

Living with dementia

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Over 850,000 people in the UK currently live with dementia*. Most are over 65, but it is also becoming more common in those aged 50 or over. There is no doubt that a diagnosis of dementia is life changing, and potentially very challenging for sufferers and their families to deal with day to day.

Happily, there are ways in which people with dementia can live healthy and productive lives, especially if they have the right help and support in place. This guide offers information on how to eat, sleep and exercise well, as well as on socialising, relationships and the best ways to communicate with someone with dementia. Organisations such as the Alzheimer's Society offer some helpful tips for how to do this.

Day-to-day life

If you or a family member has been diagnosed with dementia, you are no doubt concerned about how this will affect day-to-day life. You may already have noticed physical or behavioural changes in yourself or your loved one.

Although dementia is a progressive condition, and there is no cure, there are many ways that you can help yourself or someone else to maintain the best quality of life for longer.

**Source: Alzheimer's Society*

Eating and drinking

It is really important that people with dementia maintain a healthy diet and are sufficiently hydrated.

Sometimes they become unable to recognise that they are thirsty, or simply forget to drink. Dehydration can increase confusion, cause headaches and even lead to constipation and urinary tract infections which, in themselves, can make the symptoms of dementia worse.

Similarly, people with dementia often lose weight. This may be because they no longer recognise when they are hungry, find preparing meals difficult or may even forget how to cook. In the later stages, many people also develop chewing and swallowing problems.

A dietician or nutritionist can recommend ways to maintain a healthy, balanced diet and also eat and drink safely and enjoyably, such as:

- **Develop consistent meal routines** and eat at the same time each day. Try not to rush meals and, if you are caring for someone with dementia, offer gentle reminders to eat if they are struggling.
- **Choose easy-to-eat foods** that you know they enjoy, offering choices where you can.

- **Check kitchen cupboards** to ensure that cleaning fluids, pet food and packeted items like sugar are safely out of reach because dementia causes confusion about what is good and safe to eat and drink.

Exercise and activity

Regular exercise is as important for someone with dementia as it is for anyone else. Many dementia sufferers continue to enjoy activities such as gardening or walking, while gentle exercise like tai chi can be very beneficial, too.

Dancing and singing, particularly in groups, are good forms of exercise and help to maintain a social life and the all-important connections with people – both for the person with dementia and their carers.

Sleep

It is very important that someone with dementia gets enough sleep. Dementia can disrupt sleep patterns, resulting in wakefulness during the early hours of the morning and daytime sleeping.

To maintain a healthy pattern with good-quality sleep, try the following:

- Avoid daytime naps where possible
- Avoid caffeinated drinks and alcohol during the evening

- Turn off screens (computers, tablets and phones) at least two hours before bedtime
- Try to establish a regular routine, going to bed at the same time each night

Staying socially active

Dementia often causes behavioural and personality changes, threatening social situations, and even close personal relationships. Sufferers may avoid social interaction because they are worried about the embarrassment of not being able to remember people or behaving in a way that is unusual for them.

Having said that, keeping in touch with people and taking part in social activities is really important because it can boost confidence and overall wellbeing. It is also beneficial for carers who can easily become isolated, too.

Many activities involving other people, such as group walking or singing in a choir, are particularly good if you have dementia. Happily, up and down the country there are many dementia-friendly groups where you can meet people in a similar situation and share tips and experiences.

To find out about dementia-friendly activities in your area, visit:
www.alzheimers.org.uk/find-support-near-you

Dementia and relationships

Dementia affects every aspect of a person's life, including their relationships. If you are caring for someone with dementia, your relationship with them will alter, particularly if their condition results in changes to their personality and behaviour.

If you are suffering from dementia yourself, you will also probably find shifts in your own relationships with people around you.

Although the experience of dementia is different for everyone, its impact on relationships is often very difficult to cope with, especially at first. But, with help and support, relationships can remain positive and caring whatever happens.

Telling people about your dementia

Receiving a diagnosis of dementia is difficult to deal with personally, and you may also struggle with how, what and when to tell people. Actually, you do not have to say anything until you are ready.

The news may mean that some people treat you or your relative with dementia differently. This is usually because they have very little understanding about what dementia is, or they are fearful about what it means for the relationship.

If you are the dementia sufferer and are breaking the news to family and friends, be honest with them about what is difficult for you here and now. If they understand that you struggle with certain activities

or with remembering conversations, it will help them to help you now – and going forward.

Your GP or dementia support worker can also help you decide how and when to tell people.

For further information about these and other types of dementia, visit: www.alzheimers.org.uk/about-dementia/types-dementia



One of the first signs of dementia is memory loss. Someone may become forgetful about what they are doing or start to lose things. This can be immensely confusing and distressing.

Whether you are coping with dementia yourself, or caring for someone else, there are some simple ways to make life easier:

- Establish a regular routine. Many people with dementia find routines comforting, and as the condition progresses and the changes become more challenging, these can offer a real safety net.
- Put a weekly timetable on the kitchen wall or fridge door, and try to schedule activities for the time of day when you/they generally feel best.
- Keep keys in an obvious place, such as a key box or a large bowl in the hall.
- Keep a list of helpful numbers (including who to contact in an emergency) by the phone.
- Put regular bills on direct debits so they do not get overlooked.
- Use a pill organiser box (dosette box – available from most pharmacies) to help you remember which medicines to take when.
- Get involved with local dementia-friendly groups and activities. They will offer lots of support and advice, helping to maintain a social life and reducing feelings of isolation for dementia sufferers and their carers.

If you are looking after someone with dementia, you may need help with personal care (washing, dressing, dental care and dealing with incontinence), making sure they are eating and drinking enough and exercising safely.

Encouraging people with dementia to be independent and look after themselves for as long as possible is vital but, as the condition progresses, such daily (and often very private) activities may become difficult. It can be hard to adjust to needing help, so it is important to respect their choices and treat them with sensitivity and tact.

In the early stages of dementia, it helps to encourage the person to keep to their regular daily routines for as long as possible. If they can no longer manage personal tasks, such as washing and dressing on their own, they may feel that receiving help from a professional carer is more dignified than relying on their spouse or child.

If you are arranging care, do think about their preferences. Would they be more comfortable with a same-sex carer, for example, or someone from the same cultural background?

If you are caring for someone with dementia yourself, the following tips can help you to maintain their dignity:

- Whatever you are doing, break the process down into small stages. People with dementia often find it hard to deal with lots of information at once.
- Being organised helps things to go more smoothly.
- Involve them in making decisions and give them simple choices. Do they prefer a bath or a shower? This soap or that shower gel?
- Deep baths can be intimidating for someone with dementia, so help them to feel safe by keeping the water shallow or setting up a bath seat. The cascade of water from an overhead power shower can be alarming, too, so they may find a hand-held shower attachment more pleasant.
- Remind them, gently, what they should be doing at each stage if they seem to be struggling.
- Offer practical but non-intrusive help, like handing them their toiletries or passing them a towel.
- If they are self-conscious about being undressed in front of you, try keeping them covered as much as possible and only uncovering the part of their body that you are washing at the time.
- Make the process as enjoyable as possible – ensuring that the room is warm enough, while using pleasant-smelling toiletries helps to make the process feel more luxurious.
- Offer encouragement as often as you can.

What if you need support?

The Alzheimer's Society website has some helpful and detailed online guides for people caring for someone with dementia:
www.alzheimers.org.uk/get-support/daily-living

Advice

Washing and bathing

Find out why washing and bathing can become difficult for people with dementia, and get practical tips for helping a person to wash.

Advice

Dressing

This information for carers contains tips for helping a person with dementia to dress and advice on how to make dressing a positive experience for them and for you.

Advice

Dental care

This information describes some of the dental problems that people with dementia may face at different stages and methods for treatment and prevention, including maintaining good oral health and wearing dentures.

Advice

Eating and drinking

People with dementia often experience problems with eating and drinking. These web pages describe the most common challenges and why eating healthily is important.

Advice

Urinary tract infections and dementia

Urinary tract infections (UTIs) are a type of infection common among older people. If a person with a memory impairment or dementia has a UTI, this can cause sudden and severe confusion known as 'delirium'.

Advice

Sex, intimacy and dementia

Dementia causes many changes in people's lives, including changes to sex and intimate relationships. Here we explain how dementia can affect the sexual feelings, desires and needs of people with dementia and their partners.

Advice

Toilet problems and continence

Read our guide to toilet problems and incontinence, including causes, solutions and how this might affect a person with dementia.

Advice

LGBT: Living with dementia

If you are lesbian, gay, bisexual or trans and have dementia, this page is for you. In it we explain how you can live well with dementia.

Advice

Physical activity and exercise

Leading a physically active lifestyle can have a significant impact on the wellbeing of people with dementia.

Advice

Your relationships: How might

Advice

Staying healthy with dementia

Advice

Some people with dementia, and their carers, are entitled to have their care and support needs met by the local authority, either free or at a reduced cost. This can cover extra help or any adjustments that might need to be made to your home.

A care needs assessment will look at someone's current arrangements for living and care, what they can do and what they find difficult, and their preferences about how they would like to be supported. It will also take into account any concerns that their a carer may have. The needs assessment is free, and anyone can ask for one. Once assessed, the council may be able to recommend services such as:

- personal equipment like a walking frame or alarm
- changes to your home, like a walk-in shower, grab rails and raised toilet seats
- help from a paid carer
- access to day centres
- help with moving to a care home

Requesting a care needs assessment

You can apply for a care needs assessment via the government website, or via your GP (or your relative's GP if you are a carer).

If you would rather speak to someone, you can also find the contact details for your local authority at www.gov.uk/apply-needs-assessment-social-services

Usually, a social worker or occupational therapist will phone or visit you to ask questions about how you or the person with dementia is managing with things like washing, dressing and cooking. They might ask for a description or demonstration of how well you manage.

The assessment is your opportunity to have your say about the help you need, so it is vital to include everything, even if you are not sure that it is important. These details ensure that the care plan matches your needs as closely as possible.

Preparing for a care needs assessment

Whether the assessment is for you or for a relative, it is a good idea to sit down with a relative, friend or carer and make a list beforehand to help you remember everything you wish to say.

Think about all aspects of your life – personal care, washing and going to the toilet, preparing and eating meals, going shopping and your social life. Some people find that it helps to keep a diary for a few days beforehand, noting down what they can do alone without help, what they need help with and what they can no longer do at all.

Your needs will be measured against your local authority's needs criteria. These vary between local authorities, and are published on their websites, so have a look at them and try to use the same words to describe your needs, where possible.

Remember that the person doing the assessment will only be able to consider 'presenting' needs – that is those that are mentioned or apparent during the assessment.

So do not be tempted to leave out any of your difficulties, even if you find them embarrassing. Your assessor is a professional who understands your difficulties, but they need to know everything if they are to put in place the help you really need.

Having a friend or relative with you during the assessment is also a good idea. They can help if you struggle to explain the situation, take notes if you find it hard to remember or follow what is said, and mention things you might forget. If there is no-one who can do this for you, you could use an advocate. These are people who will sit in meetings with you and/or help you to fill in forms.

For more detailed information about how to access support, and arrange and prepare for a care needs assessment, click:

www.alzheimers.org.uk/get-support/legal-financial/assessment-care-support-england

When preparing for a needs assessment, check out this very useful Which? guide at

www.which.co.uk/later-life-care/carers-and-caring/needs-assessment/preparing-for-the-needs-assessment-aydxs7j47udr

To find an advocate, visit:

www.nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/someone-to-speak-up-for-you-advocate

People with dementia often have trouble with communication, especially as the condition progresses. In some forms of dementia, language problems are among the first obvious symptoms.

They may begin having difficulty remembering the right words, often substituting different words or phrases ('thing you sleep on' for 'bed' for example) or they might start to repeat words and phrases. As their ability to use language deteriorates, they may also behave in ways that seem strange, as they try to find other ways to communicate.

Sight and hearing problems add to the difficulty in communicating, and can make sufferers feel isolated or nervous. Happily, there are ways of making communication easier for someone living with dementia.

Preparing for a conversation with someone with dementia:

- For important conversations, choose a time of day when they are usually at their freshest and best.
- Find a quiet place to talk, without the distraction of a TV or radio, and with good lighting.
- Make sure the person can see your face easily, and try to be on their level rather than standing over them.
- Sit close to them (though not within their personal space), get their attention and make eye contact.
- Keep your body language open and relaxed.

- Take your time.
- Ensure that they are comfortable, and not hungry or in pain.

Talking to someone with dementia

- Speak slowly, clearly and calmly – in short sentences.
- Allow them time to process the information and then respond.
- Avoid raising your voice or speaking sharply.
- Try to maintain a conversation, rather than just asking endless questions which could make them feel interrogated.
- Keep the conversation simple, with one idea at a time.
- With questions, offer choices, but with a 'yes' or 'no' answer. For example, instead of asking what they would like to drink, ask "would you like a cup of tea?".
- Avoid speaking to them as though they are a child, and never talk about them as if they are not there.
- If they do not understand you, rephrase rather than repeating.
- Do not laugh at them but try to use humour, if possible, to distract attention from misunderstandings or mistakes.
- Use non-verbal communication where possible – like pointing at something.
- Try to include them in conversations. This is important for their sense of value and identity, and it can also ease feelings of isolation.

For more information about communicating with someone who has dementia, click here:

www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/symptoms/tips-for-communicating-dementia



This leaflet is part of a series designed to help people understand more about dementia – the different types, getting and living with a diagnosis, experiencing a full life with dementia and how to find the best dementia care for you or a loved one.

Visit our resource library for our other leaflets:
www.canfordhealthcare.co.uk/library

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