



Comisiynydd Pobl Hŷn Cymru
Older People's Commissioner for Wales

A Guide to Respite for People Affected by Dementia



**An independent voice and champion
for older people**

The Older People's Commissioner for Wales

The Older People's Commissioner for Wales is an independent voice and champion for older people across Wales. The Commissioner and her team work to ensure that older people have a voice that is heard, that they have choice and control, that they don't feel isolated or discriminated against and that they receive the support and services that they need.

The Commissioner wants Wales to be the best place in the world to grow older.

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A Guide to Respite for People Affected by Dementia

This guide gives you the information you need when considering respite, to help you to explore respite alternatives, and tells you what your rights are.

What is respite?

Respite can mean different things to different people and can take a number of different forms. The aim of respite is to give people a break – both people living with dementia and those who care for them - which can be very good for their wellbeing.

Respite is not just about care homes and day services. Respite might be going away on holiday through accessible, affordable and flexible short breaks. It could be a chance to undertake a hobby, keep fit or another meaningful occupation that promotes wellbeing. It could be support that provides opportunities for social contact, or the ability to maintain family and personal relationships.

Respite is often thought about just in relation to carers, but having a chance to relax, do something enjoyable or see and do new things can be equally important to people living with dementia.

Different forms of respite may be experienced together by the person living with dementia and their carer, or may be experienced apart, enabling individuals to retain their own autonomy and independence.

In order to access respite, people need to have information and support that are accessible and responsive to their circumstances, to allow them to make informed choices about respite. A positive approach to risk management should be supported, whilst ensuring the appropriate safeguards are in place to protect individuals from abuse and neglect during respite.

What do you need to think about when considering respite?

Think ahead - It can really help to start thinking about respite early on and not leave it until your situation starts to deteriorate or at times of stress. Getting to know people and places in advance can help build your familiarity with a respite option and the relationships that you have with the people running and/or using a respite service.

Talk to people you know - It may be helpful for you to include family, friends and neighbours in your discussions about respite. People around you may come up with some unexpected solutions. Other people living with dementia and carers may also have some valuable knowledge and experience to share with you.

Talk to professionals - These may include your social worker, GP or Memory Clinic staff. You can consider asking for an assessment with social services if you have not had one (see section 'Routes to Respite'). The useful contacts listed in this guide, as well as information that may be provided by local carers or dementia organisations, may also be able to help.

Try to test things out first - You may wish to go and visit places so that you can get to know people who might be providing support, or even go for a trial session. This can help you to build familiarity and confidence with a respite option.

Think about what you want from respite - Make sure the respite support that you choose fits your needs and circumstances, including what you want from respite.

Keep trying - If you feel that the respite option being offered to you is not suitable, don't give up. Respite is an adjustment for everyone and you may need some time to find what works for you. If you experience issues in terms of the availability or quality of respite support, this guide includes information about your rights and what to do if you are unhappy.

What are the different types of respite?

Respite can take many forms and it is important that it meets your individual needs, whether as a person living with dementia or as a carer. The respite options available will vary across areas, so contact your local carer and/or dementia support services, social services or some of the useful contacts listed at the back of this guide to find out more.

Outlined below are some of the main types of respite you may want to consider, depending on your circumstances.

Day opportunities and activities

This includes specific group activities like day services and social groups. You might want to think about other activity-based opportunities, such as exercise sessions, or crafts or singing groups. Some of these may be specifically tailored for older people or people living with dementia, while some might be more general community groups.

Short breaks with accommodation

This might be a short break in a care home of choice, which can offer a break apart. You can also consider having a holiday-type break away together.

For more information:

Alzheimer's Society information – 'Holidays and Travelling'

Order a copy by phoning **0330 333 0804** or download from:
<https://www.alzheimers.org.uk/get-support/staying-independent/holidays-travelling>

One-to-one support

One-to-one support means individual support either inside or outside the home. This might include befriending or 'buddying', and perhaps overnight stays where there is a particular need for this.

Support with practical tasks

Support with practical and household tasks – either for the person living with dementia or for carers – can allow more ‘breathing space’ and quality time together.

Assistive technology

There are lots of forms of assistive technology, which could make life easier for you inside the home and getting out and about. It could be a device that prompts and reminds you, keeps you safe, aids communication or helps you to access things. For more information about assistive technology, talk to professionals, such as a social worker or dementia support worker.

How to go about organising respite and getting help to do this is outlined in ‘Routes to Respite’ on the next page.

What are the routes to respite?

There are a number of different ways of organising respite which are outlined below.

Route to respite: Social Services

If you are not already in touch with social services, you may wish to request an assessment of your needs. An assessment is your opportunity to discuss your situation and may identify a need for respite.

An assessment can be for the person living with dementia (a care and support assessment) or for a carer (a support assessment). Carers have a right to a support assessment even if the person living with dementia does not have (or want) a care and support assessment themselves.

These assessments can also be undertaken jointly or separately. Your right to an assessment does not depend on whether you or the person you care for has a diagnosis of dementia.

You should be enabled to participate in your assessment. Following your assessment, you should be enabled to participate in discussion on how best to meet your needs. These discussions will form the basis of your Care and Support Plan (or Support Plan if you are a carer). If respite is one of the things you want this should be discussed when your Care and Support Plan or Support Plan is being agreed. Respite can be organised by the social worker on your behalf, but you may want to organise it yourself using a 'Direct Payment' (described on page 10).

To arrange an assessment of your care and support needs (or your support needs if you are a carer), you will need to contact your local social services department within your council.

For more information:

Older People's Commissioner for Wales – Navigating Social Services Toolkit

Order a copy by phoning **029 2044 5030** or download from:
<http://www.olderpeoplewales.com/en/publications/sswb.aspx>

Carers Wales – Assessments; A guide to getting an assessment in Wales from April 2016

Order a copy by phoning **029 2081 1370** or download from: <https://bit.ly/2A2yefH>

Route to respite: Direct Payments

Direct Payments are a payment received by you from the Local Authority to be used for an agreed purpose or need, instead of receiving a service from social services, or a service organised by them.

Direct Payments can offer more choice and control over the services you use.

However, there must be agreement between you and the Local Authority about how the money will be used to meet a need that has been identified through your assessment from social services, and how it will be managed.

A Direct Payment could be a one-off or regular payment, depending on the type of need. Both a person living with dementia requiring care and support, and carers who have been assessed as requiring support from the Local Authority, can opt for a Direct Payment to meet their need.

Arrangements for Direct Payments can vary significantly across Local Authorities, so it is important to contact your local social services department within your council to find out what is available in your area. However, there are examples of people using their Direct Payment creatively, such as:

- Paying for a break away in accommodation of your choice
- Paying for fuel or travel costs to go and stay with a friend or family member
- Paying for a football season ticket for a volunteer to regularly accompany you to attend matches

If you choose to use a Direct Payment to employ someone, such as a personal assistant, you may be taking on associated legal responsibilities as an employer. However, Local Authorities must ensure that they develop local support services for Direct Payment recipients in order to help people manage a Direct Payment.

You should not be refused a Direct Payment on the basis that you are unable to manage one or are worried about doing so: a Local Authority must ensure that you have the correct level of support that you need to manage your Direct Payment.

Where someone with care and support needs lacks capacity, Direct Payments can still be available, provided a suitable, trusted person can manage the payments on their behalf. The Local Authority must ensure that the person receiving the Direct Payment on another person's behalf has the correct level of support to allow them to manage the Direct Payment.

For more information:

Age Cymru factsheet: 'Direct payments for social care services in Wales' (Factsheet 24w)

Order a copy by phoning **08000 223 444** or download from <http://bit.ly/2n6Nkdg>

Older People's Commissioner for Wales: Navigating Social Services Toolkit (Factsheet 5: Meeting your needs)

Order a copy by phoning **029 2044 5030** or download from:
<http://www.olderpeoplewales.com/en/publications/sswb.aspx>

Route to respite: Self organised

If you do not want to go through social services or want to develop additional respite opportunities, you might want to consider organising and funding your own respite. This could be through:

- Using private agencies / care providers
- Employing someone directly to provide support when you want it (remember you will have legal responsibilities as an employer)
- Organising your own holiday-type respite

There may also be local voluntary services who provide befriending, memory cafes or other respite opportunities, where you can refer yourself.

The self-organised respite options available will vary across areas, so contact your local carer and/or dementia support services, social services (who have a duty to offer information and advice even if you do not want an assessment), or some of the useful contacts listed at the back of this guide, to find out more.

For more information:

Carers UK 'Arranging care yourself' checklist

Order a copy by phoning **029 2081 1370** or download from: <https://bit.ly/2Ea7AFI>

Ways of funding respite, including assistance to fund some of these opportunities, are included in the section 'Paying for respite' on page 13.

Some people prefer to organise and pay for their own respite, but if you are doing this because you are not getting the support you are entitled to

from statutory services or have been denied a Direct Payment, you may find the section ‘What to do if you are not getting the respite support you need’ section of this guide helpful.

Paying for Respite

Social Services Charges

If you receive respite through social services (including through a Direct Payment) the amount that you will have to pay for the respite will be dependent on the amount you can afford to pay (i.e. it is means-tested).

For more information:

Older People's Commissioner for Wales: Navigating Social Services (Factsheet 6: Paying for Care)

Order a copy by phoning **029 2044 5030** or download from:
<http://www.olderpeoplewales.com/en/publications/sswb.aspx>

Age Cymru: Paying for care and support at home in Wales (Factsheet 46w)

Order a copy by phoning **08000 223 444** or download from: <https://bit.ly/2pHsfa1>

Age Cymru: Paying for temporary care in a care home in Wales (Factsheet 58w)

Order a copy by phoning **08000 223 444** or download from: <https://bit.ly/2QyzIDy>

NHS funding

NHS continuing healthcare is a package of care arranged and funded solely by the NHS to meet complex physical and/or mental health needs. It can be provided in a variety of settings outside hospital, such as in your home or in a care home.

Eligibility depends on your assessed needs and not on any particular diagnosis or condition. It is decided through a full assessment where the 'nature', 'intensity', 'complexity' or 'unpredictability' of someone's health needs mean that they have to be actively managed by the NHS. If your needs change then your eligibility for NHS continuing healthcare may change.

For more information:

Age Cymru: NHS continuing healthcare and NHS-funded nursing care in Wales (Factsheet 20w)

Order a copy by phoning **08000 223 444** or download from: <https://bit.ly/2pLED90>

Benevolent funds, bursaries and grants

These types of funds may be linked to trades, professions, unions, specific local areas or the Armed Services.

For more information:

Carers Trust 'Grants and other sources of funding'

Order a copy by phoning **029 2009 0087** or download from: <https://bit.ly/2yoQAFF>

Communicating your needs to providers

Communicating your needs to providers can help you to get the most out of respite.

It might help if you create a checklist of what is important to you to share with the provider. For example:

- Any medicines that need to be taken, including dosage and timings
- Any sensory or physical difficulties, and how best to manage this
- Any mobility issues, and how best to manage this
- Dietary, religious and cultural needs
- Interests and hobbies
- Likes and dislikes
- Helpful ways to communicate
- Routines and helpful ways to provide support
- Contact details for you and for key people, such as the GP

You may wish to use a tool such as 'This is me', which can be used by people living with dementia and carers to tell people about needs, preferences, likes, dislikes and interests.

For more information:

Alzheimer's Society 'This is me'

Order a copy by phoning **0300 303 5933** or download from: <https://bit.ly/1boo6l9>

Emergency respite / support

Knowing there is a plan in place should something unexpected happened to a carer can help reduce stress, keep people safe and ensure peace of mind.

As part of a Social Services assessment, contingency plans should be considered if a carer was suddenly unable to meet the needs of the person they care for (if they were taken ill, for example). This is so that the Local Authority is able to respond appropriately and quickly. Options may include emergency respite.

It may therefore be useful to have an assessment so that plans for an emergency can be discussed and agreed.

Regardless of whether or not a social services assessment has been carried out, Carer 'Emergency Card' schemes are available. Carers Wales provides an 'Emergency Contact' card, for example.

Should an emergency or accident happen, the card will let emergency workers and others know that someone is a carer. The card provides spaces for emergency contacts, such as family or friends who can help.

For more information:

Carers Wales, Caring and Emergencies

Order a card or key fob by phoning **029 2081 1370** or emailing: info@carerswales.org.

More information can be found at: <https://bit.ly/2NxHuMa>

Your voice matters

Giving Feedback

Giving feedback to services about the quality of respite is a useful thing to establish what you need and to help build good practice. If you are happy about the support provided, let people know. If you have positive suggestions to make, many organisations now have systems for enabling this. You could also just have an informal chat with people providing a respite service.

If you are unhappy about a service or wish to make a complaint, see page 18: 'What to do if you are not getting the respite support you need'.

Advocacy and Independent Advocacy

Some people will need support to help them express their wishes. For many people, a family member or friend will be able to speak on their behalf. For others, the support of an Independent Advocate may be required. An Independent Advocate will not seek to advise you, they instead will help you to exercise your rights, express your views, and explore and make informed choices. An Independent Advocate supports you regardless of the demands and concerns of others.

When a person lacks capacity or is experiencing fluctuating capacity, an Independent Advocate will seek to build a relationship with the person to ensure that they can independently determine and express their views and wishes.

For more information:

Age Cymru/Golden Thread Advocacy Programme: Independent Professional Advocacy

Order a copy by phoning **08000 223 444** or download from: <https://bit.ly/2C9kZuO>

Older People's Commissioner for Wales: Navigating Social Services Toolkit (Factsheet 2: 'Voice and Control')

Order a copy by phoning **029 2044 5030** or download from: <http://www.olderpeoplewales.com/en/publications/sswb.aspx>

Older People's Commissioner for Wales: Mental Capacity – An Easy Guide

Order a copy by phoning **029 2044 5030** or download from: <http://www.olderpeoplewales.com/en/publications.aspx>

What to do if you are not getting the respite support you need

Making a complaint

You may be concerned that you are not getting the respite support you need because:

- You are having difficulty getting a care and support assessment from social services as a person living with dementia
- You don't think you have been offered or effectively provided with a support assessment as a carer
- You do not feel that you have been heard in terms of your needs for respite or the particular type of care and support that is required
- You are unhappy about the quality of respite provided
- You are being told you cannot have something that you believe you have a right to (for example, support in the form of a Direct Payment)

If you are concerned, it might help to raise any concerns informally in the first place, and there may be a way of resolving things before they escalate. If you have a social worker, it is important that you share any concerns with them and consider together how to try and resolve and improve matters. However, if you want to make a formal complaint, you should contact your Local Authority or Health Board.

Before you approach anyone, it is helpful to have a clear idea of what you want to raise concerns or complain about and what you would like to see happen as a result.

Complaints about care and support (Local Authority Social Services):

You can make a complaint if you feel that your rights have not been upheld or you feel that a Local Authority has not acted in the way that it should. You can use the Local Authority's complaints procedure if you are unhappy about the service you have received from your Local Authority social services department.

The Older People's Commissioner for Wales: Navigating Social Services Toolkit will help you understand the system and your rights under the Social Services and Wellbeing (Wales) Act 2014.

For more information:

Older People's Commissioner for Wales: Navigating Social Services Toolkit (Factsheet 8: What can you do if you don't receive the help you need?)

Order a copy by phoning **029 2044 5030** or download from:
<http://www.olderpeoplewales.com/en/publications/sswb.aspx>

Complaints about healthcare (NHS):

You can make a complaint if you feel that you have not received the appropriate care, treatment or service, or if a Health Board has not acted in the way that it should.

For more information:

Age Cymru: 'Resolving problems and making a complaint about NHS care in Wales' (Factsheet 66w)

Order a copy by phoning **08000 223 444** or download from: <https://bit.ly/2yrqUYX>

Other agencies:

All services providers, such as care homes, should have their own complaints system. Ask the management for their procedures if you wish to make a complaint.

Public Services Ombudsman for Wales:

If you are unhappy about how a complaint has been handled by a Local Authority or Health Board, you can contact the Public Services Ombudsman for Wales.

The Ombudsman now has an extended role in relation to care homes, domiciliary care and palliative care services. The new arrangements now also mean that complaints can be considered from people who arrange and fund their own care.

For further information:

Public Services Ombudsman for Wales, phone **0300 790 0203** or visit:
<https://www.ombudsman.wales/>

Useful Contacts & Information

Admiral Nurse Dementia, UK helpline (Dementia UK)

0800 888 6678

www.dementiauk.org/get-support/admiral-nursing

Age Cymru

08000 223 444

<https://www.ageuk.org.uk/cymru/>

Alzheimer's Society - National dementia helpline

0300 222 1122

Alzheimer's Society Cymru

02920 480593

https://www.alzheimers.org.uk/homepage/316/wales_cymru

AT Dementia (assistive technology)

<https://www.atdementia.org.uk/>

Carers Trust Wales

02920 090087

<https://carers.org/country/carers-trust-wales-cymru>

Carers Wales

0808 808 7777

02920 811370

www.carersuk.org/wales

DEEP (The Dementia Engagement & Empowerment Project)

01392 420076

www.dementiavoices.org.uk

DEWIS Cymru

www.dewis.wales

Local Authority Social Services & Assessments

<https://www.gov.uk/apply-needs-assessment-social-services>

Wales Dementia Helpline

08088 082 235

<http://www.dementiahelpline.org.uk/>

Young Dementia UK

<https://www.youngdementiauk.org/>

