A Carers Guide to Dementia
For Unpaid Carers of all Ages
About this booklet

This booklet is for you if you care for a family member, friend or neighbour who you think is showing signs of dementia or for someone who has already received a diagnosis. It will help you to understand more about dementia and how to support the person you care for including: how to get help, what to expect as dementia progresses, finances and legal matters, your rights as a carer and the importance of looking after yourself.

This booklet is written for carers that support someone with dementia in Wales. However, a lot of the information within this guide will be useful wherever the person you care for lives.

Although this booklet is mainly written for carers aged 18 and over, it also contains information that maybe useful for carers who are under 18. It is important that young carers have access to appropriate information and support. See the Information for young carers on page 25 and Useful contacts section on page 27 for more details.
Understanding dementia

Dementia affects one in nine of us and is not a natural sign of ageing. It is caused when the brain is damaged by diseases, or a series of strokes, causing brain cells to die. There are over 100 causes of dementia (most of which are very rare). It is possible to have more than one kind of dementia at the same time. Different types of dementia cause damage to different parts of the brain and therefore have different symptoms.

The most common forms of dementia are Alzheimer’s disease, vascular dementia, frontotemporal dementia (or Pick’s disease) and dementia with Lewy bodies. Depending on which brain cells are damaged, symptoms may include: problems with memory, reasoning, understanding, language and behaviour.

Dementia is progressive, which means symptoms gradually get worse. Although medicines and complementary therapies can help alleviate symptoms, currently there is no cure. However, there is a lot of support available to help you and the person you care for live as well as possible, for as long as possible.

In the UK, two thirds of people with dementia live independently in the community, with most of their care and support provided by family and friends.

Who can be affected by dementia?

• Dementia usually affects people aged 65 and over.

• Dementia can also affect people between 20–65 years, this is known as young onset dementia and accounts for about 5% of people with dementia.

• Young onset dementia is more common in people with learning disabilities, especially Down’s syndrome, where Alzheimer’s can affect one in three people by the age of 50.

• People from black, Asian and minority ethnic communities have higher rates of dementia, particularly vascular dementia. This is thought to be due to the fact they are more prone to risk factors such as heart disease, hypertension and diabetes.
What are the symptoms of dementia?

Depending on the type of dementia, and what stage it is at, symptoms may vary. Early on, you may notice some of these common changes in the person you care for:

- Forgetfulness, which affects their daily living.
- Difficulty concentrating and becoming disoriented.
- Problems with common everyday tasks.
- Problems naming common objects and not finding the right words.
- Getting lost easily, even in familiar places.
- Changes in behaviour such as anxiety, mood swings or depression.
- Loss of interest in hobbies.
- Loss of interest in hygiene and personal appearance.
- Anxiety about loss of memory.
- Sight and hearing loss.
- Changes in appetite which can lead to weight loss or gain.

In the middle stage of dementia, the person you care for may develop symptoms including:

- Restlessness.
- Obsessive or compulsive behaviour including repetitiveness.
- Changes in temperament from placid to aggressive or vice versa.
- Hiding or hoarding things.
- Pacing around the house or outside the home.
- Clinginess.
- Increased anxiety as the light starts to fade.
- Sleep disturbance and changes to sleep patterns.
- Delusions or hallucinations – thinking or seeing things that aren’t real.
- Increased confusion.
- Difficulty eating and drinking.

It’s important to remember everyone’s dementia journey is unique – changes in behaviour won’t always occur in sequence and some people will move more slowly through some stages than others. What is important is to make the most of where you are now.
Getting a dementia diagnosis

If the person you care for is concerned that they may have dementia it is important for them to visit their GP. Making sure that their GP is aware of concerns early on can help to rule out other causes of the symptoms. In some cases, if detected early, it maybe possible to slow the progress of dementia.

The person you care for may wish you to attend the appointment with them and this can be useful for both of you.

What the person you care for can expect from their GP
Diagnosing dementia can be difficult, particularly in the early stages. There is no single test and a GP may need to consider other potential causes with dementia-like symptoms such as: depression, deficiencies in their diet, a urinary tract or chest infection or side-effects from medicines.

The GP will usually take a family history to see if anyone related to the person you care for has been diagnosed with dementia. Depending on their concerns the GP may then carry out one or more of the following tests:

- Blood tests.
- A physical examination.
- A memory test.

Depending on the GP’s expertise and training, they may make a diagnosis at this stage, although this is uncommon. The GP should explain what the tests tell them and discuss with you and the person you care for what action needs to be taken.

If you or the person you care for do not understand something, it is important to ask questions and to request more information. Don’t be afraid to ask for an explanation if anything is unclear.
Preparing for an initial visit to the GP

- It can be helpful to spend some time with the person you care for, before their appointment, to write a list of the things you are both concerned about. This list could include: symptoms, when they began, and how frequently they occur.

- If you will be attending the appointment together you may choose to write separate lists to discuss with the GP. Your list may be different from that of the person you are caring for. It is important to be as specific as possible.

- It is also helpful for you both to put together a list of the person you care for’s past and current medical problems. It is particularly important to tell the GP if other family members have had illnesses that have caused memory problems.

- It is advisable for the person you care for to take along information about any existing medicines that they are using. This should include both over-the-counter (for example: vitamins or aspirin) and prescription medicines.

What to do if the GP doesn’t seem to think there is anything wrong

It may help if you keep a diary of concerns to show the GP and follow the tips in the section on Follow up visits to the GP on the next page. The GP will be exercising their professional judgment, so it’s always best to try to come to a mutual understanding. If however, you or the person you care for feels that their GP isn’t listening they can always seek a second opinion or change GP. See page 8 for further details.
Follow up visits to the GP
To make sure that you and the person you care for are prepared for the follow up visits to the GP, it can be useful for you both to:

- Keep track of changes in behaviour and medicines in a notebook, along with any concerns or questions you both might have.

- Try to make an appointment with the same GP each time. You can request a double appointment if appropriate, especially if you want to discuss your concerns separately.

- Write down a list of the top three things you want to discuss. This will make sure that the appointment is used to talk about the things that matter most to you both. Common concerns that carers of people with dementia talk to their GP about include:
  - Changes in symptoms.
  - Side-effects of medicines.
  - General health of the person with dementia.
  - Your own health
  - Other help you might need as a carer.

- Try and keep a log book of all health and medical appointments the person you care for is due to attend. Include the details of their different medical conditions and the professional(s) involved. This will help if you have to manage appointments for different conditions over a period of time.

What you can do if the person you care for doesn’t want to visit their GP
There may be lots of reasons why the person you care for doesn’t want to visit their GP. They may feel frightened, or they may not think there is a problem with their memory or behaviour. Explaining that there are other, potentially treatable conditions that could explain their symptoms may make it easier for them to speak to a GP.

You can make an appointment with your GP on your own to make them aware of your concerns or about support you may need as a carer. They may also be able to offer the person you care for a home visit.
Referral to a memory clinic
The GP may refer the person you care for to a memory clinic if they feel further tests would be useful.

At the memory clinic, a specialist staff member may:

- Give detailed tests to assess memory and other thinking processes.
- Take a detailed medical history.
- Offer a further physical examination.
- Offer brain scans.

Waiting times for an assessment at a memory clinic vary but the average is six weeks following the referral from your GP and then a further nine weeks to receive a diagnosis.

If getting to a memory clinic is difficult, staff can often provide assessments in the home.

They can also offer access to education and support for carers and most can signpost you and the person you care for to specialist counselling after a diagnosis of dementia.

Is a referral to a memory clinic always offered?
No, not always. If your GP is unsure about the diagnosis, they may refer the person you care for to a specialist or they may want to carry out further tests to rule out other conditions. See the Getting a dementia diagnosis section on page 5.

If the person you care for isn’t happy with the decision not to refer them to a memory clinic they can seek a second opinion. Whilst this isn’t a legal right, health professionals will rarely refuse to refer you for one. Before requesting a second opinion it’s worth asking your GP to explain their reasoning as this may help to clarify things for you. For more information visit nhsdirect.wales.nhs.uk/Encyclopaedia/s/article/secondopinion/.

Receiving written notes of the diagnosis meeting can be extremely helpful. This is not always routine, so if they are not offered, just ask. These can prove useful in helping you and the person you care for to understand what was said. You may also need proof of the diagnosis, for example when applying for benefits, contacting the DVLA or applying for insurance.
Managing medicines

Many people with dementia also have other health conditions, for example: high blood pressure, depression, heart disease or diabetes. This means that you may need to support them to manage a range of medicines.

As the person you care for’s dementia progresses their ability to manage their other health conditions and medicines is likely to deteriorate. It is common to have concerns about missed doses or overdosing.

Managing medicines is easier if you know the basics:

- What the medicines are and why they are being taken.
- When the medicines should be taken and how often, at what time of day, and whether they should be taken with or without food.
- What happens if the person you care for misses a dose or takes too many doses.
- If there are any side effects and if so how you and the person you care for can help manage them.
- If the medicines cause problems if taken with other medicines, including over the counter medicines and health supplements.

Getting a Medicines Use Review

To help manage medicines effectively, it can be worth discussing with the person you care for about asking your community pharmacist about a Medicines Use Review. This is a free medicine check-up service, which is useful if the person you care for regularly takes several prescription medicines or is on medicines for a long-term illness.
Helping someone with dementia take their medicines correctly
Depending on how advanced the dementia is, you may be able to help the person you care for by using marked pill boxes, dispensers or blister packs. Some people find that setting up reminders on a phone or a clock to trigger an alarm can be useful.

If you don’t live with the person you care for, or are out during the day, you could set your own watch or computer to remind you to call and talk them through taking their medicines whenever they need to take them. For more information on assistive technology see the Helping the person you care for to stay independent section, on page 14.

It may also be helpful to talk to the pharmacist or GP about simplifying or reducing the number of times a day the person you care for needs to take medication.

When the person you care for has more advanced dementia where it is not safe for them to take their medicines themselves, you may need to arrange assisted/supportive living, or adult day care if they take their medicines during work hours.

For more information see the Care options section in this booklet on page 15.

Your own wellbeing
Looking after you
Looking after someone who has dementia can be rewarding but it may also be stressful and extremely demanding at times. One of the things you may find difficult is living with your feelings about caring. It can help to know what these feelings might be. As a carer, you may feel:

- Worried that you are losing the person you know.
- Scared about admitting that there is a problem.
- Exhausted by caring and ensuring that the person you care for is safe.
- Frustrated with the changed behaviour of the person you care for.
• Ashamed about complaining or seeking help for fear of betraying the person you’re looking after.

• Worried about the future and possible loss of income and earnings.

• Worried about the long-term financial responsibilities of caring for someone with a progressive illness.

• Resentful that your life is no longer your own.

These are all normal emotions and there will be good and bad days. It is helpful to acknowledge these feelings and get help if you feel you aren’t coping. There are lots of other carers who know what you are going through and professionals who can help.

Talking helps
It can help if you talk about your feelings rather than bottle them up. You may want to talk to a friend or member of your family, or to a professional, such as a GP, nurse practitioner or a local dementia or carers support group. See the Useful contacts section on page 27 for information on how to find local support.

Work and caring
Caring for someone with dementia can be a huge challenge for many working carers, especially when the demands on your caring role increase. It is important to speak with your employer in the first instance, as you have rights if you wish to remain in work. For further advice and support visit dewis.wales/balancing-work-and-caring.

Try to take a short break
Whether having a walk in the park or a coffee with friends, it is important to do things you enjoy. If you can leave the person you care for on their own then make sure that you take regular breaks. If this isn’t possible you could arrange a short break either informally, with a neighbour, family member or friend, or more formally through a registered respite service.

Respite care
Unlike most of the types of care offered by care homes and domiciliary care providers, respite care is for the person doing the caring rather than the person receiving care. Visit carers.org to find out more carers.org/article/getting-break.
Find out about having a carer’s assessment with the local authority so that you can discuss respite options, alongside other needs you may have. See the section on Your rights on page 16.

**Share the care**

Looking after someone with dementia can be a round-the-clock job. The support you need is likely to change as time goes on. Often people don’t get help because no-one realises they need it. Family, friends and neighbours may be more willing to help if you explain to them the type of help you need and why you need it.

**Managing behaviour changes**

Dementia can make the world a confusing and frightening place as the person with dementia struggles to understand what is going on around them. Though it may be confusing to you, the behaviour of the person you care for will have meaning to them. It is likely to be their attempt to enhance and maintain their own wellbeing and to ease their distress. See the Staying active section on page 21 for more information.

Try these tips and hints for coping with behaviour changes:

**Establish a routine**

Sticking to a routine helps someone with dementia feel less disorientated, and gets their body-clock into a rhythm. It may help to write their routine on a board that’s kept next to a calendar (cross it off to show what day it is) and a clock, so that they know what to expect when.

**Dealing with walking about**

Around 60% of people with dementia have a tendency to walk about – pacing around the house or outside the home. If they want to walk then try to find a solution that lets them do so safely and preserves their independence and dignity. To find out about assistive technology that may help, see the Helping the person you care for to stay independent section on page 14. See also the Useful contacts section for other organisations that can advise, including the emergency services.
Support during sundowning
People with dementia can often get increased anxiety as the light starts to fade at the end of the day. They may become confused, agitated, restless or show repetitive behaviours. This is known as sundowning.

It may help to:

- Keep the person you care for busy at sundown and in the early evening.
- Encourage them to avoid stimulants such as coffee or alcohol.
- Play soothing music, read to them, or suggest a walk.
- Ask a family member or friend to call the person you care for during this time.
- Close the curtains or blinds at dusk and turn on lights to help minimize shadows.

Helping the person you care for to stay independent
While you may have concerns and worries when looking after someone with dementia, by trying to keep someone safe it is easy to become over-protective.

People with dementia can lose their confidence quite quickly, so encouraging them to continue doing things they’ve always done or finding new ways of doing things is key. It may be a long while before their condition worsens so maintaining a sense of normality is important.

Tips for maintaining the independence of the person you care for
You can try these tips whether you live in the same house as them, or not.

- Encourage the person you care for to keep a notebook or diary for things such as appointments, to do lists, and lists of thoughts and ideas.
- Keep important things like money, glasses and keys in the same place.
- Put labels on doors and cupboards.
- Place important numbers by the phone where they can easily be seen.
- Put a note on the inside of the front door (and back door) as a reminder to take keys.
- Label family photographs, both on display and in albums.
- Pin a weekly timetable to the wall.
- Mark a calendar with the date or get an electronic calendar that changes automatically.
- Write reminders to lock the door at night, turn the gas off and put the rubbish out on a certain day.

**Driving**

Having dementia doesn’t necessarily mean a person has to give up driving – one in three people are still able to drive safely for some time after diagnosis. However, by law the person with dementia must inform the DVLA and their car insurance provider about their diagnosis.

Tips and advice on driving, including supporting a person when they are no longer able to drive, can be found under the Driving section at alzheimers.org.uk.

**Assistive technology**

There are products you can buy which are designed to help manage risk and promote independence. These can give you and the person you care for peace of mind and are known as assistive technologies or telecare. They include things such as memory aids, location devices and motion sensors – for example: automated pill dispensers, doorway safety beam alarms and telephones with one touch photo buttons.

For further information on assistive technology visit Dewis Cymru at dewis.wales/Technology-to-support-you-to-live-independently. See also AT Dementia and Unforgettable on pages 28 and 30.

An occupational therapist may be able to advise on what things could be most useful. This might include adapting bathrooms so that they are dementia friendly, ensuring lighting is adequate and organising grab rails by doors where there are steps. The person you care for can ask their GP or social services for an appointment. To find out how to get in touch with these services see the Useful contacts section on page 30.
For more tips on making a home more dementia friendly visit the Dementia friendly home section at ageuk.org.uk.

**Setting up a medical ID on a phone**
Adding a medical ID to your phone and that of the person you care for can give you both peace of mind. This is known as ICE which stands for In Case of Emergency. This will allow quick access to vital information (such as medical conditions, support information and close contacts) if you or the person you care for are involved in an accident or are taken ill. The feature is pre-installed in the health app on all iPhones but you will need to add it on Android phones. Many local authorities and carer services also operate an emergency card scheme for carers. See the Useful contacts section on page 27 for details.

**Care options available**
Choosing care for the person you care for can be a difficult decision. It is important to remember that as a carer you have been taking on the role of many professionals, often for a long period of time. While this experience can be rewarding it can also be exhausting.

Having information and advice on all types of care options, eligibility criteria, and how to access them, will give you the confidence to request the right type of replacement care at the right time.

**Domiciliary care**
This is a term given to personal care and help with practical household tasks people receive at home. Domiciliary care is provided either by the local authority, private agencies or a mix.

**Intermediate care**
This is care provided by the NHS. It is a short period of intensive care designed to try and rehabilitate the person needing care to allow them to return home. Usually provided at home, it can be offered after a spell in hospital or a care home.

**Residential care**
This is where care and meals are provided full time in a residential care home. The care will include help with daily activities including washing, going to the toilet and eating. Medical needs will be addressed as and when required by a visiting GP or district nurse but there is no dedicated nursing care on site.
**Your rights**

**Getting a carer’s needs assessment**

The law is very clear on what your rights are as a carer. Following the introduction of the Social Service and Well-Being (Wales) Act 2014, regardless of the level of care you provide and amount of time you provide care, the local authority has a duty to provide you with an assessment of your own needs (carer’s needs assessments), as well as a care and support assessment of the person you care for.

Your assessment will look at how caring affects your life including, for example, your physical, mental and emotional needs, whether you need respite breaks and whether you are able or willing to carry on caring. The assessment is an opportunity to discuss exactly what your needs as a carer are, and the level and type of support required to meet those needs.

The local authority now also has a duty to meet those needs if they can’t be met elsewhere. See Carers Wales’ factsheet for more information by visiting [carersuk.org/wales/help-and-advice/factsheets-carers-wales/getting-an-assessment-in-wales](http://carersuk.org/wales/help-and-advice/factsheets-carers-wales/getting-an-assessment-in-wales).

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**Nursing care/homes**

Nursing homes differ from residential care because they cater for someone with more severe and intensive medical needs and always have a full-time state-registered nurse on duty.

**Palliative care**

Palliative care is for anyone diagnosed with a life-limiting illness, including dementia. It focuses on maintaining a person’s quality of life by relieving discomfort or distress (whatever the cause). Someone can receive palliative care for several years and it may be offered alongside other treatments, especially in the earlier stages of dementia. Palliative care also includes care for people nearing the end of their life. This is called end of life care.

Care Forum Wales has put together a useful care guide to help with choosing care providers. See the **Useful contacts** section on page 28.
**Social care or health care support**
You also have the right to be treated as a partner in care when a relative is receiving social care (assistance with daily living) or health care (nursing/medical) support. As a carer you should be consulted when the person you care for is having an assessment and any changes in their support must now take account of the potential impact this may have on you as a carer.

To understand the difference between a health care and a social care need, visit Care to be Different at caretobedifferent.co.uk/difference-between-a-healthcare-need-and-a-social-care-need/.

**Paying for care**
Once your local authority has decided that the person you care for needs care and support, it will carry out a financial assessment of their finances to establish whether:

- The person you care for has sufficient funds to pay the full cost of their care.
- They will be asked to contribute something towards care costs. Most people will need to pay towards their care home costs if their income and capital exceeds a certain amount (as of April 2018, this was £40,000).
- They need the full cost of services to be paid by the local authority.

There are strict guidelines to ensure the local authority carries out the financial assessment fairly and equitably.

For more information visit dewis.wales/your-financial-assessment.
**Direct payments**
If the person you care for is eligible to have their care funded by the local authority, they can choose to receive this funding in the form of a direct payment.

A direct payment is money that a local authority gives to someone to spend on meeting their own eligible care and support needs. The money can be spent on a wide range of products and services. Direct payments allow people to make their own choices about their care and support. Visit [dewis.wales/using-direct-payments](dewis.wales/using-direct-payments) for further details.

**Claiming benefits for you and the person you care for**
You may find it helpful to find out about all the financial help you are eligible for. See if you and the person you are caring for are claiming all the benefits that you’re entitled to. In particular, check:

- Whether the person you are caring for is eligible for Personal Independence Payment (which replaced Disability Living Allowance in 2013) or Attendance Allowance.
- Whether you are entitled to Carer’s Allowance.

Other benefits you may be eligible for include Income Support, Employment and Support Allowance, Housing Benefit and Council Tax Reduction.

**Help getting out and about**
As a carer, there are also a number of other schemes and entitlements to support you to get out with the person you care for, such as railcards, blue badge parking permits and free access to many leisure and visitor attractions. See benefits and tax credits you can claim as a carer by visiting [moneyadviceservice.org.uk](moneyadviceservice.org.uk).

Alzheimer’s Society Cymru and Carers Wales also have factsheets on benefits which tell you what’s on offer and how to claim them. See the **Useful contacts** section on page 27 and 28.
Legal and financial planning

If you are looking after someone with dementia, you may find yourself helping them manage their daily finances and paying their bills. Getting advice on legal and financial issues is essential for anyone diagnosed with dementia and for their carer. It is important to get advice before the person you care for has lost the capacity to make informed decisions about the future.

Lasting power of attorney

Many people with dementia will eventually reach a point where they are no longer able to make decisions for themselves – this is known as lacking ‘mental capacity’. When this happens, someone else – often a carer or family member – will need to make decisions on their behalf.

It is important you discuss this while the person with dementia is still able to make decisions so they can agree to what’s included. Having a lasting power of attorney in place will ensure they have chosen someone they trust to look after their affairs on their behalf.

There are two types of lasting power of attorney:

1. One for property and financial affairs.
2. One for health and welfare.

You can use an official Government tool to help you create a lasting power of attorney, you can find this online at lastingpowerofattorney.service.gov.uk/home. Alternatively, you can contact a solicitor or a local carers service if you would like to talk this through. See the Useful contacts section on page 27 for details.

Making a will

It is important for you and the person you care for to make a will regardless of whether you have any possessions or money. A will does not necessarily need to be drawn up by a solicitor but it is advisable, unless the will is straightforward, to seek advice, for example from Citizens Advice, or your local carers service. See the Useful contacts section on pages 27 and 28.

Securing your home

It is important to know what rights you have over your home, if you live with the person you care for, should they need to
go into a care home or if they die. This will depend largely on whether the person you care for owns or has sole tenancy of the home. If you are worried about how this might affect you, contact a solicitor, housing advice centre or Citizens Advice.

For more information, search Property entitlements at mariecurie.org.uk and Tenancy rights – security of tenure Factsheet 68 at ageuk.org.uk.

Supporting the person you care for when they are in hospital

It can be disorientating for the person you care for if they are admitted to hospital.

You can help by asking for the named nurse who is responsible for co-ordinating their care. Tell them and other staff that the person you care for has dementia and ask to be kept informed and involved in decision making.

It can help to write down important facts about the person and give them to the named nurse. For example, it can be useful to include details of how the person prefers to be addressed, their likes and dislikes, such as whether they prefer a bath or a shower, and the practical help they need.

Alzheimer’s Society has a leaflet called ‘This is me’ which gives you and the person you care for space to write about their hobbies and interests, things that may upset them, their personal care needs, mobility issues, sleep patterns and other relevant information. To view the leaflet online visit the ‘This is Me’ tool at alzheimers.org.uk.

John’s Campaign
Lots of hospitals across the UK are adopting John’s Campaign which is advocating for open visiting for family and friends caring for someone with dementia. Having the flexibility to visit is important for your own piece of mind and the person you care for. Check if your hospital is signed up or ask on the ward for more information. Visit johnscampaign.org.uk/#/participants.
Discharge planning
Discharge is the term used when a person leaves hospital. Each hospital will have its own discharge policy relating to either planned (pre-arranged) or unplanned (emergency) hospital admissions. Plans about the date and time of discharge for the person you care for should be discussed with you as their carer and ideally started at a reasonable period of time before discharge.

Discharge planning should include an assessment of a person’s psychological, physical and social needs on leaving hospital. For example, consideration about where the person you care for will be living, the care that they will need, what support they have if being discharged home and who will be providing it.

As a carer, you should be part of the discussion around discharge and any future planning around their care. There should be no assumption that you are willing and able to provide care without your full agreement. Many carers are unable to continue caring for many reasons and it is okay to ask for help and support.

It’s important to remember to tell your pharmacy when the person you care for has been in hospital, they can then support with the Discharge Medicines Review service to ensure that the medicines prescribed when they get home are as the hospital intended.

Supporting the person you care for to stay active, involved and healthy
Supporting a person who has dementia to remain active and still feel involved in life can be the key to maintaining quality of life, for you and them, even when they are in the late stages of dementia.

Diet and exercise
Having a good diet, exercising, sleeping well and being free of pain and infection are important for the good health and wellbeing of the person you care for. You can help them keep mobile and stimulate their senses by supporting them to take up or maintain hobbies and interests, do things around the house and garden and to stay active.
Singing and music
Singing can be a very rewarding activity for people with dementia; they may remember words of songs when other memories have been lost. Music offers people a chance to express themselves in different ways as it is less reliant on words. For more ideas, visit the Social Care Institute for Excellence at scie.org.uk/dementia/living-with-dementia/keeping-active/.

Staying healthy
Infection is a common cause of increased confusion and pain in someone with dementia. While most of us know when we feel unwell, a person with dementia may not or they may feel different but not realise that they could be ill.

Ensuring the person you care for has regular check ups, including eye, hearing and dental checks, can help identify problems before they become too serious.

If you do notice sudden and obviously different behaviour in the person you care for, seek medical advice as soon as possible. For further information about spotting the signs of infection and recognising the signs the person you care for might be in pain, see the Dementia Care website at dementiacare.org.uk/services/need-some-advice/carers-support/caring-for-someone-with-dementia/medication-and-monitoring.

Supporting the person you care for when they are in the later stages of dementia
Late stage dementia is also known as advanced dementia. Some people with late stage dementia find it hard to communicate but you can still interact with them even if they have little or no speech. Touch can provide reassurance.

Pain is a common symptom of someone with late stage dementia. If you think that the person you care for is in pain, discuss it with health professionals so that they can help treat it.
Towards the end of their life, a person with dementia may take in very little food and fluids. They will find it more difficult to move around. Their speech may be affected. They may also have bowel and bladder problems including; mild to moderate incontinence or double incontinence (both bowel and bladder) or constipation. Dementia doesn’t cause these problems but it may make them more likely due to poor communication and memory issues.

For further advice and support visit www.unforgettable.org/blog/late-stage-dementia-what-might-you-expect.

These symptoms can be challenging. If you are concerned about any of the symptoms of dementia, talk to a health professional who will be able to reassure you and offer you support and guidance. You may also find it helpful to talk to other carers or look at our Carers Road map for further information to help you prepare for the future. Visit carers.org/article/carers-road-map-guide-carers-people-dementia.

End of life care

Planning for the end of life is important for anyone who has a life-limiting condition. For a person with dementia it is important to try and have these conversations as early as possible, while they can make decisions for themselves.

You might not want to talk about death or dying while the person you care for is still fit and well, but being given the chance to let other people know their final wishes can give someone with dementia a sense of control, and provide peace of mind. Many people with dementia also worry about the impact of their condition on their family, so knowing that the future is taken care of can help.

**Advance statements, advance decisions and advance directives (living wills)**

If the person you care for doesn’t feel ready to think about the future, getting to know their values, wishes and beliefs more generally can help in the future when decisions need to be made on their behalf. Encouraging them to express their wishes in the form of advance statements, decisions or directives (these are known as living wills) can be helpful.
This allows them to make decisions about their care and treatment while they are still able to do so.

For more information on drawing up an advance statement see Compassion in Dying at [compassionindying.org.uk/making-decisions-and-planning-your-care/planning-ahead/advance-decision-living-will/](http://compassionindying.org.uk/making-decisions-and-planning-your-care/planning-ahead/advance-decision-living-will/).

**Loss and bereavement**

When you care for someone who has dementia, you may experience loss before they have died. You may find that your relationship starts to change and you find it hard to recognise the person they once were, and you may grieve for how things were before.

Grief is an entirely natural response to loss. There are many types of loss, and everyone will react and feel differently. Grief does not happen in a set way and feelings and thoughts may come and go. You may initially feel that you are coping well but could also feel detached from everything around you. Initial numbness can give way to strong feelings as the reality of your loss begins to sink in.

Emotions and physical reactions you may experience include sadness, despair, relief, denial, anger, regret, fear, fatigue, nausea, loss of concentration and poor appetite.

**Things that can help:**

- Try not to make any big decisions in the short term.
- Be kind to yourself.
- Allow yourself time to grieve.
- Spend time with friends or seek out someone to talk too (maybe from a carers or dementia service).

There is no right length of time for grieving to last but if you feel it is affecting your physical or emotional health, speak to your GP.

Cruse Bereavement Care, in partnership with Alzheimer’s Society Cymru, has produced some useful resources as part of their Bereaved by dementia project. See the **Useful contacts** section on page 28 for further details.
Information for young carers

Watching someone you know gradually getting more ill can be very upsetting. Dementia is an especially difficult condition to deal with because it can slowly change the person you care about.

Most people with dementia will gradually have more trouble remembering things and doing what they used to do, as time goes by. If the person with dementia is your mum or dad, or someone else you are very close to, their dementia is probably going to have an impact on you.

Other people may not see the changes in the person in the way that you do. This can sometimes make it hard for others to understand what caring for the person with dementia is really like for you. Someone with dementia may do odd things which embarrass, frustrate, irritate or even alarm you. They probably won’t be able to give you as much attention as before. You may feel that they have lost interest in you. Always remember that it is because of their illness – they aren’t doing it to get at you.

You may notice the person with dementia will start to depend more on you and other people.

People with dementia often seem self-centred, because the damage to their brain makes it hard for them to remember even the little things, like asking how school went today. The person with dementia may also be feeling depressed because they can’t do the things they used to do. However, with support, many people with dementia can live well and enjoy new interests.

The best thing you can do is get help. Talking to a member of your family or friends may help. You can also talk to a professional such as a GP, your teacher, a counsellor, a social worker or a young carers project worker who may be able to offer practical help. And don’t forget that you can call the Wales Dementia Helpline for free on 0808 808 2235 or text ‘help’ to 81066 anytime you need more information or support.

Remember no one should try to cope on their own.

The information above is taken from a booklet by Health Scotland called Understanding Dementia: A Guide for Young Carers. You can read it at healthscotland.scot/health-topics/dementia under the Dementia resources section.
## Your useful contact numbers

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Useful contacts

**Carers Trust Wales**
Carers Trust Wales is part of Carers Trust, a major charity for, with and about carers. We work to improve support, services and recognition for anyone living with the challenges of caring, **unpaid**, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

With locally based Network Partners we are able to support carers in their homes through the provision of replacement care, and in the community with information, advice, emotional support, hands on practical help and access to much needed breaks. We offer specialist services for carers of people of all ages and conditions and a range of individually tailored support and group activities.

You can find your nearest Carers Trust Network Partner by using our ‘Find local care and carer services’ facility online at [carers.org](http://carers.org) (any time) or calling 0300 772 9600 (Mon–Fri, 9am–5pm).

**Local carers services**
For details of your local carers services contact either your local authority, your local health board or Carers Trust for advice, information, support and respite services.

**Useful organisations**

**Carers Trust**
[carers.org](http://carers.org)
The Carers Trust website provides practical information for carers. See in particular [carers.org/article/dementia](http://carers.org/article/dementia).

**Age Cymru**
[ageuk.org.uk/cymru](http://ageuk.org.uk/cymru)
The website has lots of information on benefits and entitlements, housing, advocacy, care homes, befriending, home help and support groups for older people as well as specific advice and information on dementia. You can also call the advice line on 08000 223 444.

**Alzheimer’s Society Cymru.**
[alzheimers.org.uk](http://alzheimers.org.uk)
Tel: 0845 300 0336
The website has helpful factsheets on all aspects of caring for someone with dementia as well as information on diagnosis and treatment, an online community and details of local support services.
AT Dementia
atdementia.org.uk
Provides information on assistive technology that can help people with dementia live more independently, including product advice and suggestions with the assistive technology guide.

Care and Repair Cymru
careandrepair.org.uk
Operating in each local authority area in Wales, the service helps older people (65+) to live independently at home. This might include home repairs, adaptations, improving security, falls prevention work or improved heating. Contact your local Care and Repair on 0300 111 3333.

Care Forum Wales
careforumwales.co.uk
Represents care homes, nursing homes and other independent health and social care providers across Wales.

Carers Wales
carersuk.org/wales
Information for carers including factsheets, help and guidance plus information on getting a carer’s assessment in Wales.

Citizens Advice
citizensadvice.org.uk
Advice on a range of topics including making a will.

Compassion in Dying
compassionindying.org.uk
Tel: 0800 999 2434
Provides a free information line, publications and resources about end of life planning. Compassion in Dying specialises in advance decisions and lasting powers of attorney. Visit also its MyDecisions website at mydecisions.org.uk/ which helps people to record their wishes for care in a legally binding way.

Cruse Bereavement Care
cruse.org.uk/wales
Cruse UK National helpline: 0808 808 1677.
Provides free advice, training and support around bereavement through local branches across Wales. Support includes, crisis, face-to-face and pre-bereavement information working with all ages.
Dementia UK
dementiauk.org
Provides detailed insight into the four main types of dementia – Alzheimer’s; vascular dementia; frontotemporal and dementia with Lewy bodies. It also has advice, support and information leaflets by Admiral Nurses and a map of their UK services.

Dewis Cymru
dewis.wales
The website has information and advice on a wide range of topics relating to wellbeing including advice about your wellbeing or how you can help somebody else. It also hosts a resource directory of services in Wales.

The Lewy Body Society
lewybody.org
Gives advice and information about dementia with Lewy bodies including symptoms, diagnosis and treatment.

Marie Curie
mariecurie.org.uk
Tel: 0800 090 2309
Provides care, guidance, and support for people diagnosed with a terminal illness and their families. It offers a range of information and support online, through a freephone Support Line, via web chat and in free publications and resources. Speak to your GP or district nurse about what care is available in your area.

The Money Advice Service
moneyadviceservice.org.uk
Tel: 0800 138 7777
Free and impartial money advice, set up by the Government. The website includes guides to help improve your finances and tools and calculators to help keep track and plan ahead. Support is available online and over the phone.

Police
north-wales.police.uk
south-wales.police.uk
For advice on keeping the person you care for safe, both in and outside the home, visit north-wales.police.uk/advice-and-support/stay-safe/dementia. See also details on the Keep Safe Cymru Card scheme which operates across both forces.
Rare Dementia Support
raredementiasupport.org
Offers specialist support services for individuals living with, or affected by, one of five rare dementia diagnoses including familial Alzheimer’s disease, frontotemporal dementia, familial frontotemporal dementia, posterior cortical atrophy and primary progressive aphasia.

Social Care Institute for Excellence (SCIE)
scie.org.uk
The website hosts a dementia hub which includes a wide range of information resources on dementia from research, practical guides to e-learning courses.

Social services
nhsdirect.wales.nhs.uk/localservices/socialservicefaq/
The website provides a frequently asked questions section and contact details for all social services departments across Wales.

Tide – Together in Dementia Everyday
tide.uk.net
An open network of carers, former carers and health professionals offering opportunities to share their stories to empower and inspire other carers. See also Life Story Network at lifestorynetwork.org.uk.

Unforgettable
unforgettable.org/advice
A dedicated online resource with practical advice, carers’ stories and blogs, specialising in support products, services and reviews.

Wales Dementia Helpline
callhelpline.org.uk/dementia-helpline.asp
Tel: 0800 808 2235 or text ‘help’ to 81066.
The helpline offers emotional support to anyone, of any age, who is caring for someone with dementia as well as other family members or friends, in Wales.

Young Dementia UK
youngdementiauk.org
Provides information on signs and symptoms of young onset dementia and information about what it is like to have and live with young onset dementia. It also hosts the Young Dementia Network.