



# WELLBEING AND RESPITE

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

# 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 your well-being. It's normal to feel frustration, resentment or guilt at times, and experience good 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 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 know 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 carer's 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 **Samaritans** for free on **116 123** at any time of the 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 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 will be just for you, while others are inclusive for you to attend alone and/or with the person you care for.

In this booklet we highlight some of the many excellent services that are available to carers in Wales. Please find links to more support groups and services for carers below.

“

**I need people who understand to talk to**

**Carer of a person with dementia**

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### **Find support groups and carers' services**

[www.carers.org/the-network/the-network-in-wales](http://www.carers.org/the-network/the-network-in-wales)

[www.carersuk.org/help-and-advice/get-support/local-support](http://www.carersuk.org/help-and-advice/get-support/local-support)

[www.alzheimers.org.uk/find-support-near-you](http://www.alzheimers.org.uk/find-support-near-you)

[www.tide.uk.net](http://www.tide.uk.net)



# HELPING THE PERSON YOU CARE FOR TO STAY HEALTHY AND INDEPENDENT

**People living with 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 dementia progresses 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.

### 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](http://www.forgetmenotchorus.com)

02922 362 064

Swansea Carer's Choir is a weekly session for unpaid carers.

[www.facebook.com/SwanseaCarersChoir](https://www.facebook.com/SwanseaCarersChoir)

07851 381966

Bridgend Carer's Choir is a weekly session for unpaid carers.

[www.bridgendcarers.co.uk](http://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, photos or images on doors and cupboards can remind people

where items are kept, or of anything they need to remember, such as closing the refrigerator door.

- Place important numbers by the telephone with pictures so they're easy to recognise and access.
- Put notes on the back and front door, that remind a person with dementia to take a key when they are going out. Use a curtain or other covering over external doors and windows at night to reduce night time walking. Automated door locks following sun down may also be helpful.
- 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, and people with disabilities to improve, repair or adapt their homes, to help ensure the safety and wellbeing of older people with evolving needs. Some services may be chargeable dependant on eligibility, so it is best to visit [www.careandrepair.org.uk](http://www.careandrepair.org.uk) to ask what services are available in your area , or ask



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social services to put you in contact with your local care and repair service.

- Inform electrical, gas and water suppliers that a person with dementia is living at the property as supplier discounts / vulnerable customer measures can be put in place to safeguard their health and wellbeing. For example, the WaterSure scheme could help to make bills more affordable. visit [www.dwrcymru.com](http://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.
- Equipment to reduce the impact of noise sensitivity (hyperacusis) for people living with dementia and hearing loss who may find everyday noises in shared environments unbearable and painfully

loud. Solutions include Bluetooth mics and hearing aids that enable the person to focus on the voice of their carer.

### 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. Researching the benefits of assistive technology and sharing with social services may help you to apply for direct payments, that enable the person you care for to live independently in the community for longer.
- Some people with dementia resist using the technology, for example refusing to wear a GPS tracker.
- Try exploring technology that is attractive to the person with dementia and has other uses; e.g. an app on a person's mobile / apple watch

### Accessing assistive technology

A needs assessment and carer's needs assessment may also help you find out 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



<https://www.alzheimers.org.uk/get-support/staying-independent/how-to-obtain-assistive-technology>

[www.rnid.org.uk/information-and-support/technology-and-products/](http://www.rnid.org.uk/information-and-support/technology-and-products/)

[www.rnib.org.uk/nations/walescymru/technology-for-life/](http://www.rnib.org.uk/nations/walescymru/technology-for-life/)

[www.meetadam.co.uk/](http://www.meetadam.co.uk/)



access occupational therapy. You can also buy technology yourself and get specialist advice from sensory loss and dementia friendly organisations. Please find helpful links at the bottom of this page.

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](http://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](http://www.hynt.co.uk/en/join/eligibility-criteria)

## 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**.

- The UK Cinema Association, CEA card allows film fans with disabilities to access a complimentary ticket for an individual to accompany them at all participating cinemas. Find out more from [www.ceacard.co.uk](http://www.ceacard.co.uk)
- People who are disabled or have a health condition that affects their 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)** [www.gov.wales/blue-badges-eligibility](http://www.gov.wales/blue-badges-eligibility).



<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](http://www.alzheimers.org.uk/get-support/publications-and-factsheets/helpcards)

- **Helpcards** are available for people with dementia to use and carry with them, to make it easier to get help or assistance when out in the community.
- The National Key Scheme offers disabled people independent access to locked public toilets around the country. You can purchase a key for £5.00 (excluding VAT) from [shop.disabilityrightsuk.org/products/radar-key](https://shop.disabilityrightsuk.org/products/radar-key).
- 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](http://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 dementia progresses it is likely there may need to be a conversation about whether it is safe to continue driving. This is a sensitive issue and one

that some carers and family members have navigated by gradually taking more responsibility for driving. Where this is not possible try to be gentle, kind and clear in your communications. The person with dementia may lack insight into the deterioration of their driving skills, and the accompanying loss of independence and freedom may come as a hard blow. You may wish to involve professionals or other family members in this conversation. However you choose to handle this situation if you have any concern about the person's safety, or the safety of others, it is vital to take action to safeguard lives.

## Further information on driving

[www.alzheimers.org.uk/get-support/staying-independent/keep-driving-dementia-diagnosis](http://www.alzheimers.org.uk/get-support/staying-independent/keep-driving-dementia-diagnosis)

[www.gov.uk/dementia-and-driving](http://www.gov.uk/dementia-and-driving)

## Further information on getting out and about

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



# HELP WITH CARING

**Looking after someone with dementia can be difficult and many carers can struggle to ask for help. Dementia is a progressive life-limiting illness 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 off 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.

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

Carer

## Accessing support from a Specialist Dementia Nurse – Admiral Nurse

Dementia UK is the only specialist nursing charity that is there for the whole family. Their specialist nurses are known as Admiral Nurses and supported by Dementia UK to continually develop their knowledge in understanding the progression of different types of dementia. An Admiral Nurse can advise you about what to expect with the specific dementia of the person you are caring for and give advice and emotional support so you are not alone. Further details are available here: **What is an Admiral Nurse and how can they help? - Dementia UK**

In Wales, there are 2 Admiral Nurse services, one hosted by the Royal British Legion in South Wales helping anyone who has served/ or is connected to the armed services including widows, and those formerly married to service men and women. This can either be the person with dementia or their carer and family. Telephone support and home visits are offered. Carers can self-refer or be referred by another agency on 0808 802 8080 providing they are resident in the following areas: Aneurin Bevan University Health Board, Cardiff and Vale University Health Board, Cwm Taf Morgannwg University Health Board, Swansea Bay University Health Board. Telephone support only is provided to carers in Powys.

The Admiral Nurse service in Hywel Dda is hosted by the University Health Board. This means that referrals can only be made by GPs or other professionals working for Hywel Dda University Health Board.

In North Wales, the Memory Support Pathway for Dementia provides 5 Dementia Centres, hosted by Carers Trust North Wales. This service is available to carers and people diagnosed or living with a suspected dementia. The pathway has been set up to provide an integrated service offer to everyone affected by dementia across North Wales. Further details are available

here: **Memory Support Pathway - Dementia Centres | Carers Trust North Wales Crossroads Care Services ([nwcrossroads.org.uk](http://nwcrossroads.org.uk))** You can also call 01492 542212.

Carers outreach is also provided by **Carers Outreach Service North West Wales and Home - NEWCIS**.

## 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.

## 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

For more details please see the Care Home options booklet.

### 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.

## 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.

You can also contact a **Carers Trust Network Partner** for advice and support.

### 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.

### 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 explore whether a short break is manageable.

## Further information about respite

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

[www.carersuk.org/help-and-advice/your-health-and-wellbeing/taking-a-break/](http://www.carersuk.org/help-and-advice/your-health-and-wellbeing/taking-a-break/)

[www.alzheimers.org.uk/get-support/help-dementia-care/respite-care-wales](http://www.alzheimers.org.uk/get-support/help-dementia-care/respite-care-wales)

[www.shortbreaksscheme.wales](http://www.shortbreaksscheme.wales)



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

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



