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CARING FOR SOMEONE WITH DEMENTIA

A GUIDE FOR FAMILY AND
FRIENDS WHO LOOK AFTER
A PERSON WITH DEMENTIA

ABOUT THIS GUIDE

If you are reading this guide because you care for someone with dementia, you are not alone. Over 45,000 people in Wales live with dementia (Alzheimer's Society), a wide range of symptoms caused by diseases in the brain. There are 670,000 people in the UK who provide practical and emotional support to people with dementia, a syndrome that can cause memory loss, communication problems and mood changes.

Unpaid carers including husbands and wives, children, siblings, friends and other family members may help a person with dementia with daily tasks such as cooking and dressing, managing medicines and providing emotional support.

Caring is often rewarding but we know that it can affect a person's health and well-being, employment and personal relationships. Access to good information and support at the right time in your caring journey can be an enormous help in making sure that the more challenging aspects of caring don't impact on you too negatively. In Wales, as an unpaid carer, you have a legal right to information, advice and assistance to help you in your caring role. This includes support to do the things that matter to you such as education, employment and maintaining hobbies.

This guide gives information on a range of matters including what you can expect in the early stages of getting a diagnosis, looking after your own well-being and thinking ahead about financial and legal matters.

To get the best out of this guide

-  Dip into chapters over time, rather than reading it in one go.
-  Use the coloured text to find links to relevant websites at the bottom of the page.
-  Use bold text to find relevant pages within this guide.
-  This is a printed version of an online resource. To get the most out of this guide, you can view an interactive version at www.carers.org/wales/dementia-carers

45,000 people in Wales live with dementia (**Alzheimer's Society**).

1 in 14 people over the age of **65** have dementia (NHS).

1 in 6 people over **80** have dementia (NHS).

Nearly half of carers of people with dementia also have a long-standing illness or disability of their own (**Alzheimer's Society**).

CONTENTS

5	About Carers Trust Wales
6	Carers Trust Network Partners in Wales
8	Understanding dementia
9	Getting a dementia diagnosis
14	Young onset dementia
15	Carers' needs assessments
22	Your own well-being
27	Information for young carers
29	Paying for care and benefits
31	Claiming benefits for you and the person you care for
35	Caring for a person with dementia
40	Communication in dementia
44	Helping the person you care for to stay healthy and independent
49	Managing medicines
51	Carers and people with dementia from ethnic minorities
54	Work and caring
55	Welsh language and culture
57	Help with caring
60	Care home options
68	Supporting the person you care for during hospital stays
72	Legal and financial planning
75	Planning for the future
78	End of life
79	Life after caring

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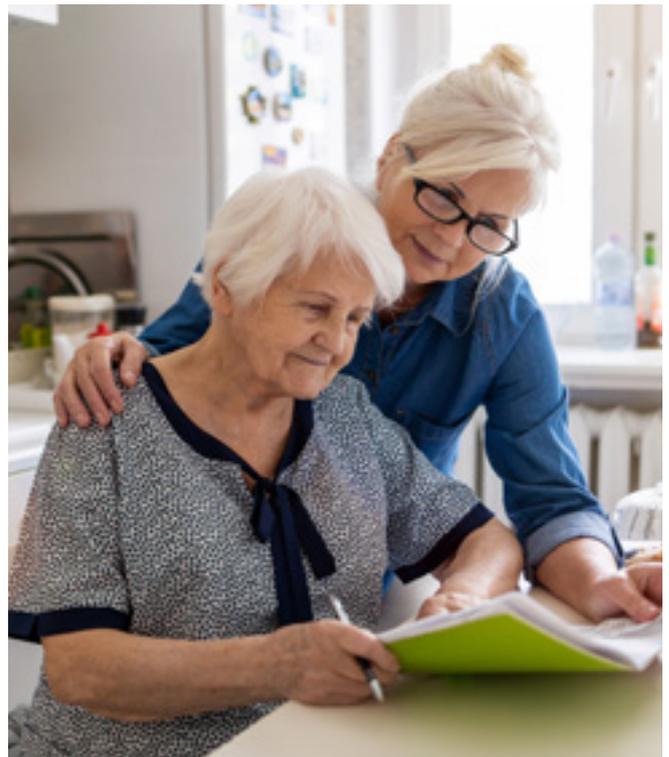
Age Cymru and Carers Trust Wales are working in partnership to develop person-centred service models to identify, and better meet the needs of older carers and carers of people living with dementia, funded by the Welsh Government Sustainable Social Services Third Sector Grant. This guide is being distributed as part of this project and additional resources will be developed to support its use over the duration of the project.

ABOUT CARERS TRUST WALES

Carers Trust Wales exists to improve support, services and recognition for unpaid carers in Wales. With our Network Partners - local services that deliver support to carers - we work to ensure that information, advice and practical support is available to carers across the country.

By working collaboratively, we inform and influence local organisations and decision makers who have the power to improve support for unpaid carers locally, regionally and nationally.

We also seek to influence decision-makers, the media and the public to promote, protect and recognise the contribution carers make, and the support they deserve.



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CARERS TRUST NETWORK PARTNERS IN WALES

Network Partners in Wales offer a wide range of services for carers including emotional support via things like talking therapies and weekly drop-in sessions through to practical help such as access to grants and advice on benefits. Each service is different, so you'll need to contact your local organisation to find out more.

We keep the details of our Network Partners up to date on www.carers.org

Carers Outreach Service

www.carersoutreach.org.uk
01248 370 797
help@carersoutreach.org.uk

Carers Trust South East Wales

www.ctsew.org.uk
01495 769996
info@ctsew.org.uk

Carers Trust North Wales Crossroads Care Services

www.nwcrossroads.org.uk
01492 542212

Swansea Carers Centre

www.swanseacarerscentre.org.uk
01792 653344
admin@swanseacarerscentre.org.uk

Carers Trust Carmarthenshire Crossroads Care

www.carmarthenshirecrossroads.org.uk
01554 754957 (Llanelli)
01267 220046 (Carmarthen)
info@carmarthenshirecarers.org.uk

NEWCIS: North East Wales Carers Information Service

www.newcis.org.uk
01745 331181 (Denbighshire)
01352 752525 (Flintshire)
01978 423114 (Wrexham)
enquiries@newcis.org.uk

Credu

www.credu.cymru
01597 823 800
info@credu.cymru

Bridgend Carers Centre

www.bridgendcarers.co.uk
01656 658479
enquiries@bridgendcarers.co.uk



As well as our Network Partners there is a range of help and advice available in all local authorities in Wales. You can find out more about these carer specific services and contact details from [***Understanding your rights as a carer \(Welsh Government\)***](#).



gov.wales/sites/default/files/publications/2019-12/understanding-your-rights-as-a-carer.pdf

As well as our Network Partners there is a range of help and advice available in all local authorities in Wales. The following contact details are taken from Understanding your rights as a carer (Welsh Government, 2012) that is available from www.gov.wales.

Local Authorities Social Services Information, Advice and Assistance Helplines

Isle of Anglesey County Council

01248 752736

Blaenau Gwent County Borough Council

01495 315700

Bridgend County Borough Council

01656 642279

Cardiff City Council

02920 234234

Carmarthenshire County Council – Delta Wellbeing

0300 333 2222 (24hrs)

Ceredigion County Council

01545 574000

Conwy County Borough Council

0300 456 1111

Denbighshire County Council

0300 456 1000

Flintshire County Council

01352 803444

Gwynedd Council

• Llŷn area: 01758 704099

• Caernarfon area:

01286 679099

• Bangor area:

01248 363240

• Eifionydd and Meirionnydd North:

01766 510300

South Meirionnydd:

01341 424499

Merthyr Tydfil County Borough Council

01685 725000

Monmouthshire County Council

01633 644644

Neath Port Talbot Council

01639 686802

Newport City Council

01633 656656

Pembrokeshire County Council

01437 764551

Powys County Council

01597 827666

Rhondda Cynon Taf County Borough Council

01443 425003

Swansea Council

01792 636519

Torfaen County Borough Council

01495 762200

Vale of Glamorgan Council

01446 700111

Wrexham County Borough Council

01978 292066

UNDERSTANDING DEMENTIA

Dementia is the name for a collection of symptoms caused by diseases that impact how the brain works. Dementia isn't a single illness or disease, although this is a common misconception.

Dementia is a *syndrome* (a set of related symptoms or characteristics) caused by diseases that affect activities in a person's brain, including the following cognitive functions:

- memory,
- language,
- recognising faces and objects, and
- judgment.

Dementia is not an inevitable part of getting older, but it is more common in older people. Dementia is a progressive illness (it gets worse over time) and there is currently no known cure. Younger people with dementia or '**young onset dementia**' refers to someone under the age of 65.

The most common conditions are:

- Alzheimer's disease,
- vascular dementia,
- dementia with Lewy bodies, and
- fronto-temporal dementia (diseases that affect the frontal lobe of the brain).

People may have one dementia or a combination of the different forms and diagnoses are not always clear-cut (World Health Organisation, 2019).

Understanding the type of dementia a person is affected by and receiving an accurate diagnosis means people with dementia and their carers can get the right support.

Further information

www.alzheimers.org.uk

www.dementiauk.org

www.nhs.uk/conditions/dementia

Dementia is an increasingly common syndrome in the UK, affecting **one in 14 people over the age of 65 (NHS)**.



www.alzheimers.org.uk/about-dementia/types-dementia/younger-people-with-dementia
www.alzheimers.org.uk/about-dementia/types-dementia

GETTING A DEMENTIA DIAGNOSIS

An early diagnosis of dementia helps everyone get the care and support they need, as well as appropriate treatment. It allows families to have as much information as possible so that they know what to expect and can plan for the future. However, too often people are diagnosed late in the progression of the disease or do not receive a diagnosis at all.

There are many reasons dementia may not be diagnosed early, including:

- Delaying visiting a health professional because of fear and worry about symptoms.
- Difficulty in noticing dementia symptoms if they appear gradually.
- Mistaking dementia symptoms as part of 'normal ageing'.
- Multiple assessments need to be carried out and these can take time. There isn't a one-off test to determine dementia.
- General Practitioners (GPs) may not be confident to make a diagnosis, and therefore they may need to refer to a specialist for diagnosis.

It is beneficial to visit a GP as soon as you become concerned about possible symptoms of dementia. It gives doctors the chance to understand and monitor changes in a person's health and behaviour over time and rule out any other underlying illnesses.

Seeing your GP may help to get an early diagnosis. This is important because it may allow the person you care for to:

- Receive treatment to slow down dementia (in some cases).
- Access local support services.
- Know what to expect and plan for their future.

First steps: visiting the GP

The first thing someone who is concerned they may be showing signs of dementia should do is visit their GP. Going to the GP with the person who has symptoms will allow you to offer moral support and provide the GP with additional information.

How to prepare

- Consider booking a double appointment so you have plenty of time.
- Write a list of behaviours or symptoms you are concerned about. Note how often they are occurring and how long you have been noticing them for. This can help identify what type of dementia is present as some dementia develop faster than others. In turn, this can help identify which specialist help is suitable **(Robinson et al, 2015)**.
- Make a list of questions but be prepared to not have them all answered in the first appointment; diagnoses can take some time.
- Family history is important. Make a note of any diagnoses or illnesses you're aware of, especially ones which affect memory. Some illnesses are hereditary; they run in families.
- Bring along a list of current medication and doses.

What to expect at the GP appointment

A doctor may:

- Check the person with symptoms consents to you being there.
- Talk to the person and you about your concerns.

- Ask about family history.
- Consider other illness that may be causing symptoms or mimicking dementia symptoms, such as depression, deficiencies in particular vitamins or problems with the thyroid **(Robinson et al, 2015)**.
- Run the following examinations:
 - physical examination, including vision, hearing and movement,
 - blood tests and urine samples, and
 - cognition tests to determine mental ability including problem solving, memory and orientation.

If your family member or friend refuses to visit the GP

If someone close to you is showing signs of dementia but refuses to visit the doctor, it can be worrying.

Whilst a GP must keep information about their patients confidential there is nothing stopping you from providing them with information that they might find useful. This can help them to ask searching questions or to follow up with the person you have concerns about.

You could also make sure you have information about dementia and the importance of early diagnosis available for the person you are concerned about.



Outcomes to a GP visit

- A diagnosis of dementia (and a referral to a **dementia specialist** for treatment and support).
- A diagnosis of another illness.
- A referral to a **dementia specialist** for further assessments.
- A suggestion to track symptoms and review at a future appointment e.g. in a month's time.

If the GP does not diagnose dementia or make a referral

If the visit to the doctor doesn't result in a diagnosis, continue to keep a diary of concerns. If symptoms progress you can share this with a doctor in future months. Dementia can take time to become apparent and some types of dementia develop slowly.

You can also ask the doctor to explain how they have reached their professional judgment. Understanding their reasoning may help you to come to terms with the decision.

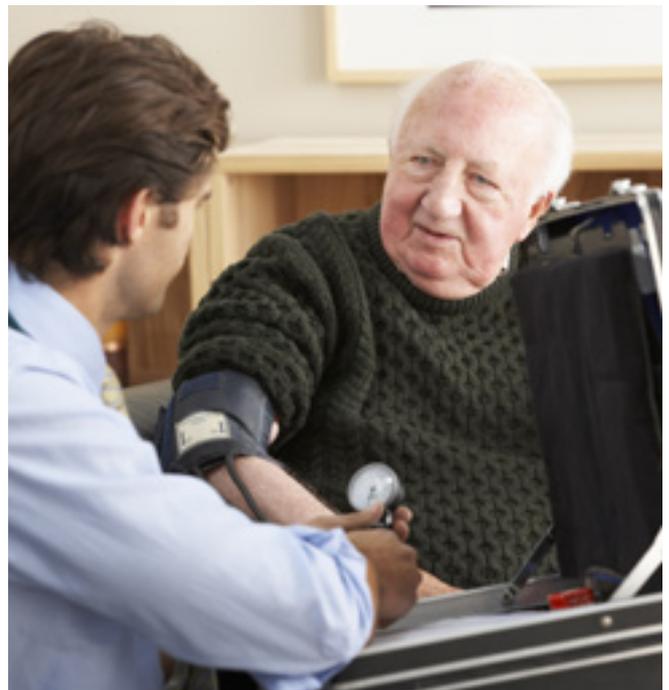
Some unpaid carers have described that it can be difficult if the person with dementia has convinced the GP that they're well. This can mean **families end up at crisis point** before they receive a diagnosis and the support and treatment that comes along with this.

In a situation where you feel the doctor is not listening to your concerns, you have a right to ask for a second opinion. Find out more here: www.wales.nhs.uk/encyclopaedia/s/article/secondopinion

“

I have tried to get support from my GP but so far they just don't seem to understand. Reason for this is that my wife does not think that she needs any help so why should I? It's not her fault but that is the way it is. ”

Carer of a person with dementia



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Referral to a dementia specialist

A GP may refer patients to a specialist dementia unit called a memory clinic. There are **28 NHS memory clinics in Wales**.

A memory clinic is a team of professionals who specialise in diseases like dementia. Health and social care professionals, who form the multidisciplinary team offer diagnosis, treatment, advice and support services. The memory clinic may be a unit in your local hospital, or it may be a service provided by the Community Mental Health Team.

Staff in memory clinics may include:

- medical doctors such as geriatricians and psychiatrists;
- psychologists;
- nurses who specialise in dementia;
- occupational therapists;
- speech and language therapists; and
- social workers.

What happens at each memory clinic varies but **examples of services include:**

- assessments, including home-based assessments, for people with symptoms of dementia;
- access to education and support for carers;
- access to counselling;
- prescription and review of medication; and
- cognitive stimulation therapy. CST is a programme that can help people with dementia improve their memory and thinking skills to help them adjust to memory loss (**NHS England, 2018**).



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www.england.nhs.uk/publication/cognitive-stimulation-therapy-cst-summary-of-evidence-on-cost-effectiveness/

The wait between a GP referral and an appointment at a memory clinic varies. The national standard should be four to six weeks, but may be longer. Speak to your GP or the memory clinic if you are concerned about the length of you have been waiting.

What further tests may be carried by a memory clinic?

- Cognition tests.
- Blood and urine tests.
- Brain scans.

Common brain scans in memory clinics

- Computerised tomography (CT or CAT) scans are carried out by radiographers using x-rays and a computer. A person will need to lie still on their back as the scanner passes over the body.
- Magnetic resonance imaging (MRI) is carried out by radiographers. A large tube called an MRI scanner uses magnetic fields and radio waves to produce images of the body. A person will need to lie still on their back and enter a large tube. It can last 15 – 90 minutes.
- An electroencephalogram (EEG) is carried out by a clinical neurophysiologist and records electrical brain activity. Small sensors are attached to the scalp which are connected by wires to a computer. The procedure lasts 20 – 40 minutes.
- A single-photon emission computerised tomography (SPECT) scan uses nuclear imaging to track blood flow and create a 3D image of the brain. It can be used to investigate which parts of the brain are being affected by dementia.

You can ask for notes of the meeting in which dementia is diagnosed. The documentation may be helpful for administrative purposes and there may have been a lot of information to take in.

Further information

www.ageuk.org.uk

www.nhs.org.uk

www.alzheimers.org.uk



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YOUNG ONSET DEMENTIA

Young onset dementia refers to anyone aged 65 or under who has dementia, and affects around 2,000 to 3,000 people in Wales. Carers of people with young onset dementia benefit from support that is bespoke for them.

It can take longer for younger people with symptoms to get a diagnosis of dementia and there are far fewer tailored support services available. Younger people living with dementia are more likely to be in employment, have dependent children and financial commitments (such as a mortgage).

As a carer of someone with young onset dementia, you may face particular challenges.

- The person you care for may choose not to continue employment, change their employment or be unable to continue employment. This may affect your choices about your own employment too.
- A change in your family finances if the employment of the person you care for is affected, or if your own employment is impacted.
- A change in your relationship with the person with dementia (including **intimate relationships**).
- A social and emotional impact on your family, such as a change to your usual routines, activities and social lives.

You can read in more detail about these issues on www.alzheimers.org.uk.

Much of the information in this guide is relevant for carers of someone with young onset dementia but you may find sections about **getting a diagnosis** (page 9), **employment rights** (page 54) and **support for young carers** (page 27) especially useful.

Meeting other carers who may be familiar with your experiences can also be really beneficial. You can find services for people with young onset dementia, including carers groups that take place across Wales www.youngdementia.org. For example, Cardiff and Vale University Health Board run a service that meet regularly for activities, including a monthly walking group.

YoungDementia UK is a UK-wide network of people where you can find lots of resources, information, advice for carers, and sign-up to regular newsletters.



CARERS' NEEDS ASSESSMENTS

Looking after a person with support needs can impact on carers' health and well-being; employment or education; and personal relationships. In recognition of this, carers' rights are protected in legislation.

The *Social Services and Well-being (Wales) Act 2014* outlines the rights of carers as well as the rights of people who are cared for. It applies to people of all ages. It outlines what local authorities are duty-bound to offer carers and the people they care for. The needs and eligibility for support are identified through a local authority carers' needs assessment.

Remember, health and social care are a devolved function in Wales. This means the Welsh Government, holds responsibility for health and social care in Wales. The UK Government does not hold responsibility for these functions in Wales. Wales has a Welsh Parliament, and a Minister for Health and Social Services. Other functions, such as welfare benefits, are controlled by the UK Government. **You can find out more on the senydd.wales website.**



Impact of caring on older carers

A disproportionate number of **older carers go without the support** they need because they do not identify themselves as a carer.

Research shows that caring can have a more **detrimental effect** on your health, well-being and finances if you are an older person.

Around **65%** of older carers (those aged 60 to 94) have a long-term health problem or disability themselves.

68% of carers say that being a carer has had an adverse effect on their mental health.

A **third** of carers report that they have cancelled treatment or an operation for themselves because of their caring responsibilities.

Key principles of the Social Services and Well-being (Wales) Act 2014

Voice and control

People should be at the centre of care and support.

Prevention and early intervention

People should get support before they reach a crisis point.

Well-being

People should be supported to reach their own well-being goals.

Co-production

Carers and people with care and support needs are encouraged to be involved in designing services.

The Act aims to promote well-being which is defined in a broad sense and includes:

- physical, mental and emotional well-being;
- access to employment, education or training;
- positive personal relationships;
- a social life; and
- safe housing.

Rights protected under the Act

- The right to have information, advice and assistance.
- The right to an assessment if your needs cannot be met by information and advice.
- The right to have your voice heard and have control over decisions about your support.

Read ***Understanding your rights as a carer (Welsh Government)***, at gov.wales/law-care-and-support-carers-rights

You can access information, advice and assistance about your caring role from your local authority. If this is not sufficient to meet your needs, you should be offered a carer's needs assessment. If the assessment reveals that you have needs which meet the eligibility criteria, you have a right to support for them.

An assessment is not compulsory and if you choose not to have one, you are still entitled to information, advice and assistance.



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Carers' needs assessments

The assessment is a formal conversation between you and the local authority to discuss your caring role and your well-being. Sometimes the local authority will ask a carers' service to complete the assessment on their behalf – it still holds the same weight. The assessment should include discussion about:

- whether you are able and willing to provide care;
- whether you are able and willing to continue to provide care;
- outcomes you wish to achieve;
- whether you work or wish to do so;
- whether you are in education or training or would like to be; and
- leisure activities that matter to you.

In the case of a carer who is a child, the assessment should include the

developmental needs of the child, and whether it is appropriate for the child to provide care in light of those needs.

A combined assessment can take place, where your needs as a carer and the person you care for are considered at the same time, but this should only happen with your consent.

Each local authority in Wales offers assessments that fulfil the requirements of the Act, but may carry out assessments differently and fulfil support needs with varying services.

If you are *not* eligible for support, you should still receive information and advice on local services that you can access.

You can also request another assessment if your circumstances change.



Advice to help with your carer's needs assessments

- **Prepare for the assessment.** To help you prepare, use the questions outlined in **Carers Wales'** factsheet. It also outlines how decisions are reached.
- **Ask questions.** During the assessment, ask questions if you are unclear. Your local authority should offer you information, advice and assistance.
- **Bring someone with you for support and confidence.** You can ask to have a family member or friend with you. You're also entitled to have an independent **advocate** with you at the assessment.
- **Access carers' services.** Contact a local carers' service (if there is one separate to the local authority in your area) to help you access and prepare for the assessment. There may be a service to help complete forms too.
- **Attend carers' groups.** Peer support can give you a chance to share concerns, hear other people's experiences and gain confidence. Your local authority should advise you about local groups.
- **Use the complaints procedure.** If you're unhappy with the service, follow the complaints procedure of your local authority.
- **Find specialist support.** If you have specific queries, you can contact organisations who may offer more information. Consider **Carers Wales, Age Cymru, Older People's Commissioner for Wales, Childrens' Commissioner for Wales**, or an organisation that specialises in specific illnesses such as **Alzheimer's Society** or **MS Society**. You can find the links to these organisation's websites in the support and services directory at the back of the guide.



I want support to know what my loved one is entitled to

Carer of a person with dementia



Further information about carers' needs assessments

www.carersuk.org

www.dewis.wales

socialcare.wales

www.alzheimers.org.uk



www.carersuk.org/images/Factsheets/2020-21_factsheets/Assessments_Wales_-_April_2020-21.pdf

Offer of support

If you are eligible for support you should receive:

- a care plan for you that you will need to sign;
- an offer of support based on your eligibility;
- information on practical support available for you;
- information on any benefits or grants you can apply for; and
- information on carers, groups and voluntary services you can access.

You may have to pay for some parts of the services that you are offered, dependent on your needs and financial circumstances. This is discussed in more detail on page 71.

Some of the support on offer may be dependent on the person you care for having a needs assessment (if you have not had a joint assessment).



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Types of support that may be offered to carers

This information is taken from **Carers Wales' factsheet**.

- Information about local carers' groups that can support you.
- Support to improve your health and well-being, e.g. gym and leisure classes.
- Support at home, e.g. help with housework or gardening.
- Help with your transport needs as a carer, e.g. a taxi fare for medical appointments.
- Equipment to help you access information as a carer, such as a laptop.

Types of support that may be offered to people with dementia

- Meals delivered to the person's home.
- Laundry services.
- Adaptations to the home, such as a grab rail.
- Personal care at home.
- A temporary stay in a residential home or a place at a day centre so that the carer can have a break. Read more about respite on page 56.



Planning for emergencies

Unexpected changes in your life may mean you are unable to carry out caring duties temporarily. Preparing for emergencies will give you and the person you care for peace of mind.

Here are some ideas to help you plan:

- If you haven't had one already, consider a **Carer's Needs Assessment** as assessments can include discussions about emergency planning. You can read more about carer's needs assessments on page 15.
- Prepare your own **Emergency Care Plan** detailing information about the person you care for. The plan should lay out the key information someone who is caring for the person you care for may need to know. You can include medications and health information, information about mobility, diet and communication, contact details for health and social care professionals and any other information you feel is relevant. Try to keep this up to date and share the document with family and friends, as well as a social worker, care worker or Personal Assistant if you have one. Read more on **Carers Wales'** and **Marie Curie's** webpages.
- Ahead of time, speak to family members, friends or neighbours who are willing to help you in an emergency. If you think the person with you care for would be happy to call for support, write the contact details of each person somewhere that is visible, or easy to access.
- Keep the contact details for your local adult social service team handy, so that they're easy to find should you or the person you care for need them.
- Your local carers service may be able to help you talk through options and prepare a plan. Some may have templates and guidance to assist you too. Visit **Understanding your rights as a carer (Welsh Government)** for your local services and details of each local authority's Information, Advice and Assistance services.



www.carersuk.org/search/planning-for-emergencies

www.mariecurie.org.uk/help/support/being-there/support-carers/emergency-plan

SPOTLIGHT ON SWANSEA CARERS CENTRE

Helping carers planning for emergencies



Liz Rees and Debra Evans are Hospital Outreach Project Workers at Swansea Carers Centre, a Network Partner of Carers Trust. Liz and Debra guide carers through the practical and emotional challenges of caring for a person who is in hospital, and help carers prepare for emergencies.

‘Carers worry about what would happen to the person they care for if they themselves are taken ill or hospitalised meaning they find themselves unable

to care unexpectedly. We offer carers advice and a template for emergency planning that’s available on **our website**. Carers make preparations based on this and complete the form which allows them to rest assured that plans are in place for their family member. We’re on hand to talk through the plan and discuss any specific worries carers may have. We offer reassurance, guidance and signpost families for specialist support if needed’.



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YOUR OWN WELL-BEING

Caring for a person with dementia can be full of positive and rewarding experiences, but it can also be physically and emotionally challenging. Looking after yourself by taking a break, staying healthy and doing things for yourself is important.

Many people juggle their caring role with employment, education, a young family or other responsibilities. Managing your time and relationships can cause stress and affect well-being. It's normal to feel frustration, resentment or guilt at times, and experience good days and bad days.

The emotional impact of seeing dementia advance in a person can also be significant, especially as the illness can progress unpredictably at times. Carers find it difficult to see the loss of independence and autonomy of the person with dementia.

You have legal rights through the **Social Services and Well-being (Wales) Act 2014** to help you have a life alongside along caring.

68% of older carers stated that caring has had an impact on their mental health.

Around **65%** of older carers have a long-term health problem or disability themselves.

A **third** of carers report that they have cancelled treatment or an operation for themselves because of their **caring responsibilities**.



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We have outlined ideas to help you manage your health and well-being.

Be open

Talking about how you feel can help you feel heard and understood. You can release feelings safely and a different perspective may bring ideas for new ways to approach your challenges.

You can talk to an empathetic friend, family member or neighbour who you trust; you may be surprised at how supportive they are. People may offer you help if they learn you need it, such as to check in on the person you care for in an emergency situation.

You can talk to a health or social care professional too, such as your GP, a nurse or staff at a carers service. They should listen to you and give you the information and advice you need. Don't worry about sharing negative or difficult feelings; professionals are used to hearing about common challenges and are there to offer empathy and support. If they can't help, they should direct you to an organisation who can.

If you are in emotional distress, struggling to cope, or at risk of suicide, call the **Samaritan's** for free on **116 123** at any time of day or night.

Carers' services and support groups

Caring for someone with dementia can be an isolating experience, as both dementia and the impact of caring are not widely understood. Looking after someone with dementia also has specific challenges due to the nature and impact of the illness on the person. For these reasons, speaking with other carers of people with dementia can be really helpful.

Local groups are a source of invaluable support for many. Groups meet regularly and share experiences and tips, laugh together and have a break from thinking about caring.

Carers' services also run courses that can support your well-being, offer counselling sessions or one-off sessions with support workers. Every carers' service is different, but opportunities can include courses on meditation and reflexology, how to manage stress or choirs.

Some sessions are just for you, and some are for you and the person you care for.

On the next page we've highlighted just one of the many excellent services available in Wales, offered by **Carers Trust North Wales**, who provide an opportunity for regular break for carers.



I need people who understand to talk to

Carer of a person with dementia



Find support groups and carers' services

www.wlga.wales/welsh-local-authority-links

www.carers.org/around-the-uk-our-work-in-wales/the-network-in-wales

www.carersuk.org/help-and-advice/get-support/local-support

www.alzheimers.org.uk/find-support-near-you

www.dementivoices.org.uk

SPOTLIGHT ON CARERS TRUST NORTH WALES: Taith Ni carers clubs



Carers Trust North Wales runs regular carers clubs across 11 sites in North Wales. Carers can go along with the person they care for, meet other carers, join in with social activities and have a break from their caring role. Members of the carers clubs value access to a wealth of knowledge and information from staff, and the opportunity to learn from the experience of peers, and say they leave feeling empowered, more confident and less isolated.

'Every week, carers come along to the sessions I run along with the person they care for. Whilst someone leads a session with people who live with dementia, I sit with my members in the carers' corner and we have a good old laugh! Carers benefit from the sessions so much that they drive for miles and miles to come along each week. They come religiously and never miss a session. I love my job and I can see what a huge difference our

service makes for families.

The groups offer a mix of practical and emotional support. We've run sessions on first aid, and how you can organise a Legal Power of Attorney, but we also have quizzes, play games and provide reassurance to let carers know 'we know what you're going through and how tough it is; we're here for you'.

Everyone gets to know each other and form really strong bonds. Members will exchange phone numbers and meet up, or keep in touch via our Facebook group. You can't replace the support carers get from peers, they're the experts after all. Carers will share their own experience of choosing a care home or the challenges they have faced. They will say 'that was me two years ago but you'll get through this, you'll be OK'.

Gwenno Davies, Dementia Support Lead, Carers Trust North Wales



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Online communities and blogs

If it's hard to get out and about to connect with people, you can find communities online too. Sometimes hearing about people's experiences can be helpful. Have a browse until you find something that suits you. Here are some we think are useful:

<https://forum.alzheimers.org.uk/> – online forum

www.takingcare.org.uk – a video library for carers curated by Marie Curie

www.carersuk.org/forum – online forum

www.carersuk.org/help-and-advice/get-support/online-meetups – online meetups

www.tide.uk.net – stories from experts by experience

www.dementiajustaintsexy.blogspot.com – a candid blog by carer Ming Ho

juliasdementiablog.wordpress.com/about – a blog by carer Julia Powell that shares support strategies.



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Books

Reading about caring and dementia can give you information and advice as well as the opportunity to hear other people's stories and experiences. Some carers find it a beneficial tool, that also encourages them to reflect on their own emotions. Reading and understanding about topic that you may be worried about, such as the end of life care, can help you feel more prepared.

The **Reading Agency** has compiled a series of books that you may be interested in, endorsed by health professionals, and are available to order from your local library. There are **specific books about dementia** and health and well-being.

Don't underestimate a short break

Whether you choose to have a walk in the park or a coffee with friends, it is important to do things you enjoy. Even gentle exercise or yoga can be really beneficial to your health.

Learn new skills

tide, 'together in dementia everyday', is a network of carers, former carers and health and care professionals. They recognise that carers of people with dementia are experts by experience and invite people to get involved in public speaking and campaigning. **Find out how to get involved in their movement and take part in the Carers Development Programme**, see link below.

“ **Three ladies who attend our carers' centre are entitled to a number of hours of respite from caring for their husbands. They ask me to arrange care at the same time so they can spend the time together sharing stories, supporting one another and having a well-deserved rest from caring** ”

Dementia support worker



INFORMATION FOR YOUNG CARERS

Wales has the highest proportion of young carers in the UK. Many young people within this group will be caring or helping to care for a parent, grandparent, relative or family friend who has dementia. This can significantly impact a young person's own health and well-being, social life and educational outcomes. Local authorities, educational institutions and carers' services play a crucial role in supporting young people with caring roles.

Friendships and identity

Many young carers report feeling 'different' from peers because of their caring role or, as one carer put it, 'like an adult trapped in a child's body'. Many end up feeling misunderstood and isolated from peers in school and college.

Young carers can also find it difficult to talk about their experiences of caring. Some are worried about stigma, while others don't want to add to their families' worries.

Health and well-being

When young carers do not speak out, there can be a significant impact on their own well-being. Many young carers end up feeling very worried and not asking for help until they reach crisis point. A recent **study** found 30% of young carers aged 15-17 reported physical health problems and 60% reported poor mental health.

Education

Caring for a person with dementia can have a significant impact on a young person's education and experiences at school or college. Missing education or being late due to caring responsibilities can mean young carers do not reach their academic potential.

Young carers also make choices about their education based on their caring roles. For example, many do not choose the further or higher education courses they would like to, as they prioritise their caring responsibilities.



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<https://me-we.eu/wp-content/uploads/2019/05/Me-We-European-brief.pdf>

Support for young carers

Many young people who have caring responsibilities do not realise their life is different from other people's and it can take some time for them to realise they are 'young carers'. This means they miss out on the opportunity to access help and support. Health, education and social care professionals can play a role in signposting young people and families to the local authority, but families can self-refer too.

Young carers must be recognised as carers and included appropriately in conversations about care, including having the opportunity ask any questions they need to. Some local authorities in Wales operate an identification card for young carers to help increase identification and recognition in health, pharmacy and education settings. Carers Trust Wales is funded by Welsh Government to support more local authorities in Wales to take up this approach.

Every local authority in Wales has support available for young carers. The offer of each service is different and may include:

- Regular young carers' clubs which give young carers the chance to have a break from caring, make friends with other young carers' and take part in fun activities or courses to help them learn skills such as CV writing or mindfulness.
- Personalised information, advice and assistance from a young carers or young adult carers support worker.
- Access to individual counselling.
- Signposting for further support.

You can contact your local authority to find out what services are available locally and find out about Carers Trust Network Partner services on page 6.

Young carers rights are protected under the **Social Services and Well-being (Wales) Act**, which means they are entitled to information, advice and assistance. If a young person's needs are not met through this, young carers should be offered, or can request, a **carer's needs assessment**, see page 15.

Schools, colleges and universities can play a crucial role in signposting young people for support and take practical steps to support their learning and education. Carers Trust Wales, funded by Welsh Government, has developed guidance for primary and secondary schools to increase identification, support and understanding in schools. **You can download factsheets, lesson plans and other resources from www.carers.org/wales/education**

Further information about young carers

Carers Trust

<https://carers.org/getting-support-if-you-are-a-young-carer-or-young-adult-carer/getting-support-if-you-are-a-young-carer-or-young-adult-carer>

What is it like to be a young adult in a family affected by a neurological illness? (Masterton-Algar, P and Williams, S, 2020)

<https://fliphtml5.com/hrros/tdfv>

Understanding dementia: A guide for young people (Alzheimer's Scotland)

www.alzscot.org/our-work/dementia-support/information-sheets/understanding-dementia

Carers Trust Wales Youth Council

<https://carers.org/around-the-uk-our-work-in-wales/carers-trust-wales-youth-council>

PAYING FOR CARE AND BENEFITS

Care and support plans outline the needs you have as a carer, and the needs of the person you care for. A financial assessment is carried out by the local authority to determine how much the person with dementia is able contribute to the cost of their care.

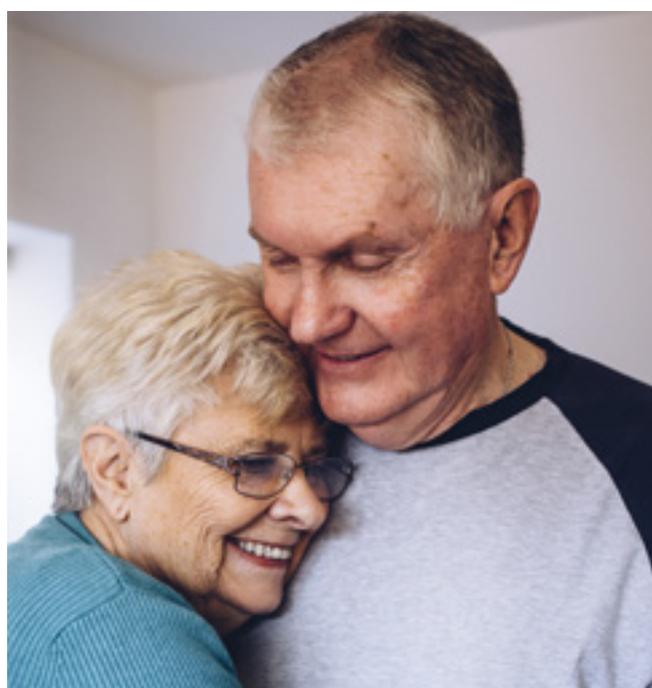
A financial assessment must be undertaken if you wish the local authority to contribute to care costs.

The assessment will consider whether the person with dementia is able to pay towards their care. Possible outcomes are:

- they are asked to pay the full cost of their care;
- they are asked to contribute to a portion of their care; or
- they do not contribute financially and the local authority will cover the costs of care.

You can find information about maximum charges for social care, and how your assets affect your contribution in **Age Cymru's factsheet**.

If the local authority contributes towards care financially then the care will be provided directly by the local authority, or you can arrange your own care that is funded by the local authority via a direct payment.



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Further information about paying for care and support

www.alzheimers.org.uk

www.ageuk.org.uk

www.dewis.wales



www.ageuk.org.uk/globalassets/age-cymru/documents/information-guides-and-factsheets/fs46w.pdf

What is a direct payment?

Direct payments are funds paid by the local authority to be used to pay for care and support. The payment means you have flexibility to choose the most suitable care. You are able to choose to spend the money in the best way to suit you / the person you care for. It can be used in a variety of ways, that include:

- To employ a 'Personal Assistant' (PA) to support the person with dementia.
- Pay for care or respite at home.

The money from direct payments can be used how you see fit to meet the needs outlined in the Care and Support plan. You can find examples of how people in Swansea have used their respite care [here](#).

If direct payment is used to employ a PA, then all the legal obligations of being an employer will need to be fulfilled too.

When does the NHS pay for care?

The health service may be involved in paying for care when needs are primarily related to health.

NHS continuing healthcare is arranged and funded by the NHS for adults with complex health needs and is delivered at home, in care homes or in hospital.

Beacon (0345 548 0300) gives free and independent advice on NHS continuing healthcare. You can find more information on Beacon at their website: www.beaconhc.co.uk

Further information about direct payments

www.citizensadvice.org.uk/wales/family/looking-after-people/direct-payments-w

CLAIMING BENEFITS FOR YOU AND THE PERSON YOU CARE FOR

Caring for someone with dementia can put a strain on household finances. Government benefits and allowances can help eligible carers to meet the costs of caring.

Attendance Allowance

This benefit is for people aged 65 and over who have an illness or disability that means they need care and support to look after themselves and stay safe. People should apply for this benefit when dementia is at a stage where they need assistance to manage day-to-day life and have needed it for at least 6 months. Assistance can include help using the toilet, eating and drinking, communicating, staying safe, or taking medication.

If this benefit is claimed by a person with dementia it means a carer is eligible to apply for Carer's Allowance and other benefits.

It cannot be claimed by people who receive Disability Living Allowance or Personal Independence Payment (PIP).

There are two tiers of rates that are payable: £59.70 per week (care is required during the day *or* in the night) or £89.15 per week (care is required during the day *and* night). If you receive this benefit, you don't need to spend the benefit directly on paying for care.

The benefit is not dependent on income or savings.

Further information on Attendance Allowance

www.gov.uk/attendance-allowance

www.carersuk.org/wales/help-and-advice



I make sure all her bills and money is looked after well

Carer of a person with dementia



Personal Independence Payment (PIP)

This benefit is for people below the age of 65 who have a long-term illness or disability that means they need care and support to look after themselves and stay safe. PIP has replaced Disability Living Allowance, for which no new applicants (over 16) are being accepted.

PIP is assessed on: (i) daily living (£59.70 or £89.15 per week) and (ii) mobility (£23.60 or £62.25 per week).

You can receive PIP whether you are employed or not and entitlement is reviewed regularly.

The Department for Work and Pensions (DWP), ask an assessor to conduct an assessment on their behalf that determines the level of help people receive. It usually takes place at a centre in Wales that people must travel to, but exceptions can be made when this is too difficult, and a home assessment may take place instead.

Some people find the assessment process difficult and overwhelming, so try and prepare as well as you can to minimise your stress.

Housing: Council tax reduction

People living with dementia may be exempt from paying council tax. Carers living with people with dementia may be eligible for council tax reduction. However, in both situations, the person with dementia must meet the 'severe mental impairment category' (SMI), which is "a severe impairment of intelligence and social functioning (however caused) which appears to be permanent".

Council tax is usually based on the number of people living in a home. However, if the person living with dementia lives with you, they may fall under the ruling of 'disregards' which means they are not counted in a council tax calculation. In practice, this means if you live with parents who have dementia, or a partner who has dementia, you would be eligible for a 25% discount off council tax as you would be counted as a single person. However, the person or people living with dementia do not have disregards applied to them automatically, they must meet the SMI category and be eligible for certain benefits, too. If there are two adults in the house that pay council tax, this exemption won't apply.

Exemptions are another form of discount which you may encounter. This is related to the property, not a person. The rules for this, and when properties are empty, can be found on www.alzheimers.org.uk and www.moneysavingexpert.com

What are the benefits you may be entitled to as a carer?

Carer's Allowance

Carer's Allowance is £67.25 per week and is a taxable benefit.

You must be caring for 35 hours a week to be eligible for the benefit.

The person you care for must already be in receipt of PIP, DLA, Attendance Allowance **(or some other benefits)**.

Your earnings from paid employment will impact how much you receive. If you earn over £128 a week you won't be eligible for Carer's Allowance.

To be eligible for this benefit, you cannot be in full-time education.

Carer's Allowance does not increase if you care for more than one person.

Further information on Carer's Allowance

www.gov.uk/pip

www.carersuk.org/wales/help-and-advice/factsheets-carers-wales/carers-allowance-wales

www.ageuk.org.uk/cymru/information-advice/care/find-care-support/



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www.gov.uk/carers-allowance

Carer's Credit

The benefit can help unpaid carers aged 16 – 65 who care over 20 hours a week.

It is not a financial benefit, but a weekly 'credit' on your national insurance credit.

It means people who are not paying National Insurance, because of caring responsibilities can receive 'credit' so that they remain qualified for benefits that include the State Pension.

It is dependent on the cared for person receiving certain benefits, such as DLA.

Considerations

- There may be differences in benefits and allowances in Wales, England and Scotland.
- Carer's benefits may interact with other benefits.
- You can contact your local authority for information and advice.
- You can find information on your local services on page 6. Some services employ benefits' advisors.

Further information on Carer's Credit

www.gov.uk/carers-credit

www.turn2us.org.uk



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CARING FOR A PERSON WITH DEMENTIA

Over time, dementia can cause changes in a person's usual habits, such as what they prefer to eat or their sleeping routines. Family members and friends can find some changes unsettling but access to good information and advice can help you care well for a person with dementia, and maintain a positive relationship with them.

Dementia can change the personality and behaviour of people and affects everyone differently. Seeing changes in a parent, partner or friend can take time to adjust to. Some changes in the person with dementia can be upsetting, exhausting and frustrating for you but there are lots of methods to help you cope. In this chapter we consider common behaviours identified by carers in **research conducted by Alzheimer's Research UK**:

- changes in sleeping patterns;
- restlessness including wandering, pacing and fidgeting;
- repeating phrases, questions or actions again and again; and
- changes in eating and drinking habits.

As well as changes in routine, many people with dementia can also have changes in personality such as stubbornness, agitation and aggression.

The **type and stage of a person's dementia** influences behaviours. Learning more about the specific form of dementia a person has can help you understand what they may be experiencing and explain why they are behaving in a way that you may find difficult.



Sleep

People with dementia can have disrupted sleep patterns. It can take time to find out the reason for this because there are many possible causes, from medical issues to being disturbed by bright lighting in a bedroom

Possible impact of dementia on sleep

- Less sleep overall.
- More sleep in the daytime and more energy in the night.
- Inability to differentiate between night and day.

Possible causes for changes in sleep patterns related to biology and ageing

- Damage to the part of brain that manages our natural clock (circadian rhythm).
- Illnesses or pains unrelated to dementia (such as urinary tract infections or depression).
- A part of the normal ageing process.

Possible causes for changes in sleep patterns related to how comfortable and suitable a person's bedroom is

- Feeling too hot or cold or night.
- Feeling disorientated in their bedroom.
- Struggling to find the toilet easily during the night.

There may be some trial and error involved in finding out the causes of sleep disturbances.

As a carer, if your sleep is interrupted regularly, you will struggle to get enough rest and this can affect your mood and well-being during the day.

Speak to a health professional if you are concerned about the sleeping patterns of person you care for, or how lack of sleep is affecting you.

Ideas to help manage problems with sleep

- Plan physical activity for earlier in the day.
- Avoid caffeine from late afternoon onwards.
- Make the bedroom a comfortable temperature.
- Have appropriate lighting. Unsuitable lighting and mirrors in the room may dazzle or confuse someone with dementia when they wake up at night. Read more on www.nhs.uk
- Consider **telecare equipment** (on page 46) that can wake you if needed.
- Ask a family member or friend to occasionally take over your caring role overnight.
- Have a carer's assessment as this can look at how much sleep you get and you may be entitled to financial help to access overnight support from care workers.

Further information on sleep

www.dementiauk.org/sleep-deprivation-dementia

www.alzheimers.org.uk

www.nhs.uk/live-well/sleep-and-tiredness/how-to-get-to-sleep

Restlessness

Pacing, fidgeting and wandering are common behaviours in certain types of dementia.

Possible reasons for restlessness

- A person with dementia may be finding it difficult to communicate their needs. They may be feeling bored, anxious or in pain.
- Confusion and disorientation can mean a person with dementia may feel they are in an unfamiliar place. This may be particularly noticeable at dusk and is known as 'sundowning'.
- Trying to find someone or something from the past.

Ideas on how to manage restlessness

- If you are able to provide a safe space to walk, such as a secure garden, there is no need to ask the person with dementia not to walk around.
- Speak and listen to the person with dementia to reassure them that they are safe.

- Remove items such as coats, handbags and shoes away from the door as these may encourage a person with dementia to attempt to leave. You can also try covering a door with a curtain.
- Speak to a professional about how **assistive technologies** (page 46) could help you and the person you care for. For example, a tracking device.
- The Herbert Protocol form helps police identify vulnerable adults if they go missing. Find the links to complete the forms for South Wales and North Wales in the footnotes below.

People with dementia can carry a **helpcard** or wear an **Alzheimer's pin badge**. You can find out more about these on Alzheimers.org.uk



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www.south-wales.police.uk/cy/cyngor/helpu-i-gadw-oedolion-syn-agored-i-niwed-sydd-a-chlefyd-alzheimer-neu-ddementia-yn-ddiogel-protocol-herbert/

www.north-wales.police.uk/advice-and-support/stay-safe/herbert-protocol?lang=cy-gb

Eating and drinking

Eating a varied, healthy diet and drinking plenty of water helps everyone, including people with dementia, to stay well physically and mentally. Being under-nourished and lacking the right vitamins and minerals can cause or worsen health problems related to dementia.

Concerns about eating and drinking are very common amongst carers of people with dementia. Mealtimes can be challenging, particularly for those caring for people with more advanced dementia.

Challenges people with dementia may face around eating and drinking

- Not recognising or articulating hunger or thirst.
- Forgetting to eat.
- Forgetting how to use cutlery.
- Struggling due to poor co-ordination.
- Loss of appetite or interest in food.
- Eating more than usual or overeating.
- Preferring sweeter tastes.
- Trying to eat items that are not food, such as napkins, or food that is out of date.
- Refusing food including spitting or holding food in the mouth.
- Eating unusual combinations of food.

Common concerns carers have about eating and drinking

- Being unsure about what a healthy diet for a person with dementia consists of.
- Worrying about weight loss.
- Finding it difficult to support the person with dementia to eat and drink independently.

- Feeling frustrated by failing to encourage the person to eat, or eat nutritious food.

Ideas on how to manage challenges at mealtimes

- Keep track of problems, likes and dislikes so you can talk about them with a health professional.
- If someone is refusing to eat, try your best to find out why. For example, depression can cause low appetite and paranoia can lead to fear around food. You may need professional advice for this.
- Provide meals and snacks that are rich in nutrients. Make sure you know what a good, healthy diet looks like. You can speak with a dietician or health professional for advice about food and nutrients.
- Serve meals in a calm environment, with no distractions.
- Sounds and smells from preparing food can encourage appetites so involve the person you care for in cooking meals if you can.
- Make sure you offer meals and snacks frequently but in smaller portions.
- Present food that is suitable and safe for the person you're caring for. This may be finger food to help maintain independence, or perhaps puréed food if swallowing is difficult.
- At mealtimes, encourage the person you care for to eat, by acting out good techniques and repeating reminders such as 'open your mouth' and 'chew the food' out loud.
- Serve one course at a time to make sure not to overwhelm the person you care for.
- Keep offering food at each mealtime even if previous meals have been refused.

- Include sweet and savoury food so that even people who prefer sweeter food are being offered a range of nutrients.
- Allow people to take their time at mealtimes and offer a choice of food.
- Touching the person you care for on their arm, or singing can encourage people to eat.

Some of the information above is taken from Stanner, S (2007) *Nursing & Residential Care*. Volume 9(1). Sara Stanner is Science Director at the British Nutrition Foundation.



Source: Public Health England in association with the Welsh Government, Food Standards Scotland and the Food Standards Agency in Northern Ireland

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COMMUNICATION IN DEMENTIA

We have conversations many times a day and although we may not realise, this communication is a very complex brain process. Dementia can impact on a person's language, memory and comprehension making the complexity of this process more apparent. Carers and people with dementia can have difficulty working out what the other person does and doesn't already know. Since this can result in misunderstandings about what was meant, it can lead to frustration on both sides.

When we communicate, we take a lot of information for granted, including the context that we're in. But dementia can make it difficult for a person to keep up with the context. This can include what's just been said, what happened earlier, and where and why the conversation is taking place and even the role or relationship with the other person. Because of this, a person with dementia might, for example, say something in a way that sounds like it is news, when in fact the other person already knows about it. They might say something that comes across as rude, ask for something it's impossible to provide, or make a comment that it's hard to make sense of.

This can lead to confusion, frustration or anger for carers, and this can then cause embarrassment or disappointment in the person with dementia. If communication does not go well, it can cause a cycle of negativity in relationships.



I try to listen carefully enough to understand what causes the changing behaviour problems and work out how best to diffuse the situation

Carer of a person with dementia



Communication challenges between carers and people with dementia

Challenge	Possible solution
Difficulties with hearing or seeing clearly.	<p>Make sure the person is wearing their hearing aids and glasses and that you face them so they can lipread too.</p> <p>Try and think about your surroundings. For example, if you are standing in front of a bright window your face may be in shade. This will make it harder for the person you're speaking with to read facial expressions or to lipread.</p> <p>It can also help to speak more slowly and simply.</p>
Struggling to find the right word. For example saying <i>fire</i> instead of <i>birthday candle</i> .	<p>Be patient and try and take the time to look for the meaning behind the words the person you are speaking with is using.</p> <p>Try not to speak over or correct the person you are speaking with.</p>
Difficulty storing information about recent events. people may ask questions to help them to rebuild the information that's missing.	<p>Be patient and relay information in a non-confrontational way. Remember, the person you are speaking with may be confused and trying to gather information to make sense of their surroundings. It can be helpful to keep notes or a memory book to help empower the person you're caring for to clarify information without having to ask you.</p>
Forgetting who people are.	<p>It can be very upsetting if the person you care for forgets who you are. At first, this is likely to be temporary, but over time the person you care for may be less able than before to put a name to your face or recall the relationship.</p> <p>Giving reminders and cues can be very helpful. For professionals this may include wearing a uniform or name tag. At home it can be helpful to write names by photographs and to give context within conversations. For example, you might say 'my brother Dafydd' rather than simply saying 'Dafydd'.</p>
Difficulty producing and understanding spoken language.	<p>If this happens, then touch (such as a hug or holding hands) can give mutual comfort. It can also be helpful to have memory books to share or to do something with the person you care for that you both enjoy, such as singing.</p>

Challenge

Difficulty keeping up with the context information

Possible solutions

To help a person with dementia, you can use the names of people, objects and activities more often, instead of, *she, them, that* and so on. For example, instead of *I saw Sian on my way back and she's fine now he's come home*, you could say: *I saw Sian when on my way home from shopping. I said, 'Sian, how are you?' and she told me she's fine now that her husband Robert is out of hospital,*

Try to avoid questions that need context such as *'did you have a nice time this morning'*. Switch it to *'did you have a nice time when you went to the garden centre this morning?'*

Using the context around you may help you recognise what the person with dementia is referring to. If they can't always recall of information, they may rely more on what they can see and hear, or on memories from long ago that they can recall more easily.

Also, keep in mind that they may not be able to estimate what you already know, so they might assume you already know what they are talking about. Rather than getting frustrated, you could try checking out possibilities, such as saying *'oh, are you talking about Ellen's wedding?'*

Use your knowledge of their personality and life to help you. It will often be easier for you to try to navigate their thought patterns, than for them to make sense of yours. Keep in mind that new contexts are more difficult to process, so keeping to routines can help. This doesn't mean you can't go out to more than one café, just that it's worth noticing whether the person is more able to take in the context when it's a place they've been to before (even if they don't recall being there).

If you want to get a good conversation going, then try visiting a familiar place or a museum with a display from an earlier time in their life. Alternatively, look at books with pictures from the time in their life they can best recall. Instead of asking questions, make comments, as this is easier to respond to. Instead of saying *'do you remember that?'* and *'what was that called?'* say things like *'ooh, look at that!'*, and *'that looks interesting'*, and *'I wonder how long it took to do the washing in those days'*. This gives the person an opportunity to say something if they have something to say, and not to if they don't, whereas a question forces them to reply.

Challenge

Frustration

Possible solution

It's important to recognise that we all communicate for a reason, and if we're unsuccessful in getting our meaning across, we're likely to get frustrated. This is equally true for people with dementia and for carers.

To help minimise frustration, you can do two things. When it's the person with dementia who's frustrated, reassure them that you want to try and help them get their message across. Try not to dismiss their words even if they don't appear to make sense or seem out of context. Instead, consider *what might be behind what they are saying*.

When it's you that's getting frustrated, the most important things are to notice that you are, and then to remember that it's the situation that's frustrating, not the person you're communicating with. Although it might be difficult, it's better to say *right, let's try a different way*, rather than letting the person feel that you are angry with them, because that will just make them feel worse.

Listening and respecting the person you care for helps to maintain their dignity and personhood. However, it can be very challenging for you.

Getting frustrated is a normal reaction but it can be negative for both you and the person you care for if it isn't managed properly. Reach out for advice from professionals and peers and give yourself the time and space to take a breath and get some space.

Don't assume yesterday's challenges will repeat themselves. Dementia symptoms can vary from moment to moment. It's worth trying again.

Some of the information in this chapter draws on a presentation **Professor Alison Wray**, Cardiff University, that you can watch that you can watch on Youtube using the link provided in the footnotes... in which she introduces her book '*The Dynamics of Dementia Communication*' (OUP, 2020).



www.cardiff.ac.uk/people/view/99217-wray-alison

www.youtube.com/watch?v=ZIMsN-_KG3k&feature=youtu.be

HELPING THE PERSON YOU CARE FOR TO STAY HEALTHY AND INDEPENDENT

People with a diagnosis of dementia can continue to lead happy and fulfilling lives. This can include keeping up with hobbies and interests, having a good social life and staying independent.

The likes and dislikes of the person you care for and their ability may change over time but encouraging people to retain confidence and continue to be independent has lots of benefits. You don't need to rush to make lots of changes to routines at once, it could take some time before the condition worsens and maintaining activity has many positive health benefits.

Health and wellness

Many people with dementia have other health problems alongside dementia. Attending check-ups for eyesight and hearing, medical appointments and any regular therapy such as physiotherapy is important. It means the person with dementia is receiving appropriate treatments, and gives professionals the opportunity to identify emerging health concerns early.

Supporting the person you care for to stay active and healthy

If dementia begins to affect a person's muscles and movement, they may reduce the amount of exercise they used to do (Eggermont, 2006). However, promoting physical activity (that is suitable and appropriate) is really beneficial for physical health and general well-being. It's also a great way to socialise and have fun. Follow

the links in the box for useful hints and tips. Promoting physical activity that works for everyone is beneficial for physical health and general well-being. It's also a great way to socialise and have fun.

Exercise can help people with dementia to:

- stay strong;
- boost their physical health;
- be able to continue to move around freely and comfortably (Pitkälä et al, 2013);
- continue to complete day-to-day tasks independently (Pitkälä et al, 2013);
- sleep better; and
- improve their mood and well-being.



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Singing and music

Singing and music can be enjoyed at home or in a regular group. It's a fun activity that boosts well-being for carers and people with dementia. Lots of choirs sing across Wales. Some carers enjoy taking part alone to meet up with friends, and others enjoy taking part in it as a shared activity with the person they care for.

The Forget-me-Not Chorus runs free community sessions in Cardiff, Newport and Colwyn Bay. It's for carers and people with dementia to enjoy together.

www.forgetmenotchorus.com
02922 362 064

Swansea Carers Choir is a weekly session for unpaid carers.

www.facebook.com/SwanseaCarersChoir
07851 381966

Bridgend Carers Choir is a weekly session for unpaid carers.

www.bridgendcarers.co.uk

Contact your local carers' service to find out about choirs in your area.

Staying independent at home

Tips to support the person you care for to stay independent

- Placing labels on doors and cupboards can remind people where items are kept, or anything they need to remember, such as closing the refrigerator door.
- Place important numbers by the telephone so they're easy to access.
- Put notes on the back and front door, that remind a person with dementia to take a key when they are going out.
- Having visual reminders about the date, appointments and upcoming events means a person with dementia can check as often as they would like to. A calendar, a timetable just for the week, or seasonal decorations can all be helpful.
- Care & Repair Cymru works to ensure that older people have homes that are safe, secure and appropriate to their needs. They help people aged 60 or over,



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and people with disabilities to improve, repair or adapt homes, such as following a hospital stay. Some services may be chargeable dependant on eligibility, so it is best to visit www.careandrepair.org.uk to ask what services are available in your area.

- The WaterSure scheme can help customers who medical condition which means they use a lot of water at home (e.g. incontinence) to make bills affordable. The scheme is open to people who have a water meter and are entitled to qualifying benefits. You can visit www.dwrcymru.com for more information.

Assistive technology

Assistive technology is a term for any product or system that is designed to help a person complete tasks that they would otherwise find difficult to do, or that makes a task safer to do. It can also include equipment that is not specially designed for people with dementia, but is helpful, such as **'Alexa'**, an Amazon product.

Examples of assistive technologies

- Safety and security equipment (such as tracking devices or home safety devices such as cooker alarms, lights that switch on automatically triggered by motion of a person getting out of bed at night).
- Equipment to support memory and orientation such as calendars and clocks that include additional information such as letting a person know whether it is morning or evening.
- Equipment to support social interaction and leisure activities, e.g. a telephone that can be programmed so the person who uses it simply presses an image of the person they wish to call.

Benefits of using such assistive technologies

- help the person you care for to live at

home independently

- boost self-confidence and well-being of the person with dementia as they complete daily tasks independently
- help you to promote the safety of the person you care for

Problems that carers note with assistive technologies

- They can be expensive.
- Some carers are unsure what is the most suitable equipment for them.
- Some carers lack confidence in using some technology.
- Some equipment may lead to **ethical questions** such as whether it's appropriate to monitor a person's movements.
- Some people with dementia resist using the technology, for example refusing to wear a GPS tracker.

Accessing assistive technology

A needs assessment and carer's needs assessment will ascertain whether you meet eligibility criteria for specialist equipment and, depending on your financial situation, the local authority may contribute to costs. Occupational therapists play an important role in advising carers and the person with dementia; you will need to speak to your GP, the memory clinic or social services team in your local authority to find out how to access occupational therapy. You can also buy technology yourself.

VAT relief can help with the financial costs of assistive technologies and home adaptations

A person with dementia who has 'a physical or mental impairment that affects their ability to carry out everyday activities' qualifies them for VAT relief for people with disabilities and long-term illnesses.

This can be applied when purchasing items designed to aid a person's independence, and includes the cost of installation and repair.

Read more about VAT relief at www.gov.uk/financial-help-disabled/vat-relief

Getting out and about

Whether you are doing some shopping, going to a hospital appointment or having a day out there are many practical tools to help you, and the person you care for, including in an emergency situation.

- Many local authorities and carers services operate an **emergency card scheme** for carers.
- **Visitor attractions** or leisure facilities may offer discounts to you and the person you care for, so it's worth doing some research in **advance**. For example, Hynt is a scheme that helps people with impairments and access requirements visit theatres and arts centres in Wales. **Read about the eligibility criteria for Hynt** at www.hynt.co.uk/en/join/eligibility-criteria
- The UK Cinema Association also offer a CEA Card that lets a cinema guest with a disability to receive a complimentary ticket for someone to go with them when they visit a participating cinema. Find out more from www.ceacard.co.uk
- People who are disabled or have a health condition that affects your mobility, or have a hidden disability, can apply for a **Blue Badge**. You can apply for a blue badge from your **local authority** and find information in **Who is eligible for a Blue Badge? (Welsh Government)**.

What is an occupational therapist?

An occupational therapist helps people to be able to fulfil the tasks that matter to them, when an illness, disability or getting older have made it more difficult for them. An 'occupation' could be daily tasks such as washing and eating; continuing employment or education; or leisure activities and hobbies. An OT can support a person with dementia to learn or relearn tasks, suggest a more manageable approach to complete the activity, or provide/recommend equipment or adaptations to make activities easier.

Your local authority may have advice about local grants.

Carers Trust Network Partners offer grants for carers or you can **access other grants**.

- **Helpcards** are available for people with dementia to use and carry with them, to make it easier to get help or assistance when they're out in the community.
- The **Welsh Ambulance Service** have committed to improving the experiences of people with dementia and their carers, who use ambulances for emergencies and planned transport.
- The National Key Scheme offers disabled people independent access to locked public toilets around the country. You can purchase a key for £4.75 (excluding VAT) from www.disabilityrightsuk.org.



<https://carers.org/out-and-about/blue-badge-parking-scheme>

<https://carers.org/grants-and-discounts/introduction>

<https://gov.wales/sites/default/files/publications/2017-09/who-is-eligible-for-a-blue-badge.pdf>

www.alzheimers.org.uk/get-support/publications-and-factsheets/helpcards

- The Sunflower Lanyard scheme is a discreet badge or lanyard that people who need a little extra support and time, or have a hidden disability, can wear to let staff (in participating venues) know that they may need additional help and support. Around Wales, many stores, hospitals and transport facilities, including Cardiff Airport, have signed up to the scheme. Sunflower lanyards can be requested (at no cost) from companies or organisations participating in the scheme. Find out who is participating local to you from www.hiddendisabilitiesstore.com

Driving

Many people with dementia continue to drive safely in the early stages of dementia. Whilst people with dementia do not have to stop driving immediately, it is compulsory to inform the DVLA. Once the DVLA have received the notice, they may contact a person's GP, or ask the person with dementia to attend a driving assessment.

Many people with dementia continue to drive for some time after their diagnosis but as most types of dementia are progressive it is likely there may need to be a conversation about eventually stopping driving. The decision to stop can be a difficult one to come to terms with. It can be a difficult conversation to have with the person you care for, especially as they may not realise that it is not suitable for them to drive anymore. Balancing the promotion of self-confidence with explaining that their driving skills are no longer safe is difficult but it is important to have these conversations if you have any concern regarding their safety or the safety of others.

Further information on driving

www.lifechangestrust.org.uk/sites/default/files/Driving%20with%20Dementia%20website.pdf

www.gov.uk/driving-medical-conditions

Further information on getting out and about

<https://carers.org/out-and-about/out-and-about>

MANAGING MEDICINES

Carers play an important role in handling and administering medicine for the person they care for. However, it is a common source of worry for carers and many do not feel confident managing medicines.

Many unpaid carers help a person with dementia to manage medication. You may need to make sure there is enough medication at home, collect repeat prescriptions and manage multiple medications if the person you care for has other illnesses alongside dementia. We've worked with **Community Pharmacy Wales** to offer you guidance that may help you.

Seeking advice

Most pharmacies offer private consultations with the pharmacist to review medication after a person has been discharged from hospital. These are called **discharge medicines review** and are an opportunity to discuss prescription changes, find out more about new medications a person has been prescribed and understand how to get the best out of them. Some hospitals will let the pharmacy know that the person with dementia has been discharged from hospital and that their prescription has changed, but you can remind or alert the pharmacy yourself and ask to book a discharge medicines review. As a carer, you can be involved in the consultation, with the consent of the person with dementia, or if you have **power of attorney**. Find out more about power of attorney on page 73.

If you have any concerns or unsure about a matter relating to medication for the person

you care for, speak to your local pharmacy or GP surgery, so they can advise you. The following page has some questions you may want to make sure you know the answers to. Remember, that you'll need to the permission of the person with dementia for you to be present when discussing their medication, or have **power of attorney**.

Many people benefit from hearing the experience of other carers at drop-in sessions or on online discussion forums, but remember to seek professional advice before making changes to how you store and administer medication.

Organising medicine

You may need to remind the person with dementia to take their medication. We've set out some steps you can take at home to help you manage, but you and the person you care for should approach your pharmacy or GP about worries and concerns about medication.

You can set an alarm on a phone, or consider making use of phone applications and other assistive technology to help you. For example, you can set 'Alexa' to remind a person with dementia to take medication. This gives a regular prompt to a person to take medication and if they are upset at having to take medication; the frustration is



www.cpwales.org.uk/

[www.cpwales.org.uk/getattachment/Services-and-commissioning/Advanced-Services/Discharge-Medicines-Review-\(DMR\)/A5-bilingual-leaflet-for-promotion-of-DMR-Service.pdf.aspx?lang=en-GB](http://www.cpwales.org.uk/getattachment/Services-and-commissioning/Advanced-Services/Discharge-Medicines-Review-(DMR)/A5-bilingual-leaflet-for-promotion-of-DMR-Service.pdf.aspx?lang=en-GB)

taken out on the technology, not you. Some carers like to set one prompt, with another alert shortly after as an additional reminder.

Mark a calendar with dates you know you will need to order new medicines. Remember to note where you need to re-order each medicine; it won't always be possible for medication to be available from the same pharmacy.

Storing medicine

Ideally, all medication should be kept in the container it is supplied in and stored in a cool, dry place. If you are having difficulty with organising medication for the person you care for though, ask your local pharmacy whether there are ways to make things easier. Options that may be offered include making the ordering process simpler or, in some cases, if there is a specific need identified for the person with dementia, medications can be packaged in blister packs.

Dosette boxes (or compliance aids) are a helpful way of arranging medications to help make sure the right medication, at the right dose, is being taken each day. However, before using a compliance aid you have purchased yourself (such as a pill box), seek advice from your pharmacy as this way of storing medication is not suitable for some medication and can make them less effective.

If a person refuses to take medication

Encourage the person to speak to their GP or pharmacist. Determining why someone does not want to take medication can help with finding a solution. For example, it may cause unwanted side effects, be difficult to swallow or have an unpleasant taste. Medication can sometimes be given in a different form which might make all the difference. **Read more about people with dementia refusing to take medicine here** www.alzheimers.org.uk.

Questions you may want to ask at the pharmacy

- What does this medication do?
- How and when should it be taken?
- How do I/we know it's helping?
- What side effects are most likely from this medication?
- What should I/we do if these side effects happen?
- What if the person I care for stops taking it, or takes the wrong dose?
- How does this mix with other medication such as over the counter painkillers or indigestion tablets, complementary and herbal remedies, or with food and drink?
- Do they really need to take all this medication?
- Is there anything that can help to remind the person I care for to take their medication?
- Can the medication come in any other form, for example as a liquid (this can sometimes be arranged for example, if the person you care for has difficulty swallowing tablets)?
- Is it possible to make the medication label large print to make it easier to read?
- Is there an alternative medication that is suitable for the dietary requirements of the person I care for (for example, not containing alcohol or animal products)?



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CARERS AND PEOPLE WITH DEMENTIA FROM ETHNIC MINORITIES

Wales has a rich diversity of cultures, languages and religions. People who are from an ethnic minority can face specific challenges in their caring role and in accessing appropriate help for themselves and the person they care for.

In our guide, we've shared ideas on how you can **look after your own well-being as a carer** on page 22, but it's important to remember that caring is a choice. You are entitled to speak honestly and openly about the impact caring has on your life, as well as your ability and willingness to care. Professionals should not make any assumptions about this based on your ethnicity or culture.

Research has shown that in many communities carers are less likely to realise that they have specific rights that can support them in their caring role. You are entitled to information and advice to help you in your caring role. If you need more support you are entitled to a **carer's needs assessment** and, if the needs you have are eligible, a care and support plan will be created for you. You have a right to be well and safe and to choose not to continue caring if you no longer want or feel able to. Read about **carers' rights** on page 16 and **carer's needs assessment** on page 15.

Carers' services

Carers' services exist to support the needs of all carers, and this includes you. Each local authority, and also local charities, offer a range of support services for carers that include weekly coffee sessions, counselling, well-being courses and choirs. Sometimes, there are sessions for particular communities. For example, Swansea Carers Centre ran sessions for Chinese parent carers and have recently begun a weekly men's group. **Get in touch with your local authority or carers' service** (on page 6) for information on current activities.

One organisation in Wales that supports carers from ethnic minorities exclusively is **Carers' Cube Newport**. The independent community group sees carers meet regularly to socialise, support each other and can find out about other local services.

Organisations that cater for the needs of people from ethnic minorities in Wales occasionally host events or resources for carers' too, so it is worth contacting them to ask. For example, **Diverse Cymru** and **Ethnic Minorities & Youth Support Team**, **Race Alliance Wales** and **Women Connect First**.



www.diverseecymru.org.uk/

<http://eyst.org.uk/contact.php>

www.womenconnectfirst.org.uk/contact/

BAME Helpline Wales is a national multi-lingual telephone helpline funded by Welsh Government, for adults seeking information, referrals and signposting. You can speak to an advisor about issues related to health, work, welfare entitlements, education, housing and personal safety.

Equality Act 2010

Every carer in Wales is entitled to access the information they need and any support they are eligible for, regardless of their ethnicity. You should not be excluded from accessing information, advice and assistance from your local authority based on your race or ethnicity. Your rights are protected under law too, as part of the Equality Act 2010. The Equality Act 2010 is applicable to organisations, including care homes, who provide a service to the public. The Act prohibits harassment and discrimination against people based on 'protected characteristics', that include race and religion. Read more on **Race Council Cymru**, **Carers UK**, **Citizen's Advice** and **Equality Advisory and Support Service (EASS)**.

Access to information

Dementia is a health condition with medical causes. Stigma around dementia is widespread in many communities but dementia is a common condition and not something anyone should be blamed for or ashamed of.

If there is stigma attached to dementia within your community you can use this guide and order leaflets from **Alzheimer's UK** to help explain dementia to friends and family members. The Alzheimer's society have produced a guide for people with a new diagnosis of dementia in **several different languages including Urdu, Arabic and Chinese**. If you prefer, you can access the **video format** of the guide in English. **Meri Yaadein**, an initiative in Bradford, have case studies of people who live with dementia on their website. You can read these at www.meriyadain.co.uk/case-studies



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<https://bame.wales/>
<https://racecouncilcymru.org.uk/know-your-rights>
www.equalityadvisoryservice.com
www.alzheimers.org.uk/get-support/publications-and-factsheets/publications-other-languages
www.youtube.com/watch?v=RLBuyglcttU
www.meriyadain.co.uk/case-studies

Care homes

If you access a service for the person you care for, such as **respite care, domiciliary care or a care home** (page 58), ask questions so you can be confident the care will be suitable for the person with dementia and cater for their cultural needs. For example:

- Does the care home have an equality and diversity policy? Are staff open to talking about the cultural needs of the person with dementia?
- Can respite care hours be given at a time that is suitable for you? For example, some Muslims may like to have care provided at a time that means they can attend the special Friday afternoon prayers at a mosque.
- Is the care home able to provide food that meets the cultural and religious needs of the person with dementia?
- Are care staff aware of the languages or memories that person with dementia may revert back to at times? You can print or order a copy of the **'This is me'** template to document the information that matters to the person with dementia and share it with care staff or social workers.
- Are care staff aware, or willing to learn, how to care well in a culturally appropriate way? For example, do they know how to care for the type of hair the person with dementia has, including special combs or shampoos?

If you experience racism within a care home, this is a breach of the Social Services and Well-being (Wales) Act. In this instance, you should speak to a care home manager about your experience. If you are unsatisfied with the outcome, you can make a formal complaint to the service provider according to their procedures. You can also contact **Care Inspectorate Wales** to raise a concern, and, if you are an older person, **Age Cymru** or **Older People's Commissioner for Wales** for advice based on your circumstance.

It's important the experiences of carers heard by decision makers or shared in news and media stories include voices representing diverse cultures and ethnicities. This is essential to making sure services are inclusive and work for everyone. If you're interested in raising awareness about caring in your community, consider joining **tide**, a network for people who are creating positive change in Wales for carers of people with dementia. As a carer, you are already an expert in caring so if you would like to use your knowledge and skills for campaigning, sign up for a training programme with **tide**. It's a chance to build up your speaking and advocacy skills, meet other carers and be part of a social movement for change.



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www.alzheimers.org.uk/get-support/publications-factsheets/this-is-me

<https://careinspectorate.wales/contact-us/raise-concern>

www.ageuk.org.uk/cymru/information-advice

www.olderpeoplewales.com/en/assistance.asp

www.tide.uk.net/our-work-in-wales

WORK AND CARING

Being in employment and caring for someone with dementia can be difficult, especially as the demands of your caring role increase. Employment also affects receipt of Carer's Allowance.

All employees in the UK with caring roles have certain statutory rights and include:

- A right to have a request for flexible working considered.
- Time off for emergencies. This is usually one or two days and unpaid.
- Parental leave.

In addition, some employers will have policies and support for carers. This may include time off for caring responsibilities or carers support groups. It is worth asking your employer for details about the support available to you. You could also talk to a trade union representative.

It is a good idea to talk to your manager about any adjustments to your working arrangements that you may need in the short or long-term.

Tips to have a positive conversation with your employer

- Remember that employers value communication and honesty.
- Find a time convenient for both of you, and a private and quiet place.
- Make sure you both have plenty of time, so the conversation is not rushed.
- Think about what you are willing to share regarding your caring role.
- Think about how your caring role may affect your work.
- Think about solutions before the meeting.
- Write down what you both agreed.

Further information about work and caring

www.carersuk.org/help-and-advice/work-and-career/other-rights-at-work

Juggling work and unpaid care (Carers UK) www.carersuk.org/images/News_and_campaigns/Juggling_work_and_unpaid_care_report_final_WEB.pdf

WELSH LANGUAGE AND CULTURE

Getting the help and support you or the person you care for need in the language of your choice is important. As well as making you feel comfortable it can help make sure you're getting the right information and assistance.

Organisations can play an important role in making resources and services available in Welsh and English, and public bodies must adhere to the Active Offer in Wales. This means they must provide services for people in the language of their choice, whether that is Welsh or English. The Active Offer is not simply about receiving information, advice or assistance in Welsh, but creating an ethos where the Welsh language and culture, are respected and valued, and no language is given greater weight than the other.

As a carer, you shouldn't have to ask for a Carer's Needs Assessment to be undertaken in Welsh, instead your local authority should proactively ask you for your preferred language of communication before any meeting takes place. If this doesn't happen it's important that you let them know if you're not being communicated with in your language of choice as soon as possible.

Building a good rapport with a professional, particularly during a difficult or upsetting conversation in a second language can mean that you're less able to convey information about your well-being or the impact of caring on you as confidently as you would otherwise. This can risk professionals not being able to capture or assess your needs adequately meaning you may miss out on the appropriate support or advice.

Using a person's preferred language is particularly important in dementia care. Dementia can progress in a manner which means it easier to use a language which was familiar in earlier years, even though a person may not have used it for a long time. In Wales, this can mean that communicating in English can be an additional challenge and Welsh is the only language they can use to convey their wishes or responses. This is another reason it is so important that health and social care professional take a person-centred approach when working with someone with dementia and their family or carers.

Dr Catrin Hedd Jones, School of Health Sciences, Bangor University

“No one should be expected to take cognitive tests or describe their feelings in a language that they do not use on a day-to-day basis as this increases the risk of incomplete information and miscommunication. There tends to be a misplaced self-consciousness by many that the standard of their spoken Welsh is not good enough. As St David uttered “do the little things” and we now have a range of online tools to support people to build on their skills and confidence to speak Welsh. Research has suggested that access to memories are linked to the language used when the events first occurred. Music is important to many as songs often relate to identity and a shared cultural history. This is why

we created a playlist of Welsh medium songs as a gift for care homes to share with residents. The playlist is available to support carers that may not be familiar with Welsh songs and you can download *Cân y Gân* from <http://dcdc.bangor.ac.uk/welsh-music.php.en> International research has shown that a shared language and culture within care homes can have a positive impact the residents’ happiness as this supports understanding and social connection. Language is not a choice, but a clinical and emotional need and it is vital that this is understood to reduce the risk of Welsh speakers becoming increasing isolated as they live with dementia”.



Links

Read a research briefing by Dr Catrin Hedd Jones for the Welsh Parliament (formerly National Assembly of Wales) (February 2018) on www.assembly.wales/research%20documents/18-017/18-017-web-english.pdf

Find a book written in Welsh that shares the experiences people living with dementia, and the professionals who worked with them on www.siopypentan.co.uk/products/na-ad-fin-angof-byw-a-dementia

The Social Care Wales’ website has a good explanation of the Active Offer, as well as further information for care and support staff on www.socialcare.wales

You can read a report about the importance of the Welsh language in dementia care on this link <https://bit.ly/3bicqht>

HELP WITH CARING

Looking after someone with dementia can be difficult and many carers can struggle to ask for help. Dementia is a progressive condition so the type of support a carer needs will change over time, too.

Recognising difficulties early on and seeking support, rather than reaching crisis point, is better for your long-term well-being and for the person you care for. Asking for help isn't a sign of weakness, or lack of compassion. You have a legal right to have your needs assessed and to have any eligible needs identified by an assessment met. You do not need to struggle alone.

“ Following my carer's needs assessment, I can ask NEWCIS to arrange care for my husband so I can attend my own hospital appointments. It's a weight of my mind because if I can't look after myself, I can't look after my husband. ”

Carer of a person with dementia

Sharing care with family and friends

Let the people around you know what type of support you need. Family, friends and neighbours may offer to help if you tell them what assistance you need. They could help by:

- sitting with the person you care for whilst you attend an appointment,
- listening to you when you've had a rough day,
- tackling paperwork together,
- driving you to a hospital appointment,
- delivering meals to you, or
- taking washing to the laundrette.

“ My husband's friends used to take him to the golf course every few weeks. They had a great time and it gave me some essential time for myself ”

Carer of a person with dementia

Short breaks from caring

Respite is a term that is sometimes used interchangeably with 'short breaks' and enables you to rest and do some of the things that matter most to you. Meaningful and appropriate breaks can help unpaid carers to live healthy and fulfilling lives and the chance to reach their potential in terms of education and employment.

Respite may be a couple of hours or several weeks away from caring to give you time to recharge your batteries. You may find it helps you stay well and feel better able to cope with caring.

A break is an opportunity for you to have time for yourself to rest, switch off and a period away from the challenges and responsibilities of caring. Many people also use the time to socialise, attend a hobby or to fit in chores such as shopping or banking.

SPOTLIGHT ON NEWCIS

**Providing short breaks
for carers when they
need them most**

'Bridging the Gap' respite scheme is delivered by NEWCIS, a Carers Trust Network Partner, and funded by Flintshire County Council. It offers a service that allows carers to choose to have paid-for care they're eligible for at the time that suits them. NEWCIS also offer respite for times of emergency or crisis so carers can get support when they need it most.



Types of respite

Day centres

The person you care for can attend regularly, take part in social activities and be looked after while you have a break.

In-home respite

The person with dementia is supported at home. This can include overnight care.

Short stays at a care home

Short holidays in the UK

Breaks may have accommodation designed especially for people with dementia and their carers. Some packages include practical support with caring too.

SPOTLIGHT ON CARERS OUTREACH SERVICE

**Making local breaks accessible
for carers in Wales**

The Carers Outreach Service, a Carers Trust Network Partner, supports a large rural community covering Anglesey, Conwy and Gwynedd and offers unpaid carers and the person they care for to access a suitable holiday. Carers can book a break at discounted rates in one of two accessible caravans at Hafan y Mor, Pwllheli. The caravan break service has allowed carers to take a holiday whilst still being able to attend hospital treatment and appointments as ambulance pickups can be arranged. Because the breaks are low-cost and local, it has given carers of people with dementia the opportunity to the chance to explore whether a short break is manageable.



How to access respite

Respite is a service that sometimes needs to be paid for. You can get help depending on the type of respite you need and your personal circumstances. You may be able to get help from your local authority, charities or **benevolent funds**, or you may need to pay for care yourself.

The first step is to ask your local council for a **carer's needs assessment**. This is a chance to discuss your needs as a carer including breaks from caring.

Read more about your rights (*page 16*).

You can also contact a **Carers Trust Network Partner** (*page 6*) for advice and support.

Further information about respite

<https://carers.org/getting-a-break/getting-a-break>

www.carersuk.org/search/taking-a-break

www.alzheimers.org.uk/get-support/help-dementia-care/respite-care-wales



Respite makes a huge difference - particularly overnight respite - you don't have to be constantly aware of what the cared for is doing

Carer



Respite enables me to keep on working full time which has a direct impact on my quality of life now and in the future (salary, pension etc). Enables me to maintain social contacts, friendships, contact with family and personal interests - which helps with my mental wellbeing

Carer



<https://carers.org/getting-a-break/getting-a-break>

<https://carers.org/carers-assessment/carers-assessment>

CARE HOME OPTIONS

Caring for a person with dementia, especially as the condition advances, can affect your own well-being (page 22), personal life and employment and education. There may come a time when a care home is the best option for the well-being and safety of the person you care for, and the option that works best for you.

Whatever your circumstances you will have to navigate difficult questions and make decisions about 'what is best'.

Considerations when thinking about living arrangements

Start thinking and planning early. This will give you time to consider all your options, and not feel the need to rush decisions under pressure and stress. You'll have more time and space to shape the future of the person you care for. Many people who move to a care home do so after being in hospital or after a period of serious illness. In such situations decisions may be rushed and you're less involved in the process as you would like. **(O'May, 2007)**.

There are no right or wrong decisions. You can decide what works for you and the person you care for, for now and for the future. Consider all the options available to you by doing plenty of research and making lists about the benefits and drawbacks of the choices you have.

It's common for carers to feel guilty, or a sense they're letting the person with dementia down. Remember though, you are considering options so your well-being and safety, as well as the safety of the person you care for, are protected. Don't neglect your needs, they matter too.

Your relationship with the person you care

for will change, especially when the time to use a care home comes. The change in relationships will take some time to get used to; make sure you acknowledge these big changes and the impact on you. It's also common for carers to encounter conflict and disagreement with members of their own family. **See link below.**

You can read in detail about financial and legal matters to consider, such as **powers of attorney**, in this guide on page 72.

Access to support and advice

- If you're finding your circumstances difficult, talk through your feelings with someone you trust. Speaking about your worries means people can reassure you, offer to support you, or signpost you to agencies to help you. Your local carers' service may have a carers' group for you to join or a support worker to speak to.
- You are entitled to have a fulfilling life alongside caring, and these rights are enshrined in the **Social Services and Well-being (Wales) Act**.
- Speaking with a health or social care professional to make a difficult choice can help you to consider what is most important for you and your family. Don't be afraid to ask for the information you need to make a decision you are comfortable with **(O'May, 2007)**.



http://myhomelife.org.uk/wp-content/uploads/2014/11/mhl_review.pdf

<https://gov.wales/sites/default/files/publications/2019-12/understanding-your-rights-as-a-carer.pdf>

- Read experiences of other carers who have been through the experience, including **this blog**.
- If you are concerned about your own health and well-being, speak to your GP or a health professional. You can also contact **Age Cymru Advice** (08000 223 444), the **Dementia UK Helpline** (0800 888 6678) or the 24-hour Wales Dementia Helpline (0808 808 2235). You can also call the Samaritan's at any time on 116 123.
- If you have a concern about the care of a person with dementia, you should contact **Care Inspectorate Wales** <https://careinspectorate.wales/contact-us> or, if appropriate, the **Older People's Commissioner for Wales' office** www.olderpeoplewales.com/en/about/contact.aspx.

Care options

In this chapter, we introduce you to the main types of care, including: care at home (domiciliary care); care homes, reablement, supported living and palliative care. We've also provided further detail about care homes. If a person with dementia moves to a care home it can be a significant change, with challenges along the way, but it can be a positive experience and there are options to make the transition as easy as possible.

Care at home

This is where someone will visit the person at home to complete personal care needs or household tasks to help the person live independently. It is also referred to as domiciliary care or home care.

Personal care includes help with getting up from bed and going to bed, bathing, dressing, meals, using the toilet and taking medication.

Household tasks includes practical help with housework, shopping or support getting out and about.

The service is provided by the local authority after an assessment, a private agency or a mix of both. The local authority may have asked (commissioned) a charity (such as our Network Partners) to deliver the service.

Intermediate care and reablement care

These services are generally shorter-term services. Intermediate care is a health care service and reablement care is a social care service. Both the services usually involve a

mix of health and social care professionals providing the assistance and services. They are not chargeable for up to six weeks. Both services promote independence at home and usually help a person to:

- return home after a hospital admission;
- prevent a hospital admission; or
- learn or re-learn household tasks they find difficult (such as preparing meals, or washing).

Further information on intermediate care and reablement care

www.ageuk.org.uk/globalassets/age-cymru/documents/information-guides-and-factsheets/fs76w.pdf

Supported living

Supported living combines housing and support services. It allows people to live independently but with some additional services, including shared facilities for socialising; housing that is adapted to include accessible entry and safety alarm systems; or an on-site warden. Various types of supported living exist and the ones most likely to be suitable for people with dementia include:

- Sheltered housing.
- Extra-care housing (or assisted living). This is a special type of sheltered housing suitable for people with mild dementia who would like to maintain independence and privacy but it isn't safe for them to live completely alone without support.

Care staff will provide services based on the care and support plan (the outcomes of a **Needs Assessment** (page 15)). The housing is often purpose-built to contain accessible kitchens and bathrooms and an alarm system for emergencies.

Further information about care

www.ageuk.org.uk/cymru/information-advice/care

www.ageuk.org.uk/cymru/information-advice/care/care-homes/finding-a-care-home

www.eac.org.uk

www.carehome.co.uk

Your local authority

www.alzheimers.org.uk/get-support/help-with-dementia-care/care-home

<http://iwantgreatcare.org>



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Care homes

Care homes are long-term residential settings for older people, which have care staff on-site 24 hours a day. Care homes provide support and care for residents, but each care home operates slightly differently. Residents are provided meals and supported with activities such as washing, dressing and taking part in social activities. Care homes may be run by a private company, a local authority or a charity.

Only some homes will be suitable for people with dementia, and the health needs a person has is an important factor in choosing the most suitable care home option.

Care homes are a regulated services that must register with **Care Inspectorate Wales**. CIW inspects each home regularly to make sure they're meeting certain standards.

Considerations when choosing a suitable care home

The preferences of the person with dementia and the type of care they need, will be important factors in finding a care home. You can find information from **inspection reports** from Care Inspectorate Wales and arrange to visit a home.

Considerations when visiting care homes

- Is the general atmosphere good?
 - Are the staff and residents interacting well?
 - Are the rooms and gardens in the home pleasant and accessible?
 - Does the home promote personal choice, such as accommodating flexibility with routines and providing a choice of meals?
 - Does the home promote personal identity, such as personalising rooms or providing private phones?
- Do residents at the care home have opportunities to socialise and enjoyable activities? For example, is there entertainment, or transport for daytrips?
 - Does the care home appear to be well managed in terms of training it offers staff and have a suitable ratio of staff to residents?
 - Does it meet your cultural or religious needs?
 - Is the location suitable for the person with dementia and you and your family?
 - Is the cost accessible to you? Are fees inclusive ('all-in') or basic, with additional costs on top.
 - Are you content with how the care home involves family carers in the care and support of residents?

Some of the information from this list is taken from Titman (2003) cited in **O'May (2007)**.

My Home Life Cymru

'My Home Life' is a project that looked at the good experiences people have in care homes and what matters to the people who live there. Although these **guides** were aimed at social care staff, they may interest you.



<https://careinspectorate.wales/service-directory>

<https://careinspectorate.wales/choosing-care-adults>

www.walesscr.org/en/my-home-life-cymru--good-practice-guides.htm

Supporting the person you care for to make a good transition to a care home

Suzy Webster, Care Home Network Manager, Age Cymru

All good care homes recognise the value of the knowledge and skills of family carers as experts in caring for the person with dementia. You know what makes them tick, their likes and dislikes, who the most important people in their lives are and what matters to them most. Fostering a good relationship with the care home from the start will help you to feel part of the care home community.

Prior to the move, you might like to:

- Ask if you can meet with staff, including the manager, the cook and the activity co-ordinator.
- Find out about the day-to-day running of the home, what activities the care home offers and which health and social care professionals visit the home.
- Help prepare the bedroom with items of interest to the person, photographs of family and friends, a special blanket, sensory items for comfort or a music player with a personalised playlist.
- Ask if you can meet some other families and volunteers at the care home.

You will start to find your own rhythm in the first few days and weeks after the move. There will be no set visiting times so you will start to make your own routines. Some days will be harder than others. You can talk to the care home manager about how you are feeling; there won't always be a solution to your concerns but a good care home manager will listen to you and take action where they can.

“When a new family comes to our home I know I have to go at their pace. Everyone is different. I do not make assumptions. My office door is always open.”

Care home manager

Take time to reflect on how you see your caring role evolving after the person with dementia moves into a care home.

You may want to be as involved as possible in caring tasks, or you may choose to step back from the practical tasks of caring. It's your choice and you should feel confident in telling the care home your wishes, so they can facilitate them where possible.

“I felt a great relief letting go of the full-time caring responsibilities; I could be a husband again.”

Unpaid carer

“I suddenly had spare hours. I wish they (care home staff) had asked me to help more. I could have helped them get to know my husband, including his intimate care needs. I wanted to contribute to the home but I was made to feel I didn't have a role to play.”

Unpaid carer

Good communication between carers, residents and care homes results in good relationship-centred care.

It's up to you and the care home to find the best way to keep in touch. Some families like to arrange regular face-to-face meetings or telephone calls with the care home manager, whilst social media platforms such Facebook and virtual meetings over Skype or Zoom provide another option. However, you choose to stay in contact, it's always nice to hear good news as well as shared concerns.”

Palliative care

Palliative care is any treatment or support that is provided for people who have a condition that is life-limiting, and this includes dementia. It may be provided for days, months or years from a variety of professionals. Care may be given in a person's home, in a care home, in a hospice, or in a hospital.

End of life care is the treatment and support provided to people who are nearing the end of their life. It is one part of palliative care. **Read about the difference between palliative care and end of life care.**

The focus of health and care professionals at end of care should include the following.

- The comfort of the person with dementia, including pain management.
- The dignity of the person with dementia.
- The preferences of the person with dementia and their individual needs. These may have been pre-arranged in **advance care plans** (page 76). You may hear these referred to as 'person-centred' care. A person-centred approach is a principle that puts a person first, not the illness they have. It's about respect and compassion for people, and retaining a person's dignity. The focus is on promoting the choice and autonomy of the individual.
- Communicating effectively with you and any family members and answering any questions you may have.

What is hospice care?

Hospice care is holistic and looks after the physical, emotional, social and spiritual needs of someone with a life-limiting or terminal condition. There are 16 charitable hospice providers in Wales offering different types of services, that may include therapeutic care (like physiotherapy, art therapy, occupational therapy), bereavement support and more. Hospice care can be provided in a person's home, in a care home, or in a hospice. Hospice care can include support for carers and help families prepare for the end of life.

To access hospice care, speak to your GP, a carers' service, or you may be referred following a carer's needs assessment.

For more information about hospice care visit www.hospiceuk.org/about-hospice-care/find-a-hospice



www.mariecurie.org.uk/help/support/diagnosed/recent-diagnosis/palliative-care-end-of-life-care#what

www.nhs.uk/conditions/end-of-life-care/hospice-care

Lesbian, gay, bisexual or trans (LGBT+)

Carers and people who are cared for that identify as lesbian, gay, bisexual or transgender (LGBT+) are entitled to appropriate support and assistance and should not face discrimination or stigma.

Ageism, lack of training and awareness and prejudice can all play a role in making a person who is LGBT+ feel uncomfortable. It can also mean the care and support provided for a person is neither adequate nor person-centred and harmful to well-being. However, a lot of work has been done in care homes and other care settings to ensure that there is better recognition of and support for LGBT+ families.

Being a carer or caring for someone who is LGBT+ does not mean that your needs and rights should be neglected. You can take some steps to help you find good support and there are organisations you can contact for more support.

Choosing a care home

When choosing a care home, ask questions about their stance on diversity and openness.

If you are confident, you can let the care home manager know that you are a gay couple, or you can choose to ask more indirect questions. For example:

- Are there many LGBT+ residents in the home?
- Does the home celebrate Pride month each year in June?
- Does the home have an up to date policy on diversity and inclusion?
- Do staff regularly receive training on diversity and inclusion?

The answers will give you clues about the attitude of the manager and the ethos of the care home and help you decide whether the person you care for will be comfortable there, and whether you will feel welcome and safe visiting them.

Listen to the tone of the answers, as well as the content.

- Does the staff member sound empathetic and open?
- Are they listening to you actively and asking you questions?

If so, it may suggest that whilst not all the policies and practices that you would ideally like are in place yet, they are a home that are willing to learn and aim to build an inclusive home that offers personalised care.

Your rights are protected under law too, as part of the Equality Act 2010.

The Equality Act 2010

The Equality Act is applicable to organisations, including care homes, who provide a service to the public. The Act prohibits harassment and discrimination against people based on 'protected characteristics', that include sexual orientation and gender reassignment. For example, if you're denied the chance to share a bedroom with the person with dementia because you're gay, or face homophobia by staff, this is a breach of the Act.

In this instance, you should speak to a care home manager about your experience. If you are unsatisfied following this, you will need make a formal complaint to the service provider according to their procedures. You can also contact **Care Inspectorate Wales** at <https://careinspectorate.wales/contact-us/> raise-concern to raise a concerns, and the organisations listed in **LGBT+ Navigating later life (Age UK, 2019)**. You can also contact **Age Cymru, Older People's Commissioner for Wales** and **Stonewall** for advice based on your circumstance.

Further information and support

Safe to be me: Meeting the needs of older LGBT+ people in health and social care services - a resource for professionals (Age UK)

LGBT+ Navigating later life (Age UK) www.ageuk.org.uk/globalassets/age-cymru/documents/information-guides-and-factsheets/ig02.pdf

www.alzheimers.org.uk/get-support/help-dementia-care/lgbt-support

www.diversitytrust.org.uk/careunderrainbow/

www.stonewallcymru.org.uk/help-advice/information-and-resources

Trans Ageing & Care http://trans-ageing.swan.ac.uk/?page_id=213



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www.ageuk.org.uk/globalassets/age-cymru/documents/information-guides-and-factsheets/ig02.pdf

www.ageuk.org.uk/cymru/information-advice/

www.stonewallcymru.org.uk/help-and-advice

SUPPORTING THE PERSON YOU CARE FOR DURING HOSPITAL STAYS

Hospital stays can be a difficult experience for people with dementia, but also for carers. Carers play a key role in helping a person with dementia get effective treatment and have a comfortable stay in hospital.

Difficulties a person with dementia may be encounter in hospital

- Feelings of confusion, disorientation and anxiety.
- Unfamiliar surroundings.
- Seeing many more people than they are used to seeing.
- Being unable to stick to their usual daily routines, such as meal times.
- Understanding instructions from staff is difficult.
- Communicating wishes to staff is difficult.

Difficulties a carer of a person with dementia may encounter in hospital

When the person you care for is admitted in hospital, it can present emotional and practical challenges for you as a carer. You will be concerned about the health of the person with dementia, and a hospital visit may disrupt caring routines that have taken time to develop. The journey to the hospital may be distressing for the person with dementia too, which can be upsetting.

As a carer, you are an expert in looking after the person with dementia and your

knowledge can help staff in the hospital know how to make the person with dementia as comfortable as possible. Let staff in the hospital know about the person with dementia, and what they are like as a person. You can include likes and dislikes, cultural and religious preferences and how they prefer to communicate. You may need to repeat the information with different members of staff. To make it easier to communicate the information, you can print and complete the **'This is me'** document from Alzheimer's Society.

Some carers can find it difficult and tiring to travel back and forth from hospital. During the course of the hospital stay, reach out to family members or friends, as they may be able to help you with lifts to the hospital. It's also worth speaking to a carers' service if you are finding it difficult to afford the cost of transport to hospital, as they may be able to access grants for this.

If you have any concerns or questions about the person with dementia, speak to staff about them and ask any questions you need to. If you're asked your opinion about treatments and are unsure, ask for the information you feel you need to make an informed decision.

Some of the information above is informed by research by **Jurgens et al (2012)**.



www.alzheimers.org.uk/get-support/publications-factsheets/this-is-me
<https://link.springer.com/content/pdf/10.1186/1471-2318-12-57.pdf>



I want health professionals recognising me, telling me what I need to know, where I can get help, the types of help available and properly thinking about how I'll be affected



Carer of a person with dementia



My local carer's centre put me in touch with a local advocacy service. It was so helpful to have someone speaking for me and advocating my rights at a time when I was so emotional and overwhelmed with information



Carer of a person with dementia

John's Campaign

John's Campaign is an initiative that recognises that carers of people with dementia are experts in looking after their family members or friends and that organisations (including hospitals) should fully involve and welcome them. This approach provides comfort to the person with dementia, the carer and can help staff (such as nurses, or paid care staff) provide the best treatment and care.

A key ask of the campaign is that carers should be able to visit the person with dementia in hospital at any time (including outside of visiting hours), and stay overnight, if necessary. **Read more here** <https://storage.googleapis.com/johns-campaign.appspot.com>

John's Campaign was founded in 2014 by Nicci Gerrard and her friend Julia Jones. Nicci's father had dementia and went into hospital due to leg ulcers. Unfortunately, John's health worsened whilst he was in hospital. Nicci set up John's campaign with Julia after he passed away.

Many hospitals have signed up to promote John's campaign and **Age UK have produced a guide for organisations wanting to take part.**

You can read articles to learn more about John's campaign <https://johnscampaign.org.uk/#/articles> and watch videos <https://www.youtube.com/channel/UCSpnKGIZ6dyu9eXMvfdvyjg/videos>.

The Butterfly Scheme supports participating hospitals to provide appropriate care for people with dementia. In these hospitals, including some in Wales, you can apply for a discreet pinbadge that indicates to hospital staff that a person has dementia. Find out more from www.butterflyscheme.org.uk



www.johnscampaign.org.uk
<https://storage.googleapis.com>

Hospital discharge

Leaving hospital (discharge) and returning home or to a care home for a person with dementia should be planned carefully. Discharge should:

- only take place if the person with dementia is medically fit and safe to leave hospital;
- be known in advance so that you have enough time to prepare;
- follow an assessment of the care and support needs of the person with dementia that is carried out by health and social care professionals together;
- take place when care and support needs identified have been met (e.g. home adaptations such as grab rails have been put in place); and
- not be planned with an assumption that you are able to care for the person with dementia. You can ask for a **carers' needs assessment** if you would like one. Find out more about needs assessments on page 17.

A discharge plan is a written document that details medical information and care arrangements. You should have a copy of this and the GP (and care home, if relevant) should also be sent one.

A discharge plan should:

- be made in partnership with you, the person and the person with dementia so that your wishes are taken into account;
- be effectively communicated to the person with dementia and you; and
- include information about medication.

The person with dementia may have the following **care** (page 57) in place before they return home:

- Temporary or reablement care.
- NHS continuing healthcare.

Remember that you have the right to choose to no longer provide care if you feel unable to do so.

If you're unhappy with a hospital discharge plan, and the person with dementia is in hospital, you can:

- Make yourself aware of the roles and responsibilities of health and social care staff involved in discharge planning, so that you know what the person with dementia, and you as the carer are entitled to. You can also ask to see the discharge policy of the hospital.
- Speak to health and social care staff at the time highlighting your concerns. An open discussion may help you understand decisions that have been made and there may be an opportunity to make changes so the discharge plan is appropriate and safe.
- Seek advice from an organisation such as **Citizens Advice** as they may be able to suggest the most appropriate form of action based on the nature of your situation. Offices may offer advice by e-mail, telephone or at a drop-in centre.



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[www.citizensadvice.org.uk/wales/about-us/contact-us/
contact-us/contact-us](http://www.citizensadvice.org.uk/wales/about-us/contact-us/contact-us/contact-us)



If you're concerned about the health of the person you care for following hospital discharge, call for medical assistance from your GP, from the NHS 111 service for

urgent care, or 999 in an emergency. You should also inform your local authority's social care team.

If you want to make a complaint after the discharge has taken place, you can:

- Approach the relevant **Community Health Council** who can advocate for patients by providing information and assistance if they wish to make a complaint to the NHS.
- Complain to your local authority about social care following the relevant complaint's procedure. Read more about this on **Citizens Advice**.
- Complain to the relevant NHS Health Board about the health care.
- If the complaint relates to both social services and healthcare, the two bodies will need to work together to respond. One of the bodies take the lead in responding.
- If you are dissatisfied with the outcomes of the options above, you can ask for the matter to be raised with the **Public Services Ombudsman for Wales**.

Read more about each of these options in **Age Cymru's** factsheet.

Further information about hospital discharge

Age Cymru

Alzheimer's Society



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www.wales.nhs.uk/ourservices/directory/CommunityHealthCouncils

www.citizensadvice.org.uk/wales/family/looking-after-people/social-services-complaints-w

www.ombudsman.wales

www.ageuk.org.uk/globalassets/age-cymru/documents/information-guides-and-factsheets/fs37w.pdf

LEGAL AND FINANCIAL PLANNING

Making legal, financial and health decisions on behalf of the person you care for.

A person's right to make their own decisions is paramount but this can become impossible for people with advanced dementia. People with dementia can appoint an attorney in advance of reaching this stage, so that a carer or family member can begin to make decisions on their behalf when the time comes.

Lasting power of attorney

An attorney is a person, such as a family member, partner or friend who has been chosen by the person with dementia to step in to make decisions on their behalf. An attorney can support a person with

dementia to manage financial affairs and make decisions about the future.

Any decision should be what is in the best interests of the person with dementia, and independence and choice should continue to be promoted. It requires a legal process to put into place.

There are two types of lasting power of attorney:

- (a) for **property and financial affairs**; and
- (b) for **health and welfare**.

The donor (in this case the person with dementia) appoints an attorney, whilst they still have 'capacity' (explained below). The donor does not lose their rights immediately. The power of attorney does not come into play until it is necessary, when the donor has lost capacity.



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www.gov.uk/lasting-power-attorney-duties/property-financial-affairs

www.gov.uk/lasting-power-attorney-duties/health-welfare

Capacity

Capacity relates to how able a person is to make their own decisions.

Having capacity means that an adult must be able to do all of the following:

- Understand relevant information.
- Be able to weigh up options.
- Remember information long enough to make a decision.
- Be able to communicate their choice.

The decisions that capacity is needed for are everyday choices such as choosing clothing and food, to bigger decisions around selling property, creating a will or having an operation.

A diagnosis of dementia does not necessarily mean a person lacks capacity.

Capacity is assessed with the intention to balance the independence of the person with conditions like dementia, with the protection of people who may be vulnerable.

When a person no longer has capacity, a spokesperson can be chosen to make decisions and act in the best interests of the person with dementia.

The legislation relating to capacity is the **Mental Capacity Act 2005** for England and Wales. A principle of this Act is that in the first instance, everyone should be presumed to have capacity, unless it is shown otherwise.

Further information on capacity

www.alzheimers.org.uk/get-support/legal-financial/mental-capacity-act

Organising a power of attorney

Arranging an attorney early is recommended as dementia is an unpredictable disease; a person's may lose capacity sooner than expected.

This power of attorney can be completed **independently online** or a solicitor can be appointed to assist with the process, but this will incur a cost. Your local carers' services may be able to help you complete the paperwork, and you can contact Age Cymru's helpline on **08000 223 444** for advice.

An official government **guide to completing the lasting power of attorney** is available online.

If a person loses capacity before an attorney is appointed, a person can still take the role of advocating for a person with dementia. This person is a **deputy**. Appointing a deputy is time-consuming and expensive, and this is another reason appointing an attorney early is recommended.

Further information on power of attorney

www.alzheimers.org.uk/get-support/legal-financial/lasting-power-attorney

www.alzheimers.org.uk/get-support/legal-financial/lasting-power-of-attorney-faq#content-start

www.nhs.uk/conditions/dementia/legal-issues



www.legislation.gov.uk/ukpga/2005/9/contents

www.gov.uk/power-of-attorney/register

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/631084/LP12-Make-and-register-your-lasting-power-of-attorney-a-guide.pdf

www.gov.uk/become-deputy

Making decisions on someone's behalf

It can feel like a huge responsibility to make decisions on behalf of a person with dementia and to determine the 'best' decision. In some circumstances, you may feel you're having to make a decision that you're not completely happy with but have little choice due to circumstance or the limited options available to you. In addition, there may be disagreement amongst family member about a decision.

We've suggested ideas that may help you below, informed by research by **Livingston et al** (2010).

- Begin discussion and plans about the future as early as possible, so that the wishes of the person with dementia can be heard and you have time to explore all the options and considerations you need to.
- Ask health and social care professionals for the information you need to make decisions you need to. You can also contact the organisations we've signposted you to in this resource for information, advice and assistance. As an unpaid carer, you have the knowledge and skills that are vital to conversations around plans and decisions for the future.
- Access support for yourself as a carer to maintain your own health and well-being, and consider taking up the opportunity to speak to other carers who may understand the challenges you're facing. You can access support via a carer's needs assessment or you can contact your local carers' service directly to find out what is available.
- Remember that balancing the needs of a person with dementia and promoting independence can be difficult. In some instances, you may not agree with a decision a person with dementia is making. In other cases, if you have the power of attorney, for example, the person with dementia may not agree

with a decision you make as their condition may cause them to be in denial about their ability.

Making a will

Planning ahead means that a person with dementia can be involved as fully as possible with decisions about the future.

A will is legal document that states how finances, property and belongings should be managed after a person dies. It allows a person to choose how their 'estate' (everything they own) is shared among their family or whomever they choose to leave it to. An executor is the person who has been chosen to deal with the will.

Wills should be made as early as possible. If a will is not prepared before a person's death, the possessions are called 'intestate' and the state may choose how possessions and property are dealt with. People who have dementia are still able to make a will, as long as they have capacity.

You can prepare a will yourself, through a will writing service, or through a solicitor.

For information about housing visit:
www.mariecurie.org.uk/help/support/bereaved-family-friends/practical-legal/property-entitlements

Further information about wills

www.moneyadvice.service.org.uk/en/categories/making-a-will

www.gov.uk/make-will

www.citizensadvice.org.uk/wales/family/death-and-wills/wills/

www.ageuk.org.uk/globalassets/age-uk/documents/factsheets/fs7_making_a_will_fcs.pdf



www.bmj.com/content/341/bmj.c4184

PLANNING FOR THE FUTURE

Making decisions about the future early lets people with dementia make their choices, beliefs and plans known to you, family members and friends as well as health and care professionals. Families are encouraged to have conversations about the end of life as early as possible.

Later stages of dementia

As dementia are progressive diseases which worsen over time, the health of person you care for is likely to deteriorate. The later stages of dementia are referred to as **advanced dementia**.

Measures and tools help health professionals to identify what stage of dementia people are at but it's not clear cut. It's more helpful to think about how much help and support a person needs in everyday tasks. Advanced dementia does not look the same in everyone, everyone will have a different journey with their communication and mobility. As dementia progresses, your caring role may take more of a physical and emotional toll as the person you care for needs more support. At this time in particular, it's important to get time to yourself by accessing **respite** (page 58), joining a **local carers' service** (page 6), and reaching out to a health or social care professional if you are struggling.

“ I want to have information so I am as prepared as possible for caring at home for the end of life stage

Carer of a person with dementia ”



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www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/how-dementia-progresses/later-stages

What is advance care planning?

Advance care planning opens up a conversation about a person's wishes for the future. A person with dementia may choose to discuss or inform you about their future care choices. They may choose to speak to health and social care staff for advice.

An **advance care plan** outlines a person's preferences towards the end of their life. It helps to promote a person's choice and control over their own care and treatment. Preparing a plan is voluntary. It can include the following:

- an advance statement;
- advance decisions;
- choices about resuscitation;
- appointing a power of attorney; and
- choosing what happens to their body after they die (including **organ donation**).

Further information about advance care planning

[www.wales.nhs.uk/sitesplus/documents/866/PIU1364\(2\)ABUHB\(Active\)\(July%202022\)%20-%20Advance%20Care%20Planning%20\(eng\).pdf%20final%20version%20now%20in%20print%20\(002\).pdf](http://www.wales.nhs.uk/sitesplus/documents/866/PIU1364(2)ABUHB(Active)(July%202022)%20-%20Advance%20Care%20Planning%20(eng).pdf%20final%20version%20now%20in%20print%20(002).pdf)

<http://advancecareplan.org.uk/>

www.mariecurie.org.uk/help/support/terminal-illness/planning-ahead/advance-care-planning

Advance statements

The advance statement is a record of a person's choices and wishes about their end of life care.

The plan may be made with health and care staff, or written by an individual themselves.

It is not legally binding in the same way as an advance decision.

Common considerations include:

- how someone wants to be cared towards the end of their life;
- where someone wants to be cared towards the end of their life;
- who they would like around them near the end of their life;
- religious and cultural beliefs.

Further information about advance statements

www.alzheimers.org.uk/get-support/legal-financial/what-is-advance-statement

Compassion in Dying (need URL)



<https://compassionindying.org.uk/making-decisions-and-planning-your-care/planning-ahead/advance-care-planning/making-acp/>

<https://gov.wales/organ-donation>

Advance decision to refuse treatment (ADRT)

These are also referred to as 'advance decisions' or 'living wills'.

These are a written statement of a person's wishes relating to any medical treatment they wish to opt out of. It can be legally binding in Wales (and England) but only if the document fulfils certain criteria, such as being signed by a witness. A valid advance decision must be adhered to by healthcare professionals (**as long as they are aware of it**). It is only taken into consideration if the person with dementia loses the ability to communicate. It can be part of an advance care plan and a solicitor is not needed to prepare it.

Compassion in Dying provides information, a template and a list of requirements that make the document legally binding.

'Do Not Attempt Resuscitation' (DNAR) form

A 'Do Not Attempt Resuscitation' (DNAR) form is prepared and signed by a doctor and informs healthcare professionals not to attempt cardiopulmonary resuscitation (CPR).

It is not the same as an advance decisions form, must be written by a doctor and applies only to CPR. The doctor should consult the person (or the attorney) before issuing one. It is a standardised form in England and Wales. It is suggested by the doctor on medical grounds based on the risk and harm of performing CPR on an individual.

Advice to help plan for the future

- It is up to the person with dementia to approach planning when they are ready.

You may not agree with how they are approaching care planning, but it is their choice. The person with dementia may be finding it difficult; give them time and space.

- Conversations should take place as early as possible. This means they are not overwhelming or scary and they are in place well ahead of when a person's health deteriorates.
- Don't try to tackle all matters in one go. Decisions can take time to reach, so return to conversations time and time again. This can help make planning feel more manageable.
- You can choose to talk to a professional to guide you through the conversations together. People who can help include staff in carers' services, nurses, your GP or hospice staff.
- Advanced care statements should involve family carers in the conversation (if the person you care for consents). It should be a conversation (ideally more than one) between health and social care professionals together with you and the person you care for.

Further information on planning for the future

https://compassionindying.org.uk/wp-content/uploads/2018/04/STARTING-THE-CONVERSATION_2018_AW_SINGLE-PAGES.pdf

www.dyingmatters.org

www.hospiceuk.org



<https://compassionindying.org.uk/making-decisions-and-planning-your-care/planning-ahead/advance-decision-living-will/telling-people>

<https://compassionindying.org.uk/making-decisions-and-planning-your-care/planning-ahead/advance-decision-living-will>

END OF LIFE

As the person you care for nears the end of their life, it can be an incredibly difficult time for you. Looking after your mental health and well-being and seeking support if you need too is particularly important at this time.

Low mood and anxiety are common feelings for carers as the person with dementia approaches the end of life. You may experience feelings of loss before someone with dementia passes away. The intensity of feelings can be just the same as grief after the death of a person. This is called 'anticipatory grief'.

Having emotional support at this time can alleviate some of the feelings and you may find comfort speaking with friends, family, or members of your faith community. It can be especially useful to speak to peers and friends in your **local carers' group** (page 6) as you may feel they can empathise better with the situation you are going through.

Whilst it's common to experience low mood and sadness at this time, clinical depression and anxiety can and does affect many unpaid carers. This is a medical condition that you can seek treatment for. If you're concerned about your mental health and experience symptoms of depression for more than two weeks (every day for most of the day) you are advised to speak to your GP. **You can read the NHS website to help you make a decision on seeking professional help.**

Unpaid carers and families also find professional advice, information and support from our **Network Partners** (page 6) or **their local hospice**, who may run outreach sessions, provide support over the telephone, or provide counselling. You can also contact organisations that include,

Marie Curie and Alzheimer's Cymru.

Taking time to talk about and plan for the future early on means when the end of life comes, you have already taken some decisions and know a little of what to expect. It is helpful to take care of some of the practical matters ahead of time, so that you can devote more of your time to taking care of yourself and your emotions.

Being an active participant in choices about end of life care (along with the person you care for) is important. You can read about how to make plans and what you should consider in the next chapter of this guide. Recent research found that nearly a third of carers did not feel "fully involved in all decision making" and "would probably have made different decisions if [they] had had more information" (Moore, 2017). Having open communication with health and social care staff can mean you are able to speak about your wishes, concerns and choices, as well as those of the person you care for too.

If you are unsure of anything, ask questions of health and social care professionals so that you can find out what matters to you, in the level of detail you need. If you want further information about the dementia of the person you care for and how it usually develops in a person, you can ask questions of health and social care staff, ask your local carers' service about upcoming courses, or access resources online, including the ones suggested in this resource.



www.nhs.uk/conditions/clinical-depression/diagnosis

www.hospiceuk.org/about-hospice-care/find-a-hospice

www.mariecurie.org.uk/help/support/being-there

www.alzheimers.org.uk/get-support/help-dementia-care/end-life-care-support-carers-family-friends#content-start

<https://link.springer.com/article/10.1186/s12877-017-0523-3>

LIFE AFTER CARING

Grief is a natural process that occurs over time and it is normal to find the experience very difficult. People experience grief differently and it can affect people emotionally, psychologically and physically. Bereaved carers of people with dementia face unique challenges.

Death marks the end of a caring role, which may have been a significant part of a person's life. When the emotional and practical parts of a caring role end suddenly, it is a huge change and can be a big shock. It's normal for you to experience a range of emotions, including low mood/ depression, anxiety, anger, a feeling of 'emptiness' or guilt, but don't feel afraid to speak to a health professional if you are worried about your well-being or health whilst you're grieving.

Caring can become a significant part of a person's identity. A carer's social circle

may be centred around carers' groups and activities for the person with dementia. When that is removed, carers may begin to reflect on their hobbies, relationships and work or education that had been put on hold as caring was prioritised.

Practical matters relating to wills, finances, housing and general administration will need to be addressed, too. You will also need to consider the financial implications of benefits that will now stop as the caring role ends. Practical advice is available from **Marie Curie** and **Age UK**.



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www.mariecurie.org.uk/help/support/benefits-entitlements/bereavement/benefits-after-death

www.ageuk.org.uk/information-advice/care/helping-a-loved-one/my-caring-role-has-changed/

Some family carers face intense distress for an extended period, beyond the grieving experience people usually experience. People who have been caring for people with terminal illnesses, like dementia, can experience this 'complicated grief', that is longer in duration and intensity than typical grief.

Support for bereaved carers

- Find information from specialist organisations, including **Marie Cure** and **Age UK**.
- Utilise the '**Tell us once**' service to let government organisations that your caring role has ended, so that you don't have to contact multiple agencies. 'Tell us once' is a way to notify government organisations (such as HM Revenue and Customs (HMRC); Department for Work and Pensions (DWP), the Passport Office and the local council about the death of the person you care for. You can do this online at www.gov.uk/after-a-death/organisations-you-need-to-contact-and-tell-us-once.
- Reach out to people for support. It may be family, friends, or a religious community.

- Contact organisations (see below) that can help you with the grieving process and offer practical advice about benefits.
- Some carers' services and hospices have sessions for bereaved carers.
- If you are worried about your health and well-being, visit your local GP. Do not use alcohol to numb your feelings, as this may worsen your health.
- Listen to the experiences of other carers' on online forums or in **books**.

Further information about grief

www.hospiceuk.org/what-we-offer/dying-matters/talking-about-dying-with-people-affected-by-dementia

www.cruse.org.uk

www.alzheimers.org.uk/get-support/help-dementia-care/grief-loss-and-bereavement

www.gov.uk/when-someone-dies



www.mariecurie.org.uk/help/support/benefits-entitlements/bereavement/benefits-after-death

www.ageuk.org.uk/information-advice/care/helping-a-loved-one/my-caring-role-has-changed

<https://reading-well.org.uk/books/books-on-prescription>



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In this guide we've given you lots of information about caring for a person living with dementia in the hope that it makes your day-to-day life easier and helps you with challenges on your caring journey.

Caring for a person with dementia can be full of joyous experiences whilst being incredibly difficult at times.

Remember that you're not alone, and there are many, many husbands, wives, sons, daughters, sisters, brothers and other family members and friends who battle with emotions, sometimes conflicting emotions, that you are familiar with too.

When you are struggling, do reach out to a friend, a family member, a health or social care professional, or charity. They'll

be able to lend you a listening ear, maybe share their experience and help you to find solution that you may not have considered or been aware of.

Your rights to live a healthy and fulfilling life as a carer, whatever that means to you, are set out in legislation. You are entitled to have your voice heard and to information, advice and assistance. There are a whole host of organisations and groups, individuals who are there to care for you; you're valued and important and your health and well-being matters.

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