

KNOWLEDGE IS POWER

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...

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

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.

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.

Use 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 helps
to talk to someone else going
through the same thing.

Connect with other
people who are living with
dementia: Peer support is
invaluable.



Benefits and allowances

PIP (Personal Independence Payment) for under 65s

This is a government provided allowance for disability (not means tested). It has 2 components, and both have 2 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.
- Citizens Advice Bureau can help you complete the form.
- Apply to the Department for Work and Pensions to see if you qualify.
- <https://www.gov.uk/pip> ☎ 0800 917 2222.

Attendance Allowance for over 65s

You might qualify for an Attendance Allowance (from the Government). This helps with extra costs if you need someone to help look after you (check if you're eligible).

This is awarded to the person who has received a diagnosis of dementia.

- <https://www.gov.uk/attendance-allowance>
☎ 0800 731 0122.

Care 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.

- Apply to the social services department of your local council (for free), and they can recommend services to help you with things like equipment, home adaptations, practical help from a paid carer, access to day centres and clubs.

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!

Specifically for carers

Needs assessment for carers

Carers are entitled and encouraged to have a needs assessment, so make sure you enquire with the social services department of your local council or carers organisation.

- You can contact the local council by phone, email or online to request an assessment.

Carer's Allowance

This is an allowance from the Government that goes to carers, if they spend over 35 hours being a carer each week.

- Income-related.
- <https://www.gov.uk/carers-allowance>
☎ 0800 731 0297.

Respite or breaks

Respite care is an arrangement that gives unpaid carers a break.

There are many different types of respite, ranging from short breaks to run errands or see friends, to a longer time spent away.

Respite care referral from Social Services

The social services department of your local council can arrange respite for you, charges may apply but these are capped in Wales.

Respite grants / Carers grants

Local carers charities may be able to fund 'respite grants'.

Many Carers Trust Network Partners across Wales offer some form of grant fund. These grants tend to be one-off and can be used in a variety of ways. Eligibility criteria will differ across Wales.

- Contact your local carers organisation and local council for advice and guidance.

Discounts you may be entitled to

Council tax reduction

You may be entitled to a council tax reduction, depending on your circumstances. Check with your local council.

- Arrange through the Council website or phonenumber.
- <https://gov.wales/local-authority-council-tax-contacts>
- You will need a letter of support from a health professional.

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/en/My-Account/Help-Paying-My-Water-Bill/WaterSure-Wales
☎ 0800 0520145

Warm Home Discount Scheme

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

- <https://www.gov.uk/the-warm-home-discount-scheme>

Discounts for Carers

This is a dedicated discount service for individuals working or volunteering in the care industry, and for those who care for a family member or friend.

- www.discountsforcarers.com



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.

- Apply through your local council (Free in Wales) or here: <https://www.gov.uk/apply-blue-badge3>
- The blue badge is for the person, not the vehicle.
- There are other schemes available (e.g. exemption from most road tolls in UK).

Mobility Vehicle through Personal Independence Payment (PIP) A car can be supplied on lease if you use mobility PIP (on enhanced rate, if you choose to use it this way). No tax to pay, insurance, service and tyres are also covered within the scheme.

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

Public transport

The orange wallet scheme (Welsh Government scheme)

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.

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

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 Disability bus pass & disability bus pass plus (this means you can travel with a companion).

- Apply to Transport for Wales, free
<https://portal.tfw.wales/en/disabled> ☎ 0300 303 4240.

Rail travel

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

Disability rail card This allows you, and 1 person accompanying you, 1/3 off rail travel throughout the UK.

Sign up for their newsletter and receive offers and discounts to other places.

- This is a chargeable card, but you can use vouchers such as Tesco to pay.
- <https://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
<https://www.bladderandbowel.org/help-information/just-cant-wait-card/> ☎ 0800 031 5406.

Key to access disabled toilets

The RADAR Key Scheme: Available from public libraries, Disability Wales or Disability UK.

- You 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 the social services department.
- Red Cross / Byw Bywyd do wheelchair hire.

National Trust Essential Companion Card

This is for the person who has a diagnosis and admits their carer(s)/companion(s) free.

- <https://www.nationaltrust.org.uk/features/access-for-everyone>
☎ 0344 800 1895.



CEA (Cinema exhibitors association) card

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

- <https://www.ceacard.co.uk> ☎ 01244 526 016.

Relaxed cinema screenings

Some cinemas offer relaxed screenings (lights left on, breaks, quieter music and no adverts before the film). Enquire at your local cinema.

The Sunflower Lanyard, wrist band or badge

This is a lanyard that indicates a hidden disability.

It is recognised in most supermarkets, airports, buses and trains.

- You can get assistance at airports, for you and your group.
- Pick one up in a participating shop, airport, station or venue at the desk or till. The lanyards are free and you don't need to provide proof of your disability.

Supermarket 'quiet hours'

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

- 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

Carers' Emergency Card

This is a card the carer can carry in case anything happens to the carer, to inform that there is a person being cared for 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

The Herbert Protocol 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 online or by phone 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 care needs assessment for the person who has the diagnosis. Depending on your needs, you may have a telecare service 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 phone Apps with GPS tracking systems, to keep your loved ones safe while out and about. Simply search 'GPS tracker' in Apps on the phone.

ICE – In Case of Emergency

By adding 'ICE' as a contact in your mobile phone it means that if anything happens to you, medics will have all the information they need to give the right treatment, and they will know who to call first.



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.

- This gives you more control over what happens to you.
- There are two types (Property & financial affairs and Health & welfare).
- You may find help or guidance from the following charities: Age Cymru, My Living Will, Alzheimer's Society.
- Information also available here:
<https://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

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

Offer advice on assessments, carer stress, working around dementia and coming to terms with it.

Social worker

They can help you with needs assessments, helping you to find useful resources and services (e.g. respite).

Community support worker

Supports people to continue to do what is important to them (after referral from the Mental Health Team).

Occupational therapist (OT)

They will help you live life to its fullest by adapting the 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 and your carers to promote physical activity and maintain your mobility and independence for as long as possible.

Dementia Friendly Communities Coordinators

Dementia Friendly Communities Coordinators are in most areas, please contact the Alzheimer's Society to find out what's available in your area and how they can help you to be involved in your community.

Useful Websites and phone numbers (available Wales-wide)

Dementia helplines

Wales dementia helpline: ☎ 0808 808 2235

Dementia UK [admiral nurse dementia helpline]:
☎ 0800 888 6678

Alzheimer's Society Dementia Connect support line:
☎ 0333 150 3456

Useful websites, support and involvement opportunities

DEEP (Dementia Engagement and Empowerment Project):
dementiavoices.org.uk

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

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

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

Alzheimer's Society: alzheimers.org.uk

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

Carers Trust Wales: carers.org

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

Dementia Carers Count: dementiacarers.org.uk

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

Dewis Cymru: www.dewis.wales

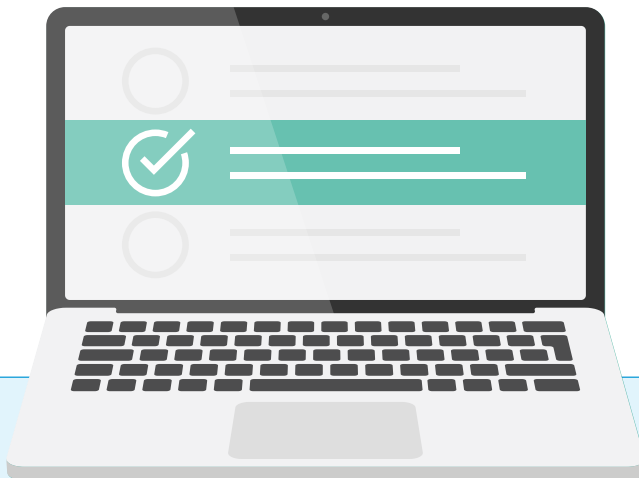
- Dewis Cymru helps you find information or advice about services and supports available across Wales.

Join Dementia Research: joindementiaresearch.nihr.ac.uk

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

Rare Dementia Support: raredementiasupport.org

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



This booklet was created in a collaboration between the following DEEP groups:
Caban Bangor University Educators, DEEP United Dwyfor & Meirionnydd and Fuse & Muse Swansea
www.dementiavoices.org.uk/deep-groups

We encourage new members to join DEEP groups.



This work is supported by the DSDC
Wales Research Centre
dsdc.bangor.ac.uk/supporting-people and
CADR Cymru www.cadr.cymru

Please visit these sites for more opportunities for support
and getting involved.



Knowledge is Power feedback

We ask you to provide feedback after reading the booklet so that we can update its content and continue to support people affected by dementia. This form is also online at: <https://bangor.onlinesurveys.ac.uk/kip>

1. Why have you accessed the booklet? Please tick, and give extra details where necessary

- Person living with dementia (PLWD)
- Family or friend of PLWD
- Within my work role Job title:
- Other Details, please:

2. Was this booklet useful? If so, how was it useful?

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3. Were you made aware of any services? If so, which ones?

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4. What do you think is missing? How else could the booklet be improved?

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Thank you for taking the time to offer feedback. If you would like more copies, or further information on how to work with us, please fill in your contact details below. All data will be anonymous. We will not use your contact details for any other purpose or share with any third parties. Contact details will be stored securely by Bangor University and will be GDPR compliant.

Contact details (optional)

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Please return this form to:

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