



advice and support for older age

**Independent
Age**

Factsheet

Living with dementia

Being diagnosed with dementia can come as a shock. This factsheet explains more about the different types of dementia and the help available to you to support and maintain your independence. It also contains helpful information about dementia for your family and carers.

Call FREE on **0800 319 6789** Visit **www.independentage.org**

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About Independent Age

Whatever happens as we get older, we all want to remain independent and live life on our own terms. That's why, as well as offering regular friendly contact and a strong campaigning voice, Independent Age can provide you and your family with clear, free and impartial advice on the issues that matter: care and support, money and benefits, health and mobility.

A charity founded over 150 years ago,
we're independent so you can be.

The information in this factsheet applies to England only.

If you're in Wales, contact Age Cymru
(0800 022 3444, ageuk.org.uk/cymru)
for information and advice.

In Scotland, contact Age Scotland
(0800 12 44 222, ageuk.org.uk/scotland).

In Northern Ireland, contact Age NI
(0808 808 7575, ageuk.org/northern-ireland).

In this factsheet, you'll find reference to our other free publications. You can order them by calling 0800 319 6789, or by visiting independentage.org/publications

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1. What is dementia?

There are over 850,000 people in the UK who live with dementia. The term dementia is used to describe the symptoms of a number of different diseases or conditions that cause the progressive decline of your brain. Dementia can often affect your ability to:

- remember
- learn
- concentrate, plan and organise things
- solve problems
- find the right words.

Dementia may also cause:

- confusion about time or place
- depression and anxiety
- personality and behaviour changes
- struggles with daily activities

Sometimes the symptoms of dementia develop slowly, while at other times it can develop suddenly and progress quickly. In either case, the effect on the person living with dementia, their family and carers can be very distressing.

Although dementia is more likely to happen the older you get, it is not a normal or inevitable part of ageing.

At the moment there is no cure for most types of dementia, although treatments and medication are available that can sometimes help slow and manage its progression.

2. Types of dementia

There are many different types of dementia. You can also have more than one type of dementia at the same time, which is sometimes called mixed dementia.

The most common types of dementia include:

- **Alzheimer's disease:** A disease that causes disconnections between nerve cells in the brain and ultimately causes brain cells to die. This leads to a gradual progressive decline in mental ability as the damage can spread to different parts of your brain.
- **Vascular dementia:** Vascular dementia is caused by damage to the blood vessels that carry oxygen to the brain. It can be caused by strokes or by diseases of the small blood vessels in the brain.
- **Dementia with Lewy bodies (DLB):** This is a physical disease of the brain. Lewy bodies are deposits of proteins in the brain. Over time, they lead to a loss of brain tissue and nerve cells.

DLB shares symptoms with Alzheimer's disease and Parkinson's disease and people with DLB may therefore be misdiagnosed. It's important that it is diagnosed correctly as people with DLB can react badly to certain medications.

- **Fronto-temporal dementia:** Fronto-temporal dementia occurs when there is damage to the nerve cells in the frontal and/or temporal lobes in the brain. The brain tissue in these lobes can also shrink, affecting language, personality and behaviour. It can be called frontal-lobe dementia or Pick's disease. Fronto-temporal dementia is rare but most cases are found in people aged 45-65.

Other types of dementia

Rarer causes of dementia can include:

- Creutzfeldt-Jakob disease
- Huntington's disease
- Parkinson's disease
- HIV
- multiple sclerosis
- Korsakoff's syndrome (associated with alcoholism)
- head injuries

More information about the less common types of dementia can be found in the Alzheimer's Society factsheet **Rarer causes of dementia** (0300 222 1122, alzheimers.org.uk).

Mild cognitive impairment (MCI)

Mild cognitive impairment (MCI) is not a type of dementia but if you have MCI you have a higher likelihood of developing dementia. MCI is a set of symptoms that include minor problems with memory, concentration, problem-solving, planning, depth perception, language and learning new skills. Although these symptoms are more than just a normal age-related decline in mental abilities, they will not be severe enough to be counted as dementia. If you think you have MCI, speak to your GP.

3. Symptoms of dementia

Dementia symptoms vary from person to person and will often depend on the type of dementia that you have. Common symptoms include:

- memory loss: you may become more forgetful, particularly about the recent past or people's faces and names
- difficulty with planning: activities that require organisation and planning may become challenging
- language problems: you may find it difficult to express yourself, understand other people or remember certain words or names
- loss of ability to learn new skills: dementia can make it difficult to learn how to use a new piece of equipment, for example
- poor mental health: you may experience depression, anxiety or mood swings
- loss of judgement: you may become less able to judge the risks you face
- orientation problems: you may get lost in familiar places or lose track of the time and date
- vision problems: you may find it harder to see objects if they are a similar colour, struggle to detect movement or have problems with depth perception

As the disease progresses, you may also experience:

- mobility problems: you may find it hard to keep your balance, be more unsteady on your feet and your movement may become slower

- changes to behaviour and personality: depending on the type of dementia you have, this can include becoming more aggressive or losing some inhibitions
- hallucinations and delusions: you may see things and people who are not there, or believe things that aren't true
- difficulties with personal care: you may find it difficult to complete tasks in the correct order and need help preparing meals, washing, dressing and going to the toilet
- incontinence: You may not recognise the need to use the toilet, or be able to locate or use the toilet
- weight loss: You may find it more difficult to eat on your own or swallow. You may also lose your appetite. This can lead to weight loss.

For more information about the common symptoms for different types of dementia, see the NHS dementia guide ([nhs.uk/conditions/dementia](https://www.nhs.uk/conditions/dementia)) or speak to the Alzheimer's Society (0300 222 1122, [alzheimers.org.uk](https://www.alzheimers.org.uk)).

Good to know



Sometimes, dementia-like symptoms can have other causes, such as a chest or urinary infection, dehydration, side-effects of medication, depression, stress or vitamin deficiencies. It's important to speak to your GP if you're worried so they can run tests to find out what might be causing the symptoms.

4. Diagnosis of dementia

If you're worried about your memory or think that you or someone you know may have dementia, speak to your GP. They will be able to investigate the cause of your symptoms.

Sometimes dementia-like symptoms are caused by other treatable conditions, such as depression, thyroid gland disorders or a reaction to certain drugs. It's important that other possible causes are investigated.

Getting a diagnosis as early as possible will help you get the right treatment, care and support, which can help you live independently and well with dementia.

What will your GP do?

It can be difficult to diagnose dementia, so your GP may use a range of tests. This can include:

- taking a medical history – asking you about your symptoms and when changes started to happen
- blood tests
- exercises to test your mental abilities

Your GP may then refer you to a specialist such as a psychiatrist who specialises in the care of older people or a neurologist. They may be based in a memory clinic. The specialist may arrange a scan which will look for evidence of strokes, brain tumour, blood vessel damage or shrinking of brain tissue.

You may need to visit the specialist or memory clinic over the course of a few weeks, or a community psychiatric nurse (CPN) may visit you at home.

If you are diagnosed with dementia, further appointments and tests will be arranged with your GP and/or a specialist.

The appointments might explore appropriate treatments and monitor how your symptoms are progressing.

Good to know



You might want to ask your doctor the following questions.

- What type of dementia do I have?
- What are the tests or investigations I should have?
- How long do I have to wait until I have the tests?
- How long will it take to get the results of these tests?
- What will happen after I get the results?

You can get more advice about getting a diagnosis for dementia from the Alzheimer's Society ([0300 222 1122](tel:03002221122), alzheimers.org.uk).

Ongoing assessment

Dementia is a progressive condition, which means symptoms get worse over time, although the rate at which this happens varies. Your GP should arrange to see you from time to time to see how you're getting on and you may see the specialist again after six months or a year.

An ongoing assessment may be a good time to consider your plans for the future, such as the treatment you might need, your living arrangements and how to manage your finances.

5. Making decisions when you have dementia

If you or someone you know has dementia, you may hear health and social care professionals talk about 'mental capacity'. Mental capacity means having the ability to understand, retain and use information in order to make and express decisions about your life.

If you've been diagnosed with dementia this doesn't automatically mean that you lack mental capacity. However, there may come a time when the progression of your condition means that you're no longer able to make decisions about various things including your finances, health or welfare.

It's a good idea to appoint a trusted person to make decisions on your behalf, should this happen. Getting arrangements in place early can give you peace of mind.

Lasting power of attorney

A lasting power of attorney (LPA) is a legal document giving someone you trust the right to help you make decisions, or make them on your behalf should you lose mental capacity. You must arrange this while you still have mental capacity.

There are two types of LPA:

- Property and financial affairs – which lets someone make decisions about your money and property
- Health and welfare – which lets someone make decisions about your personal welfare and healthcare

To set up a lasting power of attorney, you'll need to complete and register a form with the Office of the Public Guardian (0300 456 0300, gov.uk/power-of-attorney/make-lasting-power). There is a fee to register the LPA but if you receive

certain means-tested benefits or have a low income, you may get help with the cost.

Advance statements and advance decisions

An advance statement lets you explain your wishes for any care you might receive in the future. It's also a way of explaining your beliefs and values, and what would be important to you if you could no longer make decisions for yourself. It can act as a guide to your family and healthcare professionals involved in your care.

An advance decision is a way to refuse certain treatments if there comes a time when you're unable to make or communicate your decision. You could write an advance decision to make sure your doctors and family know what life-sustaining treatments, such as cardiopulmonary resuscitation (CPR) or artificial nutrition, you wouldn't want to receive in certain circumstances in the future. If it is set up correctly, an advance decision is legally binding.

Becoming a deputy

If you care for someone with dementia, you may find you need to make some decisions on their behalf if they can't make them or communicate for themselves. If they haven't already set up an LPA, you can apply to the Court of Protection to become a deputy. This can be a lengthy process so it's a good idea to get an LPA in place while they still have mental capacity, if possible.

You'll need to complete a number of application forms when applying to become a deputy. This will include an Assessment of Capacity form, which requires a GP, psychiatrist, speech and language therapist, social worker or another professional to conduct a formal capacity assessment for the person you would like to become a deputy for.

Contact the Office of the Public Guardian ([0300 456 0300](tel:03004560300), [gov.uk/become-deputy/overview](https://www.gov.uk/become-deputy/overview)) to find out more.

Good to know



For more information about powers of attorney, advance decisions, advance statements and becoming a deputy, see our guide **Planning for the end of life** and factsheet **Managing my affairs if I become ill**.

6. Living well with dementia

A diagnosis of dementia can make people feel they have to stop making plans or taking part in activities but you can continue to have a good quality of life. You may need more support but you can keep doing the things you enjoy for as long as you are able to. There are lots of things you can do that will help you to live well.

Look after your health

It's important to look after yourself, for example by eating a balanced diet, taking regular exercise and following a daily routine. Other illnesses or infections can make your dementia worse so get regular check-ups with your GP and dentist, as well as eye and hearing tests.

If you find you have difficulty with speaking or swallowing, ask your GP or consultant to refer you to a speech and language therapist. They can advise on exercises, diet and medication that may help.

Technology can also help you to manage your condition. Telehealth devices can monitor your health or remind you when to take medication, for example. Ask your GP for more information or see our factsheet **Technology to help you at home**.

Good to know



Depression can sometimes be difficult to diagnose when someone is living with dementia. Speak to your GP if you think you might be depressed. They may prescribe antidepressants or refer you for a talking therapy, such as counselling. Read our guide **Dealing with depression** to find out more.

Stay active

Being active can keep you in touch with people and help you to stay independent. Taking regular exercise is good for your physical and emotional wellbeing. Walking, swimming, dancing, tai chi and yoga are all good activities and some centres offer sessions tailored for older people or people living with dementia. Some exercises such as chair aerobics can be done at home.

Staying active isn't just about physical exercise. There are many other activities you could enjoy, such as gardening, arts and crafts, cooking, visiting the theatre or a museum, and going on day trips or on holiday.

There are also activities specifically for people living with dementia, such as 'singing for the brain' groups or memory cafés, where people with dementia and their carers can socialise and share experiences. You can find information about local groups on Dementia Connect (alzheimers.org.uk/find_support_near_you) or contact the Alzheimer's Society (0300 222 1122, alzheimers.org.uk).

If you drive

You must inform the Driver and Vehicle Licensing Agency (DVLA) about your diagnosis. Call them on [0300 790 6806](tel:03007906806) or visit gov.uk/dementia-and-driving. The DVLA will send you a questionnaire and speak to your GP or consultant. Some people may also be asked to take a driving assessment. You may not have to give up driving straight away, as long as it's safe for you to continue driving.

You must also tell your car insurance provider about your diagnosis. If you don't, your policy may become invalid.

Read our guide **Behind the wheel** for more information on driving safely and reporting a medical condition.

Make your home dementia-friendly

Staying in familiar surroundings can sometimes help you live independently for longer and there are things you can do to make your home safe and comfortable. For example, you could:

- improve the lighting in your home
- remove anything that could cause you to trip, such as loose rugs or trailing wires and clutter
- if you haven't already, install alarms such as smoke and carbon monoxide detectors
- use bright and contrasting colours so you can see things more clearly, for example a different coloured toilet seat may be easier to see
- label cupboards and drawers so you know what's inside. Open shelves can also make it easier to find things.

For more information, see Age UK's guide **At home with dementia** (0800 169 6565, ageuk.org.uk).

An occupational therapist can offer advice and support to make living in your home easier and safer (see chapter 7). Contact your local council's adult social services department and ask for an occupational therapy assessment.

If you live alone

Living alone can be challenging but with support and help you may be able to stay in your own home for a long time.

- Plan ahead – ask your local adult social services for a care needs assessment to consider help with personal care, housework and shopping, and day care. Our factsheet **First steps in getting help with your care needs** has more information.

- Talk to your family, friends and neighbours about whether they can help with any tasks or transport.
- Leave a spare set of keys with someone nearby who you trust.
- Keep in touch –use social media such as Facebook and Skype or join groups such as a local memory café.
- Keep a list of emergency numbers near your telephone where you can find it easily.
- Make sure your home is safe – there is lots of technology that can help, such as automatic lights and shut off devices that turn off a cooker or a tap if they've been left on. You can find out about assistive technology and telecare from atdementia.org.uk.

7. What help is available for people with dementia

Living with dementia can cause stress, financial hardship and a sense of isolation. It's important to get as much support as possible.

Support from the NHS

If you have symptoms of dementia, your GP can refer you to the local hospital's psychiatrist for older people or a local memory clinic. If you're diagnosed with dementia, the psychiatrist will advise you about medication that might help to control the condition or slow down its development. Day hospitals and day centres may provide follow up support. You may also receive other services, such as:

- support from a community psychiatric nurse (CPN) or Community Mental Health Team for advice, specialist care and/or treatment
- talking therapies such as counselling, Cognitive Behaviour Therapy (CBT) or psychotherapy to help you deal with the diagnosis, or treat depression or anxiety
- Cognitive Stimulation Therapy, which can help keep your mind active. It involves doing themed activity sessions in a group over several weeks
- an Admiral Nurse – a nurse specialising in dementia who can offer practical advice and emotional support, and be a single point of contact for health services. Find out if you have one in your area by contacting Admiral Nursing Direct ([0800 888 6678](tel:08008886678), dementiauk.org)
- home visits from district nurses for nursing care, such as changing dressings or giving medication

- speech and language therapy to help with swallowing or communication difficulties.

Talk to your GP if you're interested in any of these services.

If you have complex health and care needs, the NHS may be able to fully cover the cost of your care at home or in a care home. This funding is called NHS Continuing Healthcare and, if you're assessed as eligible, is arranged by your Clinical Commissioning Group (CCG). For more information, see our factsheet **Continuing Healthcare - should the NHS be paying for your care?** or call our Helpline ([0800 319 6789](tel:08003196789)).

Support from your council

If you may need some additional care and support, you have a right to a care needs assessment from the adult social care team at your council. A care needs assessment will look at how you manage every day activities, such as washing and dressing, cooking, doing household tasks and getting out and about. It works out what help you need, what you're eligible for and how you might get it. This could include support services such as personal care at home, meals at home, day centres.

For more information about getting a care needs assessment, see our factsheet **First steps in getting help with your care needs**. To find out about services you may be able to receive, see our factsheet **Getting care services at home**.

You may also receive other services, such as an occupational therapy assessment to help you stay as independent as possible. An occupational therapist can:

- advise you on ways to complete daily activities you're finding difficult such as dressing, bathing and doing your favourite hobbies
- improve your home safety by advising you on safety devices and alarms

- arrange equipment or adaptations that can keep you independent at home. For more information, see our factsheet **Adapting your home to stay independent**
- advise any carers you have on ways to support you, for example by encouraging you to keep doing household activities and showing them how to use reminiscence and life story work to share memories.

You may also receive telecare, which is technology-based equipment such as pendant alarms to call for help if you fall or medication reminders that sound an alert when it's time to take a tablet. For more information, read our factsheet **Technology to help you at home**.

If you're caring for someone with dementia, see chapter 11 for the help you may be eligible for.

Independent advocacy

If you're living with dementia and decisions need to be made about your health or care, you may benefit from the support of an independent advocate. This is someone who can help you express your opinions, understand and explore your choices and make sure your rights are being upheld.

Under the Care Act 2014, councils must provide an independent Care and Support Advocate if you have substantial difficulty in being involved in assessments and decisions about your care, and you don't have someone like a friend or family member to support you.

Even if the council doesn't have a duty to provide you with an independent advocate, you can still arrange one for yourself. An independent advocate may be particularly helpful if there's a conflict of interest, such as a dispute among family members as to the best care for you, or a disagreement with the council about care decisions.

An independent advocate can try to establish your wishes and needs and represent your points of view to the professionals involved. For more information, see our factsheet

Independent advocacy.

Support from the voluntary sector

Many charities and voluntary organisations provide services such as advice, advocacy or social activities to support people with dementia and their carers.

If you have received a diagnosis of dementia, you may want to take a look at the following organisations:

The Alzheimer's Society (0300 222 1122, alzheimers.org.uk)

Provides help and support to people living with dementia and those caring for them. They produce a wide range of guides on dementia, and have a national helpline offering specialist advice. They have a network of local branches which offer a range of services, such as dementia advisers, and advice and support groups for carers.

They also have an online directory of services for people living with dementia at alzheimers.org.uk/find_support_near_you. Your area might have choirs, church services, film screenings, yoga or exercise classes, cycling groups and many other activities designed especially for people living with dementia.

You could also speak to your local library or council adult social care team about local support.

Dementia UK (0800 888 6678, dementiauk.org)

Offers specialist support through their Admiral Nurse helpline. They work with people with dementia and their carers and families to provide specialist practical and emotional support.

Age UK (0800 169 6565, ageuk.org.uk)

A national organisation with local Age UKs that often provide services such as good neighbour schemes, handyperson and gardening services, lunch clubs and advice services. Contact the national office for details of your local Age UK.

8. Financial support for people with dementia

If you're living with dementia, you may have extra expenses, such as paying for care, so it's important to make sure you're receiving all the benefits you're entitled to.

Disability benefits: Attendance Allowance and Personal Independence Payment

While you won't usually qualify automatically for a disability benefit just because of your condition, if you have personal care needs or require supervision you may be eligible for help.

Attendance Allowance is paid to people who need help with personal care such as washing, dressing and going to the toilet, or who need supervision to avoid putting themselves or others in danger. This benefit is not means-tested. You must have reached State Pension age to make a claim.

People under State Pension age can make a claim for Personal Independence Payment (PIP). This has replaced Disability Living Allowance (DLA) for new claimants. You cannot claim PIP or DLA at the same time as Attendance Allowance.

If you're terminally ill, your application can be fast-tracked and paid at the highest rate. You need to be expected to live for no more than six months. Speak to your GP about supporting your claim if you think this could apply to you.

Good to know



If you receive Attendance Allowance or DLA/PIP, you (or the person responsible for paying the council tax) may be able to get a reduction in your council tax bill.

For more information, see our factsheet **Council Tax Support and Housing Benefit**.

For more information about these benefits, see our factsheets **Attendance Allowance** and **Personal Independence Payment and Disability Living Allowance**.

Getting more from your Pension Credit

If you receive Guarantee Credit, you might be eligible for extra money if you have a severe disability. You may qualify if:

- you also get PIP daily living component at either rate, Attendance Allowance at either rate, or DLA at the middle or higher rate of care
- nobody is getting paid Carer's Allowance for looking after you, and
- you live on your own (except in some specific circumstances). Some people are still considered to be living alone for the purposes of the severe disability addition even when someone is living with them. For example if the other person is blind, or a young person that they get child benefit for.

For more information, read our factsheet **Pension Credit** or call us on [0800 319 6789](tel:08003196789).

Good to know



If you don't receive Pension Credit, but the other criteria outlined above apply to you, you could get extra help with:

- your rent (if you get Housing Benefit)
- your council tax – in addition to the reduction you might already get if you receive Attendance Allowance, Disability Living Allowance or Personal Independence Payment (see section above about disability benefits).

Ask your local council if a reduction in what you pay has been included.

You can use our online benefits calculator to see if you could be entitled to any extra money (independentage.org/benefit-calculator) or call our helpline on 0800 319 6789 to arrange a free benefits check.

Claiming benefits

Some benefits forms can be long and complicated so it's a good idea to get help and advice to complete them, for example from your local Citizens Advice (03444 111 444, citizensadvice.org.uk).

There may be questions about activities you find difficult or impossible to carry out. When you're thinking about the help you need, consider the bad days as well as the good.

Certain benefits can start on the day you first call the relevant office, so don't delay making a claim even if you don't have all the information you need. You can always supply the additional information later.

Keep records of any contact you have with benefits offices, including the names of people you speak to.

If you're turned down for a benefit, you can challenge the decision. There is usually a time limit. Get advice from your local Citizens Advice or the local council's welfare rights unit. You might want to call the Alzheimer's Society National Dementia Helpline for guidance (0300 222 1122, alzheimers.org.uk).

Looking after your benefits

You may need practical support with managing your finances. If you're getting benefits but can't manage the money yourself, it's possible for you to arrange for someone else that you trust

to collect the money from your bank account. Your bank or building society can arrange this if you write to them.

If you lose mental capacity and haven't set up a lasting power of attorney (see chapter 5), you can apply for someone else, known as an appointee, to manage your benefits for you. This will usually be a close friend or relative, but could also be a representative from an organisation, such as a solicitor or someone from your local council. Find out more at gov.uk/become-appointee-for-someone-claiming-benefits.

Who you phone depends on the benefit:

Attendance Allowance	0800 731 0122
Disability Living Allowance	0800 121 4600
Personal Independence Payment	0800 121 4433
Pension Service (for State Pension)	0800 731 0469

For all other benefits, contact your local Jobcentre Plus.

If you receive Housing Benefit or Council Tax Support, contact your local council.

For more information and advice about benefits, call our Helpline (0800 319 6789, independentage.org).

9. Suitable accommodation for someone with dementia

While many people with dementia can live at home for a long time, there may come a time when you will need to move into different or specialist accommodation.

Sheltered housing and extra care schemes

In some areas, sheltered or extra care housing schemes have been set up to provide accommodation and support for people living with dementia. You have the independence of your own home with a bit more on-site support from wardens or carers.

For more information on housing options see our guide **Choosing where to live** and our factsheet **Sheltered housing and extra care housing**. You can also contact your local council or the Elderly Accommodation Counsel (housingcare.org).

Care homes

Many residential care homes or nursing homes cater specifically for the needs of people with dementia. You can get a list of local dementia care homes from the CQC website (cqc.org.uk) or from the Elderly Accommodation Counsel (housingcare.org). The Alzheimer's Society can also provide you with a list of specialist care homes ([0300 222 1122](tel:03002221122), alzheimers.org.uk).

Good to know



You can read the past inspection reports of care homes in England by contacting the Care Quality Commission ([03000 61 61 61](tel:03000616161), cqc.org.uk).

Looking at these reports may help you choose a care home. It may be possible to have a trial stay at the care home to see if it would be suitable.

To do



If you care for someone living with dementia and think they need to move into a care home, contact their local council to request a needs assessment. If they are assessed as needing to go into a care home, they'll also have a financial assessment to decide how much they'll have to pay towards their care home fees. For more information, see our factsheet **Paying care home fees**. You might also find our guides **How to find the right care home** and **Settling into a care home** useful.

10. Dementia and the Mental Health Act

Occasionally, a person with dementia may behave in such a way that it puts themselves or those around them at risk. If this occurs, it may be necessary for them to be hospitalised while they are assessed or treated. They can voluntarily attend in-patient hospital treatment, or can be compulsorily detained under a section of the Mental Health Act against their wishes. You may have heard this called 'being sectioned.'

If you think someone living with dementia is putting themselves or others at risk, contact the local mental health team, your GP or call the emergency services if the situation is urgent. You may also find it helpful to read the Alzheimer's Society's factsheet **The Mental Health Act 1983 and guardianship** to find out more ([0300 222 1122](tel:03002221122), alzheimers.org.uk).

Good to know



If you've been hospitalised under certain sections of the Mental Health Act, you may be eligible for free help and support after you leave hospital. These are called Section 117 after-care services and they may include healthcare, care services or residential care.

Speak to a nurse, social worker or other NHS or social services professional to find out more. If you need more information and advice, contact our Helpline and arrange to speak to an adviser ([0800 319 6789](tel:08003196789), independentage.org.uk).

11. Caring for someone with dementia

There are over 700,000 people in the UK caring for someone living with dementia.

Caring for someone with dementia will often have a big impact on your life. You may feel resentment, frustration, anger and guilt. These feelings are normal and it's important to remember there's no right or wrong way to feel. You may find your caring role also brings rewarding and positive moments.

Getting practical support

Anyone who cares for a friend or relative and may need support has a right to a carer's assessment from their local council. It doesn't matter how much care you provide to someone – if you feel that you could benefit from some support, you're entitled to an assessment.

The assessment will look at whether you are willing and able to continue your caring role, what impact your role has on your wellbeing and what things you would like to do in your day-to-day life. It will also look what support you may need to continue caring.

If you qualify for help, the council could consider support in a range of areas such as:

- 'replacement care' for the person you care for, so you can have breaks from caring during the day or throughout the year
- practical help with things such as housework or gardening
- support to improve your health and wellbeing, such as gym membership

- training to feel more confident in your caring role, such as moving and handling training
- emotional support, from a local carers group for example

You may also be entitled to a benefit called Carer's Allowance.

For more information, see our guide **Caring for someone** and factsheet **Carer's Allowance**.

Getting emotional support

It's important that you look after your emotional wellbeing and mental health. If you're feeling low, anxious or stressed, consider talking to someone about how you're feeling, such as a friend, family member or your GP.

It may help to speak to people who are in similar circumstances to you. Carers UK ([0808 808 7777](tel:08088087777), carersuk.org) provides advice and support to carers. It also runs support groups where you can talk to people in similar circumstances.

The Alzheimer's Society has an online support forum called Talking Point (alzheimers.org.uk/talkingpoint). Their local dementia advisers can also offer practical and emotional support ([0300 222 1122](tel:03002221122), alzheimers.org.uk).

12. Practical tips for caring for someone with dementia

Communicating with someone who has dementia

Sometimes it can be difficult to communicate with someone who has dementia because they can get confused or they are unable to clearly express what's on their mind. There are simple things that you can do that may help, such as making sure that any hearing aids, glasses or dentures they have are working properly.

Speak clearly and slowly to the person with dementia rather than raising your voice. Alternatively, they may find it easier if you write down what you want to say. Offering simple choices rather than leaving questions open-ended can also be effective.

The Alzheimer's Society has a factsheet called **Communicating** which has more detailed advice ([0300 222 1122](tel:03002221122), alzheimers.org.uk).

Past memories

Talking about the past can be a valuable experience for both you and the person living with dementia. Although dementia is responsible for memory loss, for many people it is usually short-term memory that is most severely affected.

Reminiscence therapy focuses on older memories and it can be comforting for both of you to talk about the past and share experiences. Using old photographs, postcards, music and even visits to places, can help with this. However, in some circumstances, recalling memories can cause distress. Call the Alzheimer's Society for advice ([0300 222 1122](tel:03002221122), alzheimers.org.uk).

Helping with personal care

Someone living with dementia may need reminders or help to carry out personal care tasks such as washing and drying or getting dressed. If possible, encourage them to do as much as possible for themselves.

For example, laying out clothes in the right order can make it easier for a person living with dementia to dress themselves. Slip-on shoes and easy-fastening clothes (such as those with Velcro instead of buttons) can make dressing easier. Try to support them to choose what they want to wear.

It may feel difficult or inappropriate for you to supervise or wash the person with dementia. If so, speak to the council to request a needs assessment and ask about the possibility of a carer to help with bathing. See our factsheet **First steps in getting help with your care needs** for more information.

Eating

Some people living with dementia lose their appetite or find it difficult to use cutlery or swallow food. Eating may be easier for them if the table is laid simply with just one set of cutlery, for example. You can also buy specially designed cutlery to make eating easier. The Disabled Living Foundation ([0300 999 0004](tel:03009990004), livingmadeeasy.org.uk) has information on different types of aids to help you eat and where you can get them.

If the person with dementia has problems swallowing, ask their GP for a referral to a speech and language therapist who specialises in swallowing problems. You should also ensure their dentures are fitted correctly, if they wear them.

People living with dementia may also get restless or distracted during meal times. Meals should be unhurried and made at the same time each day. Avoid distractions, such as having the TV on or people coming and going during meal times. The person

with dementia may need to be prompted to eat, but don't put pressure on them if they're getting distressed.

Continence

Incontinence can be a problem for someone living with dementia. It's always important to check first that a treatable medical condition isn't causing the incontinence by speaking to their GP. Their GP may refer them to a local continence advisor or service. There are a number of aids available to help with incontinence, such as washable absorbent bed pads and incontinence pads which are available free from the NHS. You can get information and advice from the Bladder and Bowel Community's medical helpline ([0800 031 5412](tel:0800 031 5412), bladderandbowel.org).

Walking

It's quite common for people living with dementia to walk around or try and leave a room or their home. This can happen when they are motivated to start something or go somewhere but can't remember what they intended to do. They may also be bored, restless or trying to keep up an older routine, such as walking to work or taking the children to school.

These symptoms may be worrying for the carer, especially if the person tries to leave their home. It may help to understand that they may be searching for something rather than simply walking aimlessly. It may also help to make sure they go on regular accompanied walks or take other forms of exercise. The Alzheimer's Society ([0300 222 1122](tel:0300 222 1122), alzheimers.org.uk) can offer further advice on wandering.

Changes in behaviour

As the dementia progresses you may notice changes in the behaviour of the person living with dementia. This will vary from person to person but may include pacing or fidgeting,

following you around, putting things in unusual places, or increased agitation or confusion in the late afternoon or evening, known as 'sundowning'.

Try to work out if there are any triggers or patterns to the behaviour, such as time of day or environmental factors like heat or noise. It can be helpful to keep a record. If the behaviour causes distress, seek help from their GP or any specialist involved in their care, such as a community psychiatric nurse (CPN). In some cases, there could be a medical or physical cause such as pain or an infection.

Aggressive behaviour

Some people living with dementia show aggressive behaviour, either verbal or physical. This is a symptom of the disease, which can appear or disappear at any stage of the illness. Aggressive behaviour may be a reaction to something they feel frightened about. They may also be anxious or bored. Their GP, psychiatrist or community psychiatric nurse (CPN) may be able to advise and help you manage aggression or agitation.

For more information, see the Alzheimer's Society factsheet **Changes in behaviour**. They can also provide advice on challenging behaviour and dealing with aggression ([0300 222 1122](tel:03002221122), alzheimers.org.uk).

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