements

Driving

Having a diagnosis of dementia doesn't necessarily mean you have to stop driving straightaway. But it does mean telling certain people and possibly taking a driving assessment. As dementia progresses, there will be a time when stopping driving becomes essential.

If you have a driving licence, the law says you must inform the Driver and Vehicle Licensing Agency (DVLA) in Great Britain or Driver and Vehicle Licensing Northern Ireland (DVLNI) promptly about your diagnosis of dementia. You must also tell your car insurance company.

The DVLA or DVLNI will request a report from your doctor and might also ask you to take a driving assessment. The DVLA or DVLNI will use these to decide whether you can still drive.

Many people with dementia choose to stop driving voluntarily. It's best to stop if you feel less confident or become confused even on familiar routes. Having to stop driving can be difficult to adjust to but there can be some benefits. These include feeling less stressed and saving money on insurance and fuel. Taking control of alternative travel options, such as getting a free bus pass, can help you with the transition, as can talking through how you feel with family and friends.

For more information see factsheet 439, Driving and dementia

Working

It's possible to continue working after a diagnosis of dementia. Some people find working helps them to feel better physically and emotionally. Others might feel that stopping is for the best.

Getting help

If you're experiencing difficulties in your job, consider talking to your employer or getting advice. Advice is available from a range of places, including your GP, human resources department at work, Advisory, Conciliation and Arbitration Service, your trade union if you have one, the Citizens Advice Bureau and the disability employment adviser at your local Jobcentre Plus office.

Talking to your employer

In some jobs you're legally obliged to tell your employer about your diagnosis, so you will need to check your contract. If you drive as part of your job, you should let your employer know straightaway.

You might feel anxious about telling your employer about your diagnosis, but doing so will help give you protection under the law. Once your employer knows, they must try to make 'reasonable adjustments' so you can keep working if you're able.

Leaving work

At some stage, you might decide to stop working or retire early. It's important to seek advice about your pension rights. This is particularly important because the State pension age is changing for some people.

Benefits for people of working age with dementia

People of working age with dementia might be eligible for a range of benefits. Depending on individual circumstances these can include:

- Disability living allowance (DLA) or, from June 2013, Personal independence payment (PIP). These are based on daily living, care and mobility needs, not on the dementia diagnosis. They aren't means-tested or based on National Insurance contributions. There are two components to DLA: personal care needs and mobility needs (for example difficulty walking outside), with different rates for each component according to how much help is needed. However, DLA is being phased out. From June 2013, new claims for DLA won't be taken and people under 65 will need to apply for PIP instead. PIP will have daily living and mobility components. (If you already receive DLA you will be transferred to PIP some time before March 2018.)

- Working tax credit – this is a means-tested benefit that can be claimed by some people who are working and on a low wage. Working tax credit is being phased out from 2014, and will be replaced by Universal credit (see below).

- Statutory sick pay – this can be paid for up to 28 weeks if someone has a job but has been sick and unable to work. It isn't affected by any savings. This benefit is paid by the employer, who can give information about claiming.

- Employment and support allowance – this is the main benefit for people of working age who are unable to work due to ill health. It can be based on either a National Insurance record or a means test. It can also provide some support for paying mortgage interest.

- Income support – this is a means-tested benefit paid to certain people, including some carers, who aren't expected to look for work. It's intended to provide for basic living expenses and can be paid on top of other benefits such as Carer's allowance. People who were receiving Income support because of sickness or disability will gradually have this replaced with Employment and support allowance.

- Housing benefit and Council tax support (see Other benefits on page 59).

It's important to have a full benefits check. Speak to an adviser at the Benefit Enquiry Line, Age UK or Citizens Advice Bureau.

Universal credit

There will be changes to the benefit system in 2013. The new Universal credit will replace many working-age means-tested benefits in Great Britain from October 2013 and Northern Ireland from April 2014.

5 Services for people with dementia

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5 Services for people with dementia

Key points: Services for people with dementia

There is support available to help you live well and stay independent for as long as possible.

The main sources of information and support are the NHS, social services, private companies, and charities and not-for-profit organisations.

To find services in your area, start by contacting your local memory service, social services department, GP, Alzheimer's Society or Citizens Advice Bureau. NHS Choices also provides details of local services.

Organisations such as Alzheimer's Society and Age UK can support people with dementia, their families and carers in a range of ways. These include dementia support workers and support groups, telephone helplines and information materials. You will find contact details on pages 106–117.

Lots of different health and social care professionals can support you – from community nurses to social workers and dementia support workers.

If you need non-medical support at home, the first step is to ask social services for a community care assessment.

Social services will draw up a care plan that looks at how they can meet your needs. They may charge you for some services or they may cover the costs, possibly in the form of a personal budget or direct payment (money from the local authority that you use to pay for your care and support).

There are some services specifically designed for the different needs of younger people with dementia. Your memory clinic, GP or local Alzheimer's Society can tell you about what is available in your area.

Where to go for support

A diagnosis of dementia can be daunting and raises many questions about the future. Asking for help can feel difficult, particularly if you've always been independent. You might not feel you need it straightaway, but it can be useful to know that a wide range of information and support is available. For example, health and social care professionals can support you in a number of ways. Attending a support group can help you to meet people in a similar situation and share your feelings, experiences and useful information. This support can help you to enjoy a good quality of life and to live in your own home for longer, if that is what you would like to do.

Most people will know how to contact their GP for free healthcare. You might not know as much about the social care and support system offered by the local authority (council). It provides or arranges a variety of non-medical care and help. Some services are free but you may have to contribute to the costs of others, depending on your income and savings.

National Health Service (NHS)

Most people will have already used health services through the NHS such as a GP or specialist (for example a consultant). You may also have attended a memory clinic. Services provided by the NHS are free.

There are a wide range of NHS professionals who can help, such as:

- GPs
- medical specialists, eg psychiatrists (for mental health), geriatricians (for older people) and neurologists (for diseases of the brain and nerves)
- nurses, eg practice nurses, district or community nurses, community psychiatric or community mental health nurses, and specialist dementia nurses such as Admiral Nurses
- psychologists (for assessment of memory problems and talking therapies)
- audiologists (for hearing)
- optometrists (for sight)
- dentists (for teeth)
- physiotherapists (for exercise and mobility)
- chiropodists (for feet)
- occupational therapists (for maintaining everyday skills)
- speech and language therapists (also help with problems related to swallowing)
- counsellors (for talking therapies)
- dietitians (for advice on diet and nutrition).

'I had the strength of a really wonderful community psychiatric nurse. Her main brief was to help [my wife] but along the way she gave me lots of guidance on caring and on aspects of the illness I didn't understand. I could call her and email her with any questions. She was a tremendous help.'

David, Northamptonshire, carer for a person with Pick's disease (frontotemporal dementia)

Social services and social care

Social services staff can help work out what care and support someone with dementia and their carer needs. They may also arrange for care and support to be provided, often by a different organisation. Social care professionals include social workers, home care assistants and home carers.

These staff can help people to remain independent for as long as possible in their own home. Services provided or arranged by the local authority might include:

- help in and around the home – eg with shopping, cooking, cleaning, or washing and dressing
- equipment and adaptations to make life easier and homes safer – eg a raised toilet seat, hand rails or a carbon monoxide detector
- help with meals at home
- help with taking medication
- arranging a place at a day club or support group
- help managing money and paying bills, dealing with paperwork and claiming benefits
- respite care (temporary care to allow carers to take a break)
- intermediate care or re-ablement (eg where staff support people at home after a hospital stay)
- extra care housing (homes where care and support are available on site).

Information and advice from social services are free for everyone. It's also free to have your needs assessed (see How to access social care on page 79). When it comes to receiving care and support services, some people will get them for free but others will need to pay. This will depend on the level of a person's needs, and their income and savings.

If someone is caring for a person with dementia, they can have their own needs assessed too. See Support for carers on page 85.

Charities and not-for-profit organisations

Charities and not-for-profit organisations can be a valuable source of local support, advice and information for people with dementia, their families and carers. National organisations include Alzheimer's Society, Dementia UK and Age UK. You can call their national helplines, visit their websites or drop into a local office (if there is one) for more information. Ask whether the following services are available locally and how to access them:

- dementia advisers
- dementia support workers
- specialist dementia nurses
- dementia support groups
- dementia cafés
- day centres
- befriending
- singing groups
- advocacy services
- telephone helplines
- discussion forums
- information – online and in factsheets or booklets.

For organisations and contact details see Alzheimer's Society services and support on page 106 and Other useful organisations starting on page 110.

Private companies

A wide range of private companies provide care and support services at home (sometimes called domiciliary care) for people with dementia. Someone with dementia might pay for a care assistant using their personal budget (see page 81) or from their own money.

For a list of local registered private agencies, contact your local social services, the UK Homecare Association, or visit the website of the relevant regulator: the Care Quality Commission (in England), Care and Social Services Inspectorate Wales or the Regulation and Quality Improvement Authority (in Northern Ireland). For contact details see Other useful organisations starting on page 110.

For more information, see factsheet 454,
How health and social care professionals can help

Dealing with different professionals

- If you're unsure about someone's role, ask them to explain it.
- Consider asking a friend or relative to be with you when you see professionals.
- Write down what you want to discuss with someone before you see them.
- Write down anything important they tell you.

How to access social care

Community care assessment

The first step for getting support at home is to ask for a community care assessment. This aims to find ways to help you maintain your independence and quality of life. It is sometimes called a care assessment or needs assessment, and will involve a discussion between you and someone from social services. You might also be asked to fill in a questionnaire, which they can help you with if required.

The assessment might cover living arrangements, what you are and aren't able to do for yourself, any worries you have and how you would like to be supported. Friends or family members can contribute to the discussions.

Social services may also ask the GP and other professionals for their opinions.

To arrange a community care assessment, you or a relative or friend can contact social services directly. Alternatively a GP, consultant or other professional involved in your care can make a referral. Assessment, information and advice are always free.

'We now get direct payments and pay for my carer directly. I get Disability living allowance too. Social services tell you about all the support you can have. There are things I was offered – respite, meals on wheels – that I didn't want.'

Graham, East Sussex, living with Pick's disease (frontotemporal dementia)

Getting help: a care and support plan

Social services will appoint someone, usually a social worker, to be responsible for planning your care and support. The social worker will draw up a written care and support plan and give you a copy.

Social services should work with you to agree how to meet your needs in a way that suits you best. They might offer to provide some services themselves or suggest private companies or charities that can help. Some people affected by dementia choose to arrange services for themselves.

Some people will have to pay towards their social care. Contributions depend on income, savings and assets. The value of your home won't normally be taken into account if you are living there.

Personal budgets

If the local authority is paying for some or all of your care, they should talk to you about a personal budget. This is an agreed amount of money allocated to you by the local authority to pay for care and support that meets your assessed needs. Personal budgets are designed to make sure that someone can choose and receive the help that meets their needs.

A personal budget can be used in many different ways. Social services will help you write a plan which will say what type of care and support you want, and how the personal budget will be allocated. There are no restrictions to say that care services have to be organised through social services. Some people choose to receive their personal budget as a direct payment. They can then use it to employ a personal assistant, or to pay for home care from an agency.

Tips on personal budgets

- You can choose to receive your personal budget as a direct payment. This means that you or a family member or friend is responsible for keeping records of how it's spent in line with your support plan.
- Alternatively, you don't have to receive your personal budget as a direct payment if you don't want to. You can ask social services to manage it for you, or ask them to arrange for a local organisation to help you to manage it.
- Ask social services for help and information about personal budgets. They can tell you about local organisations that can help you understand how to use one.

Services for younger people

If you have been diagnosed with dementia and are in your 40s, 50s or early 60s, you will have very different interests, care and support needs from someone diagnosed in their 80s or 90s. For example, younger people are more likely to be working (or have a partner who is), have dependent children or possibly dependent parents, and still have a mortgage.

Services for people with dementia have often been developed around the needs of older people, and in some cases access is restricted to those over 65. Even where a service is open to younger people, the type of care and support provided may not always be appropriate or flexible enough to meet individual needs.

The number of services suitable for younger people is growing, but progress is slow and services may not be available in your local area.

Ask your memory clinic, consultant, GP or social services about support and services for younger people with dementia. Contact Alzheimer's Society about putting you, your family or carers in contact with others in the local area, or in similar circumstances. Alzheimer's Society's online discussion forum, Talking Point, includes a section for younger people with dementia and their carers.

You might also find it helpful to visit websites and subscribe to newsletters that support people with a particular type of dementia.

As a younger person, if you're eligible for funded social care you're more likely to be offered a direct payment to pay for your care. This can help you get support that's tailored to your needs.

For more information see factsheet 440,
Younger people with dementia

6 Support for carers

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6 Support for carers

Key points: Support for carers

Caring for someone with dementia can be very stressful and at times upsetting, but also rewarding.

Carers often go through a wide range of emotions, including loss, guilt and anger. They may also have positive feelings, such as satisfaction from being able to support the person with dementia.

A lot of information and advice is available to support you in your caring role. Sources of support for carers include family and friends, health professionals, memory services, social services, carers' support groups and organisations such as Alzheimer's Society.

As a carer, it's important to look after your own health and wellbeing. Try to eat a balanced diet, and to get enough sleep and exercise. Make sure you have some time to yourself.

There are practical tips that can make caring for someone with dementia a little easier. For example, encourage the person to keep doing what they can to retain their independence.

When communicating, make eye contact, listen carefully, be aware of your body language and speak clearly.

As a carer, you may well find changes in the person's behaviour difficult to cope with. This might include them repeating themselves, following you, pacing and shouting out. Keep in mind that they aren't doing these things deliberately, and try not to take it personally. They may be in pain or trying to tell you something, for example that they are bored or frustrated.

Talk to a doctor – ideally a specialist – about behaviour that is challenging or causing either of you distress or worry. There are things that can be done to help.

Looking after yourself

If someone close to you has been diagnosed with dementia, it's important not to underestimate the impact this may have on you. Whether you're the husband, wife, partner, daughter, son, brother, sister or friend of the person, your relationship will change. Many people find that they have taken on the role of a 'carer' without making any decision to do so.

Caring for and supporting someone with dementia can be stressful and at times upsetting. It can also be very rewarding. It's important that you look after your own health and wellbeing, and turn to others for support when you need it. There is advice available to help you understand dementia and do all you can to support the person you care about.

Emotional support

When you're caring for someone with dementia, you're likely to experience a wide range of emotions at different times. These may range from positive feelings – you get satisfaction from supporting the person – to other feelings of loss, grief, guilt, embarrassment and anger. You may also feel awkward about any reversal of your previous roles. It can help to know that this is normal for lots of people caring for someone with dementia.

Try and take time to reflect on how you're feeling, and talk to someone you trust. You might choose a professional, a friend or family member, or someone at a carers' support group. If you use the internet, you could try an online discussion and support forum like Talking Point. For more information see Alzheimer's Society services and support on page 106 and Other useful organisations on page 110.

Practical support

Caring for a person with dementia can become gradually more demanding, physically and emotionally. Getting support will make it easier for you to cope and better for the person you care for.

There are many sources of support, including:

- Friends and family – while it can be difficult to accept help, try to involve family members and share responsibilities as it will take the pressure off you a little.
- Benefits and your employer – if you work, explore flexible working options with your employer. If you decide to stop working, take advice about your pension entitlements. Find out about any benefits you might be entitled to. See page 57 for more information.
- Social services and the carer's assessment – as a carer you're entitled to have your individual needs assessed by social services upon request. You may be offered support services to help you in your caring role. The local authority might charge for some of these services, taking your income and some savings into account.
- Support workers – many voluntary organisations have trained dementia support workers who can provide practical information, guidance and support about caring for someone with dementia. They can offer home visits or support over the phone.
- Support groups – local carers' support groups give you a chance to chat to others going through similar experiences. You can share practical tips and get emotional support. Ask your memory service or local Alzheimer's Society about groups in your area.

- Online discussion forums – these can be a helpful source of support at any time of the day or night. You can talk online with other people who are going through similar experiences to seek advice and share practical suggestions. See page 106 for more information.
- National Dementia Helpline (0300 222 1122) – trained advisers can support you, provide information and refer you to other sources of support. See page 106 for more information.

Your health and wellbeing

As a carer, it can be easy to put the other person's needs first and ignore your own. Looking after yourself is vital for your own health and wellbeing. It will also help make sure you can do your best to care for the person with dementia.

Your health

It's important to make sure that you eat a balanced diet and make time for regular exercise and physical activity. Even going for a walk can help.

See your GP about your own health on a regular basis. If you're having problems sleeping, ask your doctor for advice. If you have to help move or lift the person you're caring for, ask your GP to refer you to a physiotherapist for advice so that you don't risk injuring yourself. If you feel sad or anxious a lot of the time, talk to your GP about it as early as possible, as these could be signs of depression.

'It's really important to try and get some time on your own, for yourself. I go and read a book upstairs, or I take the dog out. You need that little space.'

Ann, Wiltshire, carer for a person with dementia

Your wellbeing

Try to make sure you have some regular time to relax or do something just for yourself – this can have a big impact on your wellbeing. Try to get out regularly to meet friends.

If possible, consider an outing or short break, as this can relieve stress and leave you feeling refreshed. Find out about day care or respite support for the person you care for so that you can take time out knowing they are well looked after.

For more information see factsheet 523, Carers: looking after yourself

Tips for supporting a person with dementia

Much of how you care for the person will come naturally and be based on instinct. You will probably know the person best, and you shouldn't underestimate the value you can bring to their care. It's important to continue to see the person and not just their dementia.

Everyday care

With time, dementia will affect the person's ability to carry out tasks in everyday life that they would have found straightforward previously. Try to support and encourage them to continue to do as much as they can for themselves. When you help out, try to do things with them, not for them. This can help the person retain their independence as well as improve their wellbeing, confidence and self-esteem.

You might find the following tips useful when you're caring for someone close to you:

- Focus on what they can do rather than on what they can't. This will help to promote their independence. For example, lay clothes out for them to dress themselves as far as possible.
- They may find it hard to remember or concentrate on things, so try to be flexible and patient.
- Put yourself in their shoes – try to understand how they might be feeling and how they may want to be cared for.
- Offer support sensitively and try to give encouragement.
- Make sure they have meaningful things to do, from everyday chores to leisure activities. Do things together if you can.
- Include the person in conversations and activities as much as possible.

Communicating

How dementia affects the way someone communicates will vary. In most types of dementia, people will at times struggle to find the right words or follow a conversation. This can be upsetting and frustrating for you and the person with dementia. However, there are lots of ways to help you understand each other:

- Make eye contact. Try to listen as carefully as you can, even when you are busy.
- Make sure you have the person's full attention. Consider whether any distractions, such as noise, are affecting things.
- Notice your body language. Think about how you use gestures, facial expressions and touch. You can give a lot of reassurance through physical contact, if it feels right.
- Speak clearly and think about the words you use. If you aren't being understood, use simpler words or explain things differently.

- Stick to one topic at a time and make sure questions are straightforward – having too many choices can make decisions difficult.
- Bear in mind that other things, and not just dementia, can affect communication – hearing or eyesight problems, pain or side effects of medication.
- If it feels right, it can sometimes help to deal with misunderstandings and mistakes using humour. Laughing together can ease tension. But you will need to judge how the person responds to this.
- When others are around, ensure you involve the person in the conversation and avoid talking across them.

For more information see factsheet 500, Communicating

Changes in behaviour

At times, people with dementia behave differently from how they used to. Many carers find dealing with this more difficult than adjusting to symptoms such as memory loss.

While it can be very difficult, it's best to deal with any potentially tense situations as calmly as you can – take some deep breaths or leave the room for a while if you need to. Keep in mind that even where behaviour appears to be targeted at you, this may be just because you're there.

If problematic behaviour persists or causes distress, seek advice and support from the GP, memory service, community mental health nurse or Admiral Nurse (mental health nurses who specialise in dementia). If behaviour persists and you're not in contact with a dementia specialist, ask for a referral to one.

Unusual behaviour

Behaviours that may seem unusual include:

- repetition – eg asking the same question, or repeating an action, over and over
- restlessness – pacing or fidgeting
- lack of inhibition, such as socially inappropriate behaviour in public – this is particularly common in the behavioural form of frontotemporal dementia
- night-time waking, sleeplessness and 'sundowning' (increased agitation or confusion in the late afternoon and early evening)
- following you around or calling out to check where you are
- putting things in unusual places, and then forgetting where they are
- suspicion – eg the person thinking someone has taken something belonging to them, when they have actually mislaid it.

It may help to remember that the person isn't being deliberately difficult and their condition may be affecting their sense of reality. Try to think of things from their perspective and offer reassurance. It's important to think about what the person is trying to communicate to you. Working out what the problem is, if there is one, will be the first step to resolving it. Try to avoid correcting or directly contradicting the person with dementia. At times it might be appropriate to try to distract the person, for example by changing the conversation, having something to eat or going for a walk together.

Behaviours that challenge

Someone with dementia – particularly as the disease progresses – can develop challenging or distressing behaviours. These are increasingly called 'behaviours that challenge' but you may still hear them included under the broader term 'behavioural and psychological symptoms of dementia' (BPSD). Challenging behaviours can become severe and very distressing, for carers and for the person with dementia.

Behaviours that challenge might include:

- becoming very agitated
- shouting or screaming – perhaps in response to mistaking something they can see for something else, or seeing things that aren't there (hallucinations)
- behaving aggressively, either physically or verbally.

These types of behaviour are often very upsetting. Symptoms might be caused by a general and curable health problem, such as pain or discomfort due to constipation or an infection. See the GP for a medical assessment.

Try to understand why the behaviour is happening. It might be an indication that the person has a need that isn't being met. If there are no physical causes, it may be that aspects of the person's care or home environment are causing the behaviour. Boredom and frustration are two common causes. It can help to keep a record of when the behaviours happen to help you understand them or spot any triggers. The person's own reality and perception of time may both be different from yours.

See if activities, particularly social ones, help. You could also try aromatherapy, massage, or music or dance therapy. Contact with animals can help some people. Other useful activities, if available, include talking therapies, reminiscence therapy or life story work. See Non-drug treatments on page 31 for more information.

For more information about unusual and challenging behaviour see factsheets 525, Unusual behaviour and 509, Aggressive behaviour

If these approaches don't work, or if symptoms of challenging behaviour are severe or very distressing, the doctor might suggest medication. This may be one of the drugs mentioned in Drug treatments on page 37, an antidepressant or anti-anxiety medication.

If these drugs don't help, the doctor may recommend an antipsychotic drug. If so, talk to the doctor about the benefits and risks. These drugs don't work for everyone and can have serious side effects. Antipsychotics should be offered only after all non-drug options have been exhausted, and only then for a short period (up to 12 weeks).

For more information, see factsheet 408, Drugs used to relieve behavioural and psychological symptoms in dementia

6 Support for carers

Person-centred care

You may come across the term 'person-centred care'. In the context of dementia, person-centred care means health and social care professionals should be offering care that reflects these principles:

- valuing the person with dementia – treating them with dignity and respect, promoting their rights
- treating them as an individual – understanding their history, lifestyle, culture, likes and dislikes
- seeing things from their perspective
- providing a positive social environment in which they can live well, with opportunities for nurturing relationships in the wider community.

Care of a person with dementia, wherever it's given, should always be based on these principles. You and the person with dementia, where possible, should always be involved in developing person-centred care. As a partner, family member or friend, your knowledge and understanding of the person is invaluable.

7 Research

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Key points: Research

Researchers are finding out more about what causes dementia and how to diagnose it better. They are developing new treatments and ways to improve quality of life for people living with the condition.

If you, or someone close to you, have been diagnosed with dementia, you may want to take part in research. This could mean being part of a clinical trial to test a new treatment or giving blood for genetic research. Or you could give your views on the healthcare and support services you have received.

You can go online to register your interest in getting involved in dementia research. Or you can ask at your memory service about trials in your area.

7 Research

You can get advice and guidance on getting involved in health research from NHS Choices. You will find their contact details on page 115.

Alzheimer's Society has a Research Network that you can join to help influence how funds are allocated to research projects.
Email **research@alzheimers.org.uk**
or phone **020 7423 3603** to get involved.

How to get involved in research

Researchers, in partnership with many people with dementia and their carers, are working hard to find a cure for dementia. They are looking into its causes, how it might be prevented, ways of diagnosing the disease earlier and how to improve quality of life for people living with the condition.

Taking part in research

Many hospitals support research into dementia. This important work would not be possible without the help of people affected by the condition. Taking part in research can take many forms. It might mean being in a clinical trial to test a new treatment, giving blood for use in genetic research, or giving views on the quality of healthcare and support services. Taking part offers an opportunity to provide advice and share your opinions with researchers.

You have a right to choose to take part in relevant and appropriate research as part of your care and treatment within the NHS.

Most people who take part in research value the opportunity to make a difference. They say that they welcome the chance to try new treatments or services, to influence and improve care and to have their condition monitored more closely. Some people help decide which research is funded rather than take part in research directly.

Getting involved

If you or your carer would like to take part in research, there are several ways to do it. Ask the GP or at the memory service about research happening in your area that you can help with. You can also register your interest online (see Dementias and Neurodegenerative Diseases Research Network – DeNDRoN – in Other useful organisations starting on page 110).

Research studies often need people to fit specific criteria such as a certain type or stage of dementia. Your age, the medication you are taking and other health conditions might mean that there isn't always a study suitable for you. However, you can also explore what research is taking place in your area through the UK Clinical Trials Gateway (see DeNDRoN in Other useful organisations).

If you do take part in research, you will be fully informed and asked to give your consent. You can leave the study at any time without affecting the rest of your care.

You can find out more about research in dementia from Alzheimer's Society or Alzheimer's Research UK (see Other useful organisations starting on page 110 for contact details).

Influencing dementia research

Alzheimer's Society funds and supports a range of research. This is carried out in partnership with dementia researchers and people affected by dementia to improve the quality and relevance of the research that is funded. Alzheimer's Society's Research Network, made up of over 230 people with dementia, carers and former carers, plays an integral part.

Research Network volunteers share their views by reviewing research proposals, discussing projects with researchers, helping to set research priorities and raising awareness of the importance of dementia research. All volunteers receive training and support. Volunteers can be involved as little or as much as they would like and it's possible to volunteer from home. If you'd like find out more about the Research Network, visit **alzheimers.org.uk/researchnetwork**, email **research@alzheimers.org.uk** or call **020 7423 3603**.

8 Alzheimer's Society services and support

Alzheimer's Society provides a range of services and resources to support people affected by dementia.

National services

These are available wherever you live in England, Wales and Northern Ireland.

National Dementia Helpline – 0300 222 1122

The Helpline is for anyone who is affected by dementia or worried about their memory. Trained advisers provide information, support, guidance and signposting to other appropriate organisations. The Helpline is open 9am–5pm Monday–Friday and 10am–4pm Saturday and Sunday. You can also contact the Helpline by email at **helpline@alzheimers.org.uk**

Talking Point online discussion forum

Talking Point is an online support and discussion forum for anyone affected by dementia. It's a place to ask for advice, share information, join in discussions and feel supported. Talking Point is available 24 hours a day, every day of the year. Visit **alzheimers.org.uk/talkingpoint**

Information

Alzheimer's Society produces a wide range of information for people with dementia, carers, family and friends. This includes the factsheets listed throughout this guide. You can read this information at **alzheimers.org.uk/factsheets** To request printed copies, use the order form on page 121 or phone **0300 303 5933**.

Local services

Alzheimer's Society provides a range of local services in England, Wales and Northern Ireland. Please note that not all the services listed below are offered everywhere, due to the availability of funding. Contact your local Alzheimer's Society office or the National Dementia Helpline for more information about Society services in your area or visit **alzheimers.org.uk/localinformation**

Dementia Adviser services

Dementia Advisers provide information, advice and guidance to people with dementia and their carers, from diagnosis onwards. They help people affected by dementia identify what information is needed and provide resources and advice to meet these needs.

Dementia support services

Dementia support workers provide expert practical advice and support to help people with dementia, their carers and family to understand the condition, cope with day-to-day challenges, and to prepare for the future.

Dementia Cafés

Dementia Cafés provide a safe, comfortable and supportive environment for people with dementia and their carers to get together and socialise, receive information and share experiences.

Singing for the Brain® groups

Singing for the Brain® is a stimulating group activity based on the principles of music therapy for people in the early to moderate stages of dementia and their carers.

Community support services (including befriending)

Befriending services connect people with dementia with a volunteer who has similar interests. This enables people with dementia to continue with hobbies and interests in their own home or local community, supported by the volunteer.

Community support services are provided by either volunteers or staff to support people to get involved and socialise in their local community. Unlike befriending, the service is not based on shared interests but solely on the needs of the person with dementia.

Support groups for people with dementia

Support groups for people with dementia provide a safe and supportive environment where attendees can talk about issues they are facing. They can share practical information and experiences with others who understand what they are going through.

Support groups for carers

Support groups provide a friendly and supportive environment for those caring for someone with dementia to talk to other carers about their experience.

Carer Information and Support Programme

The Carer Information and Support Programme is a series of workshops for people caring for a family member or friend with dementia. The workshops provide family carers with practical information on caring for someone with dementia and the chance to share their experiences with others.

Advocacy services for people with dementia

Advocacy helps people with dementia to express their views, to access information and services, and to secure their rights. Using their professional expertise, a trained advocate will support and empower someone with dementia to make informed choices and decisions, for example about the care they receive.

Day care and support services

Day care and support services give people with dementia the opportunity to continue their hobbies and interests, try out new activities, and socialise with others in a friendly and safe environment outside of their home.

Home care and support services

Specialist home care and support services offer people with dementia personalised one-to-one support in their own home to help them maintain their independence.

9 Other useful organisations

Action on Elder Abuse
enquiries@elderabuse.org.uk
www.elderabuse.org.uk

A specialist organisation with a focus exclusively on the issue of elder abuse.

Age UK
0800 169 6565 (advice)
www.ageuk.org.uk
www.ageuk.org.uk/cymru (AgeCymru)
www.ageuk.org.uk/northern-ireland (AgeNI)

Aims to improve later life for everyone through information and advice, services, campaigns, products, training and research.

Alzheimer's Research UK
0300 111 5555
enquiries@alzheimersresearchuk.org
www.alzheimersresearchuk.org

A leading dementia research charity.

AT Dementia
0116 257 5017
info@trentdsdc.org.uk
www.atdementia.org.uk

Provides information on assistive technology that can help people with dementia live more independently.

Benefit Enquiry Line (BEL)
0800 882 200
0800 243 355 (textphone)
www.gov.uk/benefit-enquiry-line

Provides advice and information on the benefits you can claim if you're disabled or a carer.

Benefit Enquiry Line Northern Ireland
0800 220 674
0800 243 787 (textphone)
www.nidirect.gov.uk/benefit-enquiry-line

Provides advice on benefits to people in Northern Ireland.

British Psychological Society
0116 254 9568
enquiries@bps.org.uk
www.bps.org.uk

Provides access to a list of clinical and counselling psychologists who offer private therapy services.

Care and Social Services Inspectorate Wales
0300 062 8800
cssiw@wales.gsi.gov.uk
www.wales.gov.uk/cssiwsubsite/newcssiw

The independent regulator of health and social care services in Wales.

Care Quality Commission
03000 616161
enquiries@cqc.org.uk
www.cqc.org.uk

The independent regulator of health and social care services in England.

Carers Trust
0844 800 4361
info@carers.org
www.carers.org

Works to improve support, services and recognition for anyone living with the challenges of caring for a family member or friend.

Carers UK
0808 808 7777
adviceline@carersuk.org
www.carersuk.org

Provides information and advice about caring, alongside practical and emotional support for carers.

Citizens Advice Bureau (CAB)
www.citizensadvice.org.uk
www.adviceguide.org.uk (online information resource)

Citizens Advice Bureau offers free, confidential, impartial and independent advice to help people resolve problems with debt, benefits, employment, housing and discrimination. To find your nearest CAB, use the website above or look in the phone book.

Dementia UK
0845 257 9406 (Admiral Nurse helpline)
direct@dementiauk.org (Admiral Nursing Direct)
www.dementiauk.org

National charity committed to improving quality of life for all people affected by dementia. They provide Admiral Nurses who are mental health nurses specialising in dementia care.

Dementias and Neurodegenerative Diseases Research Network (DeNDRoN)
www.dendron.nihr.ac.uk
http://public.ukcrn.org.uk/search
(UK Clinical Research Network Study Portfolio)

DeNDRoN is part of the National Institute for Health Research Clinical Research Network, supporting research to make patients, and the NHS, better.

Department for Work and Pensions
www.gov.uk/dwp

Government website with details of benefits and pensions, and how to claim them.

Driver and Vehicle Licensing Agency (DVLA)
0300 790 6806
www.gov.uk/contact-the-dvla

Government-funded agency that issues driving licences and vehicle registration documents in Great Britain.

Driver and Vehicle Licensing Northern Ireland (DVLNI)
0845 402 4000
dvlni@doeni.gov.uk
www.dvlni.gov.uk

Government-funded agency that issues driving licences and vehicle registration documents in Northern Ireland.

GOV.UK
www.gov.uk

Online government services and information, replacing Directgov and covering benefits, driving, housing, money and tax, working and pensions.

Law Society
020 7242 1222
contact@lawsociety.org.uk
www.lawsociety.org.uk

The body representing solicitors in England and Wales.

Mind
0300 123 3393
info@mind.org.uk
www.mind.org.uk

Mental health charity that publishes information on all aspects of mental health and provides a range of support through local associations.

NHS Choices
www.nhs.uk
www.nhs.uk/service-search (for local services)
www.nhs.uk/carersdirect (or call 0808 802 0202)
www.nhs.uk/conditions/clinical-trials (guidance on getting involved in health research)

The UK's biggest health website, provides a comprehensive health information service that aims to put people in control of their healthcare.

NHS Direct Wales (Galw Iechyd Cymru)
0845 4647
www.nhsdirect.wales.nhs.uk

NHS Direct service for people in Wales – it provides information in English and Welsh.

NHS 111 service – previously NHS Direct (England)
0845 4647
111
www.nhsuk/111

Information on a wide range of health topics. Telephone service gives access to round-the-clock clinical information, confidential advice and reassurance. NHS 111 (telephone 111) replaces NHS Direct England.

NI Direct
www.nidirect.gov.uk

Official government website for Northern Ireland citizens. Information and services about benefits, driving, housing, money and tax, pensions, health and wellbeing.

Office of the Public Guardian and Court of Protection
0300 456 0300
customerservices@publicguardian.gsi.gov.uk
www.gov.uk/office-of-public-guardian

Provides information and advice on powers of attorney and deputyship. It also helps attorneys and deputies to carry out their duties and protects people who lack mental capacity to make decisions for themselves.

Pension Service
0800 731 7898 (claim line)
0845 606 0265 (general queries)
www.gov.uk/contact-pension-service

Helps with State pension eligibility, claims and payments, including Pension credit.

Regulation and Quality Improvement Authority
028 9051 7500
info@rqia.org.uk
www.rqia.org.uk

The independent regulator of health and social care services in Northern Ireland.

Silver Line
0800 328 8888
info@thesilverline.org.uk
www.thesilverline.org.uk

Supports older people by signposting to services, offering a befriending service to combat loneliness and empowering those who may be suffering abuse and neglect.

Solicitors for the Elderly
0844 567 6173 (for help finding a solicitor)
admin@solicitorsfortheelderly.com
www.solicitorsfortheelderly.com/public/search

An independent, national organisation of solicitors, barristers and legal executives who provide specialist legal advice for older and vulnerable people, their families and carers.

UK Homecare Association Ltd
020 8661 8188
enquiries@ukhca.co.uk
www.ukhca.co.uk

The national association for organisations who provide social care, including nursing services, to people in their own homes.

10 Checklist

Below is a checklist of things you can do after reading this guide. These will help you to live well now and make plans for the future:

1 ☐ Understand more about your diagnosis – for example, the type of dementia you have, and what your drugs are for (if prescribed). (Page 7.)

2 ☐ Talk to others about how you're feeling and ask your GP if there are any therapies or activities that could help you. (Page 31.)

3 ☐ Try some methods to help you to cope with memory loss. (Page 43.)

4 ☐ Introduce exercise to your daily routine and review your diet to make sure it's balanced. (Page 48.)

5 ☐ Organise regular checkups with your GP, dentist, optician and chiropodist. (Page 49.)

6 ☐ Arrange a benefits check for you and your carer. (Page 57.)

7 ☐ Write or update your will and appoint an attorney. (Page 60.)

8 ☐ Tell the DVLA/DVLNI and your car insurer about your diagnosis (if driving). (Page 65.)

9 ☐ Ask social services for a community care assessment and a carer's assessment. (Page 79.)

10 ☐ Get in touch with Alzheimer's Society to find out about local services for you and your carer. (Page 106.)

Order factsheets

How to order

You can view and download (as a pdf) factsheets at **alzheimers.org.uk/factsheets** To order in print, please complete the Factsheets order form.

You can order up to six factsheets free. More than six factsheets are 20p each.

To place an order, please complete the Factsheets order form and send it to:

Alzheimer's Society Publications Orders
PO Box 1504
High Wycombe HP12 9DS

If you have any questions, please call on **0300 303 5933** or email us at **orders@alzheimers.org.uk**

You can make payment by card or cheque.

For organisations

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We can accept purchase orders. To set us up on your procurement system please email **publications@alzheimers.org.uk**

Factsheets order form

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Surname

Address

Postcode

Telephone

Email

Please note that there is a postage and packing charge of £4.95 on every order.

☐ I enclose a cheque payable to Alzheimer's Society.

☐ I would like a pro forma invoice (organisations only).

I would like to pay by: ☐ Visa ☐ Mastercard

Name on card

Card no Security code

Issue date Expiry date Issue no

Signature Date

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Data protection
Alzheimer's Society would like to contact you about fundraising, campaigning and services for people affected by dementia. If you would prefer us not to contact you please call Customer Care on **0845 306 0898** or tick this box before you return your form. ☐
We will not sell your details to third parties. We may need to pass your details to companies, such as printers, authorised to act on our behalf.

Factsheets order form

Item code	Publication title	Quantity	Cost

Alzheimer's Society would like to acknowledge the Department of Health for their support and contribution of funding towards the production and distribution of this guide.

The Department of Health is working with organisations including Alzheimer's Society to go further and faster in improving dementia care, focusing on raising diagnosis rates and improving the skills and awareness needed to support people with dementia and their carers.

Alzheimer's Society would also like to acknowledge the following organisations for their endorsement of this guide:

- The Royal College of Psychiatrists – the professional and educational body for psychiatrists in the UK.
- The Royal College of General Practitioners – a network of more than 45,000 family doctors working to improve care for patients. It works to encourage and maintain the highest standards of general medical practice and act as the voice of GPs on education, training, research and clinical standards.
- The Association of Directors of Adult Social Services – the body that represents all the directors of adult social services in England.

Feedback

We hope that you found this publication helpful. If you have any comments, and in particular suggestions for how it could be improved in the future, please get in touch.

Please write your comments below and send them back to us using the contact details below.

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FREEPOST RTEB-KSER-JZYZ
Alzheimer's Society Publications team
Devon House
58 St Katharine's Way
London E1W 1LB

or email publications@alzheimers.org.uk

Notes

Notes

This booklet has been reviewed by health and social care professionals and people affected by dementia. We would like to thank them for their generous and valued contributions.

It can be downloaded from our website at **alzheimers.org.uk/dementiaguide**

Sources are available on request.

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Alzheimer's Society

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Alzheimer's Society
Devon House
58 St Katharine's Way
London E1W 1LB

020 7423 3500
info@alzheimers.org.uk
alzheimers.org.uk

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