

KNOWLEDGE IS POWER

WALES

**Handy hints that might help
make life a little easier after
a diagnosis of dementia**

**“Dementia is life changing, but it’s not life ending.
Take advantage of every opportunity offered to
you. You must learn to ask for help, because nobody
should be going through this on their own”.**



**This booklet was written by people living with dementia,
for people living with dementia.**

It includes information and advice that we hope you may also find useful.

Some advice from us to you...

The Knowledge is Power Series

In the summer of 2019, the Caban group (dscd.bangor.ac.uk/caban-group) met at Bangor University and discussed what helps them to be resilient while living with dementia. During the discussion, the group shared their diagnosis experience, how difficult it can be, and how people often get either far too much or far too little information at the time of diagnosis. After the meeting, the group said that they would like to create a helpful booklet with what they felt was 'just the right amount of information', to share with others.

The group then set out to create this booklet with other DEEP groups in Wales (DEEP United Dwyfor & Meirionnydd, and Fuse & Muse Swansea) to help others living with dementia. The booklet was published in 2020 and updated in 2023. The development of the booklet was supported by the Dementia Services Development Centre (DSDC Wales) at Bangor University.

After sharing the first Knowledge is Power booklet, the group felt they had more knowledge to share, and decided to create a second booklet: Knowledge is Power 2, which includes handy and helpful tips for day-to-day life with dementia. Available at dscd.bangor.ac.uk/products-created

“Try to make the most of the services and supports that are available to you.

Knowing what is out there really can help you – knowledge is power!”

Keep smiling, live for the day, and don't give up!

You may wish to join a group or class that suits you, there are lots out there.

Do things that make you feel empowered - Focus on what you can do.

You might like to see if you can get involved in helping others who have a diagnosis or who want to learn more about dementia, by going to talk to people about your experiences of living with dementia.

You can try using strategies to help you adjust: Things like using new technology can help with reminders. I use Alexa, she reminds me about everything.

If you feel tired or have a 'down day', take care of yourself and have a rest.

It's okay to feel down, it might help to talk to someone else going through the same thing.

You might wish to consider connecting with other people who are living with dementia: Peer support can be invaluable.



Benefits and allowances

Needs Assessment

If you think you, or someone you know, needs help to cope day-to-day, the first step is to get a Needs Assessment. The assessment is to help understand your needs, circumstances, capabilities, and the outcomes you wish to achieve to help you live as well as possible with dementia. You may be offered help with home adaptations, practical help from a paid carer, or advice on local support groups and clubs to support your well-being.

- Apply for a Needs Assessment to the social services department of your local council:
www.gov.uk/apply-needs-assessment-social-services

PIP (Personal Independence Payment) for under 65s

This is a government provided allowance for disability and is not means tested. It has two components, and both have two rates, basic and enhanced: 1) help for day-to-day living needs, and 2) for mobility support/needs.

- It can be a gateway to accessing other types of support.
- Apply to the Department for Work and Pensions to see if you qualify.
- www.gov.uk/pip ☎ 0800 917 2222.

Attendance Allowance for over 65s

If you need someone to help look after you, you might qualify for an Attendance Allowance. This will help fund the extra care and support you may need. It is not means tested. This is awarded to the person who has received a diagnosis of dementia.

- www.gov.uk/attendance-allowance ☎ 0800 731 0122.

Direct Payments

If you have been assessed as needing social services support, you may be offered, or can request, a Direct Payment instead of receiving the support arranged by your local council. Direct payments can offer more flexibility and choice over how your well-being is supported. They can be used to employ a personal assistant or carer, enable access to activities which may support your confidence, independence, health, or pay for respite.

- Usually discussed during a Needs Assessment.
- Apply to your local council's social services department:
www.gov.uk/apply-needs-assessment-social-services
- You can watch Teresa's story about how Direct Payments enabled her to arrange an alternative to traditional support here: www.bit.ly/Teresa_story

Help to access support

Citizens Advice

Citizens Advice can help access the support you are entitled to. They can explain and talk through your rights and eligibility, and support applications for different benefits and allowances. They offer confidential advice over the phone, online, or in person.

- www.citizensadvice.org.uk/wales ☎ 0800 702 2020

Advocacy

An advocate is someone who can help make your voice heard when decisions are made about your support. An advocate can be a person you know and trust, like a family member or friend, or a person from a local charity or your local council.

- Find the advocacy services available in your local authority:
www.ageuk.org.uk/cymru/our-work/advocacy/hope---helping-others-participate-and-engage/advocacy-services-in-wales

Specifically for carers

Caring for someone with dementia can bring many joys and satisfaction, but it can be challenging and can have an impact on your health, your financial and emotional well-being, and family relationships. There is support and advice to help you adjust to the changes in your life.

- A number of organisations can help or provide guidance, including: Carers Wales, Carers Trust, Dementia Carers Count, and TIDE (Together in Dementia Everyday). For contact information please see pages 16-17.

Carer's Needs Assessment

If you provide care and support for someone living with dementia, you are also legally entitled to have an assessment of the support you need to help you in your caring role and to support your personal well-being.

- This assessment should consider: The extent you are able and willing to provide care; your wishes or need to work and participate in education, training, or leisure activities that are important to you; emergency care planning; your eligibility for Carer's Allowance.



Carer's Allowance

The Carer's Allowance is a standard rate by the Government available to carers providing regular and substantial care. It forms part of your taxable income.

- For each week you receive Carer's Allowance you will automatically get National Insurance credits.
- You may not receive the full Carer's Allowance if you are receiving other benefits such as a state pension.
- www.gov.uk/carers-allowance ☎ 0800 731 0297
- www.carersuk.org/help-and-advice/financial-support

Carer's Credit

Carers who do not qualify for Carer's Allowance may qualify for Carer's Credit. The Carer's Credit is a National Insurance credit that protects gaps in your National Insurance record due to your caregiving responsibilities.

There are other forms of financial support and benefits you may be entitled to because of your caring role:

- www.carersuk.org/help-and-advice/financial-support ☎ 029 2081 1370
- www.carers.org/money-and-benefits/intro ☎ 0300 772 9600

Guide for Carers

Carers Trust Wales has created a guide for family and friends who support someone with dementia, that brings together practical information and emotional guidance to support their well-being.

- The guide is called "Caring for Someone with Dementia: A guide for family and friends", available at: www.carers.org/resources/all-resources/117-caring-for-someone-with-dementia-gofalu-am-rywun-dementia

Short breaks and respite

This is to support the caring relationship and promote the health and well-being of the carer and the person with dementia.

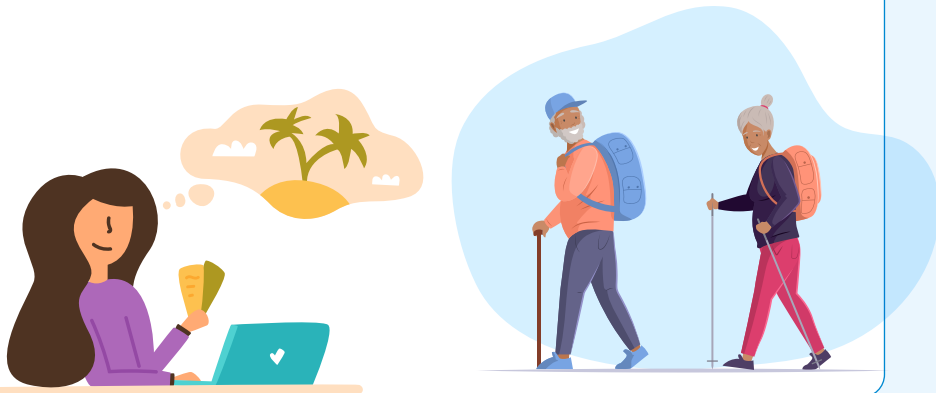
A short break is a form of service or assistance which enables the carer(s) to have sufficient and regular periods away from their caring routines or responsibilities.

Breaks from caring responsibilities may:

- be for short or extended periods
- take place during the day or overnight
- be enjoyed together through community activities or groups and supported holidays
- involve replacement care, in or away from the home, allowing the carer and the person with dementia some time to themselves.

There are many ways a break can be supported, and across Wales options will vary. Your local council may work closely with local charities and private providers who provide short breaks on their behalf or that you can privately fund.

- Contact your local carers organisation and/or local council for advice and guidance on the options available for you.
- Short break needs, preferences, and options can be discussed during a Carer's Needs Assessment.



Discounts you may be entitled to

CarerSmart

CarerSmart is a Carers Trust club that is open to carers, people with care needs, staff, and volunteers from across the Carers Trust network.

You can benefit from a wide range of offers, including free legal advice, reductions on insurance renewals, and discounts on holidays. Joining is simple and free.

- carers.org/grants-and-discounts/carersmart-discount-club

Council tax reduction

You may be entitled to a council tax reduction, depending on your circumstances. You will need a letter of support from a health professional.

- Apply through your local council website or phoneline.
- www.gov.wales/local-authority-council-tax-contacts

Discounts for Carers

This is a service that connects unpaid family or friends who are carers, and those working or volunteering in the care sector, to money saving discounts.

- www.discountsforcarers.com

Home Discount Scheme

You could get money off your winter electricity or gas bill under the Warm Home Discount Scheme.

- www.gov.uk/the-warm-home-discount-scheme/low-income

WaterSure Wales

Water rates cap (for metered water).

You may be eligible to have a cap on your water rates.

- Dŵr Cymru Welsh Water www.dwrcymru.com
☎ 0800 0520145

Travel and mobility

Car

A Blue Badge for car parking A Blue Badge is for people with a disability, including dementia, to place on the car dashboard to give parking concessions. The Blue Badge is linked to the person with dementia, not the vehicle. It is free to apply in Wales.

- Apply through your local council or here: www.gov.uk/apply-blue-badge
- There are other schemes available (e.g., exemption from most road tolls in UK if you register your car).

Mobility Vehicle through Personal Independence Payment (PIP) A car can be leased if you use mobility PIP (on enhanced rate if you choose to use it this way). The scheme also covers tax, insurance, servicing, and tyres for the car.

- This only applies for three years. If the person who has the diagnosis is no longer using the car it must be given back.

Community Transport

Your area may have a local community transport scheme providing door-to-door accessible transport for people who have care and support needs. These not-for-profit services include dial-a-ride schemes and community car services that help people get to health appointments, shops, social groups, and activities. Every community transport scheme has its own eligibility criteria, and charges apply.

- To find out if there is a scheme in your area, please contact the Community Transport Association.
- www.ctauk.org ☎ 07944 521395

“Always check ahead of travelling about assistance available at airports, train stations, on buses and so on”.

Public Transport

The orange wallet scheme is for anyone who may find it difficult to communicate their needs when travelling on public transport in Wales. It has plastic pockets to put in words and pictures to help you communicate.

- Order an orange wallet by phoning ☎ 03333 211 202, or email: Community@tfwrail.wales

Bus Travel

Local bus companies may offer ‘journey assistance cards’ you can show to a staff member, such as “count my change for me”. Please check with your local bus companies (e.g., Arriva Wales).

Bus passes To travel free by bus you can apply for a disability bus pass or a disability bus pass plus (this means you can travel with a companion).

- Apply to Transport for Wales, for free.
- portal.tfw.wales/en ☎ 0300 303 4240.

Rail Travel

Network Rail offer assistance at stations, but it is advisable that you book it in advance. Some stations have a ‘Calm Corner’ waiting room to get away from the crowds and noise in the station (check particular stations and ask when booking your ticket).

Disability rail card This allows you, and one person accompanying you, 1/3 off rail travel throughout the UK. This is a chargeable card, but you can use vouchers such as Tesco Clubcard vouchers to pay.

- www.disabledpersons-railcard.co.uk ☎ 0345 605 0525.

Access assistance

'Just Can't Wait' toilet card

This is a card to use in a shop or café when you just can't wait to use the toilet (if accessible).

- Available from the Bladder and Bowel Community.
www.bladderandbowel.org ☎ 0800 031 5406.

Key to access disabled toilets

RADAR keys open locked accessible public toilets across the UK.

- Available from public libraries, Disability Wales, or Disability UK.
- You will have to pay a small amount for the key but then it's yours to keep.

Wheelchair access

You may be eligible for a wheelchair/walker from your local council. Apply to your local social services department.

Wheelchair hire services are also available UK wide:

- Red Cross: www.redcross.org.uk/get-help/hire-a-wheelchair.
- Byw Bywyd: post@byw-bywyd.co.uk ☎ 01286 830101.

National Trust Essential Companion Card

This is for the person with dementia to bring one or two carers or companions with them, free of charge.

- www.nationaltrust.org.uk/who-we-are/about-us/access-for-everyone ☎ 0344 800 1895.



CEA Card (Cinema exhibitors' association card)

This is a card which enables carers to accompany the cardholder for free into certain cinemas. This has a nominal charge for the administration.

- www.ceacard.co.uk ☎ 01244 526 016.

Relaxed cinema screenings

Some cinemas offer relaxed or dementia friendly screenings, where the lights are left on, breaks are provided, the music is quieter and there are no adverts before the film. Enquire at your local cinema.

Sunflower Lanyard

This is a lanyard, wrist band or badge, that indicates a hidden disability, so staff in supermarkets, airports, on buses and trains can recognise that you may like some extra support. You can get assistance at airports, for you, and for your group.

- Pick one up in a participating shop, airport, station or venue at the desk or till. The lanyards are free from businesses that are members of the scheme.
- www.hiddendisabilitiesstore.com

Supermarket 'quiet hours'

Many supermarkets have a 'quiet hour' when they turn the music off and staff are especially aware to help customers.

- Check with your local supermarket. If they don't have one, enquire if they might be willing to start one.

"The Sunflower lanyard really works and doesn't highlight you as vulnerable, just highlights you might need help! I use it all the time and it costs nothing but is worth everything".

Schemes and campaigns

Carer's Emergency Card

This is a card the carer can carry in case anything happens to them, to inform others that they care for a person who may be alone at home.

- Available from local carers organisation or local council.

Message in a bottle scheme

The Lions Charity run a free 'message in a bottle' scheme to store important information (contacts, diagnosis, and medication) in the fridge and/or car, including a sticker to make someone aware the information bottle is there.

The Herbert Protocol

This is a national scheme that encourages family and friends to put together useful information, which can then be used in the event of a vulnerable person going missing.

- Contact your local police force to obtain the form, fill it in and keep it safe at home. This can easily and quickly be shared should someone go missing.

Medical ID bracelet or necklace

You can buy medical identification jewellery to help show what your needs are if anything happens to you.

"Keep going, keep up as much independence and activity as you can".

Telecare devices

This is a personal alarm, which you wear as a pendant or bracelet, that lets you call for help if you need it.

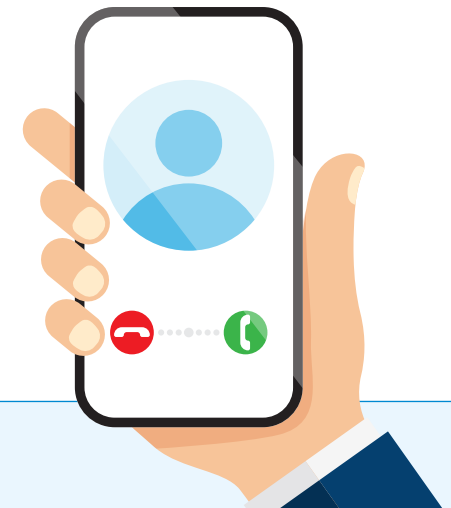
- Contact your local council's adult social services department and ask for a free Needs Assessment for the person with dementia and you may have a telecare device provided.
- Speak to your GP or an Occupational therapist. They may recommend a telecare system as part of a continuing health or care package, but there's often a charge for telecare services.

Mobile phone Apps with GPS tracking systems

If you have a 'smart phone', you can get free Apps with GPS tracking systems, to keep your loved ones safe while out and about. Search 'GPS tracker' in Apps on the phone.

In Case of Emergency - ICE

By adding 'ICE' as a contact in your mobile phone it means that if anything happens to you, emergency workers will know who to call first to get the information they need to give treatment in an emergency.



Legal considerations

Lasting Power of Attorney (LPA)

This is a legal document that lets you appoint one or more people to help you make decisions or to make decisions on your behalf if you cannot make your own decisions. There are two types: property and financial affairs, and health and welfare.

- This gives you more control over what happens to you.
- www.gov.uk/power-of-attorney

Advanced care directives (or a 'living will'/'advance decision')

This is a legal document where you specify what actions should be taken for your health if you are no longer able to make decisions for yourself.

- You may find help or guidance from the following charities:
Age Cymru, My Living Will, Alzheimer's Society.



Support you may come across

Community Psychiatric Nurse (CPN)/ Young Onset (under 65s) Dementia Nurse

Can help understand your experiences and help you make positive changes in ways that are meaningful and important to you.

Psychologists and Psychological therapists

Can help understand your experiences and help you make positive changes in ways that are meaningful and important to you.

Social worker

Can help you with Needs Assessments, and suggest useful resources and services (e.g., peer support groups).

Community support worker

Support you to continue to do what is important to you to support your well-being and quality of life.

Occupational therapist (OT)

They will help you live life to its fullest by adapting your home environment and focusing on what you can do to maximise your safety, quality of life, and your engagement in activities.

Speech and language therapist

Can help with communication and difficulties with swallowing.

Audiologist

Can help with hearing difficulties.

Physiotherapist

Can work with you to promote physical activity and maintain your mobility and independence for as long as possible.

Dietician

Provide advice to optimise nutritional intake to improve health and wellbeing.

Podiatrist

Take care of your feet to help you to remain mobile, prevent falls and promote independence.

Places to find support, opportunities to get involved and to connect with others

Dementia helplines

Alzheimer's Society Dementia Connect: ☎ 0333 150 3456

Dementia UK: ☎ 0800 888 6678

Wales dementia helpline: ☎ 0808 808 2235

Support and involvement opportunities

Alzheimer's Society: www.alzheimers.org.uk ☎ 0333 150 3456

- The Alzheimer's Society website has lots of information, advice, and support.

Carers Trust Wales: www.carers.org ☎ 0300 772 9600

- Carers Trust work to improve support, services, and recognition for anyone who is caring for someone.

Carers Wales: www.carersuk.org/wales ☎ 029 2081 1370

- Provides advice and information to carers and the professionals who support carers.

Cruse Pre-bereavement Support: www.cruse.org.uk

☎ 080 8808 1677

- Cruse Bereavement Care Cymru and Alzheimer's Society Cymru have trained volunteers to help people with dementia, their families, and carers to deal with feelings of loss and grief.

DEEP (Dementia Engagement and Empowerment Project):

www.dementiavoices.org.uk ☎ 07720 538851

- You can join groups, watch and create Dementia Diaries and get involved in making changes for people living with dementia.

Dementia Carers Count: www.dementiacarers.org.uk

☎ 0800 652 1102

- Dementia Carers Count supports family, friends and partners taking care of someone living with dementia. They provide free courses led by healthcare professionals.

Dementia Services Development Centre, Bangor University:

dsdc.bangor.ac.uk/supporting-people ☎ 01248 388872

- DSDC offers opportunities to take part in research and to share lived experiences with researchers and students. They also support the Caban group, new members are always welcome.

Join Dementia Research: www.joindementiaresearch.nihr.ac.uk

- This is a service which allows people to register their interest in participating in dementia research and to be matched to suitable research project.

Rare Dementia Support: www.raredementiasupport.org

☎ 020 3325 0828

- A service that aims to empower, guide, and inform people living with a rare dementia diagnosis and those who care about them.

Together in Dementia Everyday (TIDE): www.tide.uk.net

☎ 07841 447064

- TIDE provide opportunities for carers to connect, support carer confidence and well-being, and seek to influence practice and policy at a local and national level.

3 nations dementia working group: www.3ndementiawg.org

- Membership is open to anyone with a diagnosis of dementia, you receive a newsletter about how you can get involved. Associate membership is also available for carers, professionals, and academics.



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An electronic version of the booklet is available at: dsdc.bangor.ac.uk/products-created

If you have any questions or would like to order copies of this booklet, please get in touch with Catrin Hedd Jones: c.h.jones@bangor.ac.uk ☎ 01248 388872



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