

Respite care in Wales

Wales factsheet
Factsheet W462LP
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Respite care is the term for types of temporary care or activity that give a short break to anyone who has a main responsibility for caring for someone else.

This factsheet is for carers of a person with dementia. It tells you what respite care is, the different types that are available, and how to pay for it. It also offers tips to help you, and the person you care for, to get the most out of respite care.

This factsheet is for people living in Wales and does not cover England and Northern Ireland, where the systems are different. For information on respite care in these countries see factsheet 462, **Replacement care (respite care) in England** or NI462, **Respite care in Northern Ireland**.

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Respite care in Wales

What is respite care?

Respite care is temporary care or support that gives the person's main carer a break from caring. Respite care can be arranged for a short time, for example while you go to the shops or meet friends. It can also be arranged for a longer time, for example if you want to have a break for a few days, or spend some time away. In some parts of Wales it can also be provided when the carer has a temporary urgent health issue.

Having a break from your caring role can improve your physical and mental wellbeing, and be good for your relationship with the person you care for. Respite care can also have benefits for the person with dementia. It can be a good way for them to enjoy different hobbies and interests and maintain or develop relationships with others. This can improve their wellbeing, as it can help them to remain involved and active.

Respite care can include:

- care at home
- day centres and community groups
- holidays or short breaks
- a short stay in a care home
- the 'Shared Lives' scheme
- carers' emergency respite care schemes
- help from friends and family
- spending some time away together.

The right type of respite care for the person with dementia will depend both on their – and your – needs. For example, if you want to attend a class for a couple of hours a week you might choose to have care at home, or a day centre. If either you or the person with dementia needs a longer break, a short stay in a care home might be more suitable.

Speak to a professional such as a social worker about the different care options available. You may be able to choose more than one type of care, depending on what is available in your area.

For information on the different ways you can access respite see 'Arranging respite care' on page 10.

The next section has more information on different types of respite care.

If you are a Welsh speaker or bilingual, it can be helpful to know that any social care provided in English must also be available to the same standard in Welsh. This includes respite care. Alzheimer's Society provides information about respite care in Welsh. See factsheet W462WEL, **Gofal seibiant yng Nghymru for more information.**

Types of respite care

Care at home

Many people prefer care provided in the person's own home because it means they can stay in a familiar environment and maintain their daily routines. There are a number of ways that this can be arranged.

Care agencies and other care providers

Care agencies provide different types of respite care in the person's own home. These range from a personal assistant or support worker making daily visits, to help with personal care or social activities to 24-hour live-in care.

Some local carers' organisations offer a respite care service. This often involves a regular carer coming to spend a few hours with the person with dementia. Your local carers' centre can give you information on what is available locally. Carers' centres are independent charities that deliver support services for carers in local communities. Carers Wales or your local authority can provide details of your local carers' centre (see 'Other useful organisations' on page 20 for more details).

In some parts of Wales, carers are allocated a respite care budget. They can use this to access a range of respite care providers when it suits them best. This scheme is run by NEWCIS – see 'Other useful organisations' on page 20.

Support workers (personal assistants)

Respite care at home can involve a support worker or paid carer (often called a personal assistant) coming into the home. They may be employed by a care agency or by you or the person you care for. They may do any of the following:

- come in during the day to give you time to do something you want to do (such as going to the shops, visiting friends or attending a class)
- help with personal care such as washing and dressing
- spend time with the person with dementia doing things they enjoy inside or outside their home

- come into the person's home to provide care and support during the night, so that you can get some sleep
- stay with the person or make regular visits so that you can go on holiday or have a break away from home.

Friends and family

If the person with dementia wants to stay at home, a friend or family member could stay with them to give you a break. Alternatively, the person could stay with family and friends.

It can be helpful for the person with dementia to spend time with someone they know. People who know them may be familiar with their routine, likes and dislikes, which can be reassuring for you and the person.

It is not always possible for friends or family to provide care or they might not know how best to help. If you do have someone you can ask, let them know specifically how they can help, for example spending time with the person so you can have a rest. This helps people to know what you need and means you get help that works for you and the person with dementia.

Care away from home

Day centres and community groups

Day centres provide opportunities for people with dementia to meet other people and perhaps take part in activities. Some day centres specialise in supporting people with dementia, and some are run specifically for younger people with dementia.

It may take the person a while to adjust to attending a day centre, and initially they may need support and encouragement to go. You might find it helpful to go with the person for their first few visits. It's important for staff at the day centre to get to know the person and their likes, dislikes and support needs. This will mean they can help the person settle in and make sure that activities meet their needs. See 'Giving information to respite care providers' on page 16 for more advice on how you can help with this.

Some people may be more comfortable joining a community group or club, such as an arts and crafts group or sports club. For more information see booklet 77AC, **The activities handbook**.

Ask your local authority what day centres or community groups are available in your area, or go to alzheimers.org.uk/dementiadirectory. Dewis Cymru can also help you find local groups – see ‘Other useful organisations’ on page 20.

Holidays and short breaks

Another form of respite care is for you and the person with dementia to take a short break or holiday together. Some organisations provide specialist holidays for people with dementia and their carers. They include support with caring and facilities that are accessible and more suitable for people with dementia. You might find that being away from your normal environment means you can focus on spending quality time with the person you care for. Your local carers’ centre can give you more information about this.

When arranging a holiday or short break it’s important to make arrangements with the holiday company in advance, if you can. This means you and the person you care for know what to expect. It also gives the company time to organise support for you both. The person with dementia may need extra support to cope with a new environment or changes to their routine, such as leaving the bathroom light on and door open at night. Finding a holiday company that caters for people with dementia can make things easier and mean you both have a more enjoyable holiday. For more information and advice on travelling, including details of specific providers, see factsheet 474, **Travelling and going on holiday**.

Care homes

Some care homes offer opportunities for people with dementia to stay for a short period of time. There are different types of care homes which provide different levels of care, including:

- Residential care homes, which look after a person's general living requirements, such as accommodation and meals, as well as helping with personal care, such as washing and bathing.
- Nursing homes, which provide nursing care (as well as personal care) with a registered nurse on site 24 hours a day.
- Care homes that are registered as dementia care homes. They specialise in providing care and support for people with dementia. These can be either residential or nursing homes.

Arranging respite care in a care home depends on a room being available, so it is best to plan ahead. Rooms may not be available at short notice. Planning ahead for when respite care will be needed can be difficult, but it can be helpful to make arrangements for the future if you can.

Arranging respite care in a care home can feel like a big step to take. However, some care homes will allow you both to drop in for a coffee, or for the person you care for to spend a few hours there, perhaps for dinner or activities. Or the care home may offer a day care service. These options can help the person to become familiar with the home in advance of a longer stay. It can also help you to feel more confident in your decision to take a break. Speak to the manager there about what may be possible.

It's important to note that lockdowns or restrictions due to coronavirus may affect access to some types of respite care. For example, care homes and day centres may close or they may have strict rules that limit people using them. If this happens speak to your local authority about what is still available to support you.

Other options

Shared Lives

The Shared Lives scheme is another option for respite care. The idea is usually that someone with care needs can live or stay in the home of someone who is an approved Shared Lives carer. This could give you time for a short break or to recover from an illness, for example.

The exact arrangements will vary depending on the needs of the person. For example, someone with dementia may move into the home of a Shared Lives carer to stay with them for a while. Sometimes, the Shared Lives carer could provide daytime support – either in their own home or the home of the person with dementia.

The scheme is not available everywhere but it is expanding. Your local authority or the Shared Lives scheme will be able to provide more information about whether this is currently available near you. See ‘Other useful organisations’ on page 20 for more information.

Carers’ emergency respite care

There may be times when you are unable to care for the person you support. For example, if you are suddenly taken ill or have an urgent issue to deal with at home. In these situations, some local authorities or carers’ organisations will provide emergency respite care for the person with dementia. They will usually provide care lasting between 48 and 72 hours, depending on the situation. Your local authority or local carers’ centre can provide more information and let you know what is available in your area.

It’s a good idea to carry a ‘Carers Emergency Card’ if these are available in your area. The schemes work differently in different areas. They are free, identify you as a carer and mean the person you care for has support if something happens to you. Check with your local authority or local carers’ centre to see if these are available in your area. You may be offered one after you have had a carer’s assessment.

Alternatively, Carers Wales provide cards and key fobs with spaces to fill in your own emergency contacts, for example family or friends who can help. See ‘Other useful organisations’ on page 20.

Arranging respite care

You can arrange respite care through your local authority or you can contact a personal assistant, homecare agency or care home directly. This section has more information on these options.

Arranging respite care through the local authority

Your local authority's social services team is responsible for helping you to find different types of respite care. They will work out how they can support you and the person you care for by assessing your care and support needs. If you have an assessment this is a 'carer's assessment'. If the person with dementia has an assessment this will be a 'care needs assessment'.

In some areas, respite care for a person with dementia is provided as a result of a carer's assessment, while in others it's provided after a needs assessment for the person themselves.

It is important that both you and the person with dementia have your care and support needs assessed if possible. You can have a joint assessment (if you both consent to this) or separate assessments. If your needs change you should ask social services for a reassessment, also known as a review. This will show whether your or the person's needs have changed and may lead to extra care and support being provided, including respite care.

If the person with dementia chooses not to have a care needs assessment, or if they are found not to be eligible for care and support after an assessment, you can still have a carer's assessment.

In Wales, you and the person with dementia have a legal right to a needs assessment or a carer's assessment if it appears that you may have care and support needs. This is regardless of the type and frequency of the care you provide, and your income and savings. To request an assessment you, the person with dementia, or a professional can contact your local authority's Social Services team.

You have a right to an assessment in Welsh if you are a Welsh speaker or bilingual.

Social services must provide clear information and advice about the services available in their area, and how you can access them. This information should be given for free from the beginning of this process. If you feel that the local authority is not supporting you appropriately in your caring role, or not providing you with the information you need, you can make a complaint. Ask them for a copy of their complaints process.

For more information about needs and carers assessments, see factsheet W418, **Assessment for care and support in Wales**.

Arranging respite care yourself

If you choose to arrange respite care without any help from the local authority, it is your responsibility to find and arrange the respite care whether it is at home or in a care home. If you are paying for a personal assistant or a carer from a homecare agency, check that they can provide respite care in a way that meets the person's needs. This could be for a few hours a day, a series of regular visits (for example a few times a day) or 24-hour support at home.

The Care Inspectorate Wales registers and inspects adult social care services (including providers of respite care). It has more information (including quality ratings) about homecare providers and care homes in your local area. For more information see 'Other useful organisations' on page 20. You can also search our online dementia directory for services in your area. Go to **alzheimers.org.uk/dementiadirectory**

Paying for respite care

Charges for respite care can vary. With local authorities, some respite care services may be provided free of charge. Other services may have a cost that will be charged to the person with dementia. The local authority will assess the person's financial situation to decide whether or not they should pay, and if so, how much. This is called a 'financial assessment'.

If after a financial assessment a person with dementia is funding the respite care themselves, they can contact the organisation providing the respite care directly. They should ask questions about availability and cost. You may be able to help them with this, by making sure that they know the questions to ask.

If the local authority is funding the respite care there may be a limit on what they will pay. Their priority will be to meet the person's needs at the lowest cost. For example if a care home is cheaper than 24-hour live-in care, the local authority is likely to choose this option. However, any decision cannot be based on cost alone. It must be based on the needs and choices of you and the person you care for, and the local authority must discuss the arrangements with you both.

This section tells you more about the payment or funding arrangements for different respite care options.

Care homes

A person who goes into a care home for up to eight weeks is known as a 'short-term resident'. Short-term residents should be charged as if they are receiving care services in their own home, rather than in a care home. The amount should take account of the person's circumstances, such as their income and any costs related to their condition (for example extra heating or laundry costs). The local authority must always leave the person with enough money to run their household. There is also a maximum weekly charge they can apply, as with homecare.

If a person goes into a care home for more than eight weeks, they are usually known as a ‘temporary resident’ and their financial assessment for respite care will be different. It will follow similar rules to an assessment for permanent care. However, there are key differences. For example, it will not take into account the person’s main or only home.

Care at home

If respite care is provided in the person’s own home, the local authority can ask the person with dementia to pay a ‘reasonable’ amount toward the cost. As with short-term stays in care homes, the person must be left with enough money to continue to run their home and to live.

A maximum weekly charge applies to homecare, but you won’t necessarily have to pay the maximum amount. It will depend on your savings, income and how much the care costs.

For more information on various ways to pay for respite care, and the amounts you might be expected to pay, see factsheet W532, **Paying for care and support in Wales**.

Direct payments

If the person with dementia has had a care needs assessment, the local authority’s social services team will work out the amount of money that will meet the person’s needs.

A person with dementia who is receiving funds from the local authority may decide to receive this as a direct payment. A direct payment aims to give people greater choice over how they spend their money to meet their needs.

Examples of what a direct payment can be used for include:

- employing a personal assistant
- taking a holiday with a carer
- paying for respite care in a care home (for up to four weeks in any 12-month period).

As a carer, your support needs can be paid for by the local authority as a direct payment, depending on a financial assessment. You could use the direct payment in a number of different ways, such as hiring a paid carer from an agency (for example, to help with shopping trips) or paying for a supported holiday or for education.

Your local authority can give you information on direct payments and eligibility. For more information see factsheet 473, **Personal budgets**. The majority of this factsheet applies to England, but the 'Direct payments' section is also relevant to Wales.

Other types of funding

You, or the person you care for, may be able to get help with respite care funding from a charity, grant-making trust or benevolent fund. Ex-service organisations, as well as organisations that support people who have been employed in certain jobs or industries may also help. Your local carers' centre can advise on what is available locally. There may also be national organisations that can help. Turn2Us can give you more information on this – see 'Other useful organisations' on page 20 for details.

Carer's allowance

If you receive Carer's allowance, your entitlement to this may continue for up to 12 weeks if the person you care for enters respite care. However, it may end sooner than this if the person goes into a care home. This is because, for you to be eligible for Carer's allowance, the person must be receiving a 'qualifying benefit' – either Disability living allowance (DLA), Personal independence payment (PIP) or Attendance allowance (AA). Any benefits the person receives will stop 28 days after they go into a care home. Your Carer's allowance will continue until their entitlement to the qualifying benefit they get stops.

You should speak to the Carer's Allowance Unit to discuss any change of circumstances that's likely to affect your benefit or if you need more information about Carer's allowance. Your local Citizens Advice or Age Cymru will be able to help you with this – see 'Other useful organisations' on page 20.

For more information about different types of benefits see factsheet 413, **Benefits for people affected by dementia**.

Choosing a respite care provider

It can feel daunting to find the right care option for the person with dementia and also your needs. It's a good idea to meet with care providers to find out more about how they work and how you feel about them. Here are some questions you might want to ask them.

- What training do the staff have? Does it include dementia care training?
- What experience do they have of working with people with dementia?
- Will there be a care plan to meet the needs of the person with dementia?
- How often do they assess the person and their needs?
- Are they able to meet any religious or cultural needs the person with dementia has?
- If the person's first language is Welsh, what services do they offer Welsh speakers?
- What types of activities can they offer the person with dementia?
- If the person has young-onset dementia, are staff willing and able to offer care and activities for the person based on their age?
- Do they keep notes, and can you see these?
- How do they manage unexpected events, such as staff sickness?
- Are there any additional charges?
- Is there a trial period, and how long is it?
- What insurance is in place and what does it cover?
- What is their complaints process?

If you're choosing homecare, you may also want to ask:

- Will the person always have the same carers?
- Can the person change carers?
- Are their costs based on an hourly charge?
- Do they charge more for nights, weekends or bank holidays?
- Have they had a background check (known as a 'DBS check')?

It can be helpful to ask for examples of how they've met other people's needs and what they would do in certain situations. This means that you can get a better understanding of how they cope with different situations.

If you are looking at respite care in a care home see booklet 690, **Selecting and moving into a care home** for more information on what to think about and questions to ask.

Giving information to respite care providers

It is helpful to give information about the person with dementia to anybody providing respite care. This can make it easier for a person with dementia to adjust to a change of environment or carer. It can also help anyone providing respite care to support the person and meet their needs. This information can be used to write a care plan with you and the person with dementia. It will help everyone to know what care and support has been agreed and should be reviewed regularly.

This is me is a simple leaflet for anyone receiving professional care who is living with dementia. It can be used to record details about a person who can't easily share information about themselves. It is available in English, or in a bilingual Welsh and English version (**Dyma fi**). You can download a copy from [alzheimers.org.uk/thisisme](https://www.alzheimers.org.uk/thisisme) or order a copy for free by phoning **0300 303 5933**.

The information you provide to respite carers about the person with dementia will vary. You might want to include:

- what the person with dementia likes and dislikes – this could range from food preferences to a favourite jumper
- details of their routine – what time they get up, what time they like to eat or any activities they enjoy doing throughout the day
- specific ways to support them if they become upset or distressed
- any medicines they need to take
- any sensory or physical difficulties they may have
- their dietary, religious and cultural needs
- their hobbies and interests
- if the person will be staying at home during the respite care period, details about the running of the home such as which key locks which door, how the washing machine works or which day the bins are collected
- important phone numbers, such as the GP
- emergency contact details, for example for you or another family member or friend.

Adapting to respite care

Respite care can be a big support for you and the person you care for. However, it can be difficult to adjust to. You will probably have some worries, for example about how the person is settling in, whether they are being well cared for, or if their routine is being disrupted.

The person with dementia may also have concerns about respite care. It can help to talk to them and find out if they are worried about certain things. If you know what's troubling them it will be easier for to find ways to support them. It may also mean that you can look at ways to address the issue.

For example, if the person is concerned about being in an unfamiliar environment, you could make sure they take a few favourite items, such as photographs, with them to make it feel more familiar. Following some of the tips on page 17 may help. Care providers can find it helpful to know about the person's worries. It means they can put things in place to address these and tailor the support they provide.

It is normal to be nervous about respite care. However, these feelings shouldn't stop you from using it if you feel it would help. Caring for a person with dementia is a complex and challenging job. There are positive and negative aspects, and everybody will cope with their situation in different ways.

Taking a break from caring is not always an easy decision to make, and you may feel worried or guilty. You may feel that respite care will create more stress and that the quality of the care will not be good enough.

Try to remember that having a break can do both you, and the person with dementia, good. It may mean that you can carry on caring for longer.

Respite care: tips

If you care for a person with dementia and are thinking of arranging respite care, there are some things that can help.

- Talk about it – It can help to talk openly about respite care with the person you care for. It will give you both a chance to discuss your options and your feelings.
- Arrange for assessments with the local authority – If both you and the person with dementia have an assessment of your needs, it will help you to know what you need and the options you have.
- Plan ahead – New environments can be challenging for a person with dementia. It can help to set up a regular respite care routine, to help both you and the person adjust. Some people find it helpful to arrange respite care early on, rather than waiting for an emergency or things to become hard to manage. This can support you to carry on caring, be an opportunity to try different types of respite care to see what works best and help the person with dementia adjust.
- Consider short breaks or visits to start with – This will mean you, the person with dementia and the care providers can get to know each other. It may help to build confidence before a longer visit.
- Talk to the respite care providers and visit them – This will help you and the person with dementia get to know them. It will also give them an opportunity to get to know you both. It can help to develop relationships and give you confidence in the care they provide. You may want to arrange for the person with dementia to spend time with the respite care provider (possibly with you to start with) before the respite care starts or as part of a trial.
- Focus on the positives – You may be worried that respite care won't provide the same level of care as you can, or that the person will become unsettled. It is natural to be worried, but try to focus on how the break will support you in your caring role. The person with dementia may also benefit from respite care – for example, by meeting new people or taking part in hobbies and activities.

- Keep trying – Respite care is an adjustment for everyone. If something doesn't work or doesn't go to plan, try not to give up. There may be other options you can try to find out what works best for you and the person with dementia.
- Talk to others – Talking to other carers about your feelings can help. They may be able to give you tips and suggestions. However, remember what works for one person may not work for another. You may also want to talk to a professional (such as a support worker) about how you're feeling.

Talking Point is Alzheimer's Society's online community for people with dementia, their carers, family members and friends. You can ask questions, share experiences and get information and practical tips on living with dementia. Visit alzheimers.org.uk/talkingpoint

For more information on all aspects of caring see booklet 600, **Caring for a person with dementia: a practical guide**. Factsheet 523, **Carers – looking after yourself** can give you more advice on maintaining your wellbeing while in a caring role.

Other useful organisations

Age Cymru

0300 303 44 98 (advice line, 9am–4pm Monday–Friday)
advice@agecymru.org.uk
www.ageuk.org.uk/cymru

Age Cymru aims to improve later life for everyone through information and advice, services, campaigns, products, training and research.

Care Inspectorate Wales

0300 7900 126
ciw@gov.wales
www.careinspectorate.wales

Care Inspectorate Wales regulates, inspects and reviews all adult social care services in the public, private and voluntary sectors in Wales.

Carers Trust

0300 772 9702
wales@carers.org
www.carers.org

Carers Trust works to improve support services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

Carers Wales

0808 808 7777 (helpline, 9am–6pm Monday–Friday)
info@carerswales.org
www.carerswales.org

Carers Wales provides information and advice about caring, alongside practical and emotional support for carers.

Citizens Advice

0800 702 2020 (advice line, 9am–5pm Monday–Friday)
www.citizensadvice.org.uk

Your local Citizens Advice can provide information and advice in confidence or point you in the right direction to further sources of support. Trained Citizens Advice advisers can offer information on benefits in a way that is easy to understand. To find your nearest Citizens Advice, look in the phone book, ask at your local library or look on the website. Opening times vary.

Dewis Cymru

www.dewis.wales

Dewis Cymru provides information and advice about wellbeing in Wales. It has details of local services including groups and clubs.

NEWCIS

enquiries@newcis.org.uk

www.newcis.org.uk

NEWCIS provides information, support and training to carers living in North East Wales. For people living in Denbighshire, Flintshire and Wrexham, they offer the 'Bridging The Gap' scheme. This is where carers are allocated a respite care budget that they can use to access a range of services when it suits them best.

Shared Lives Plus

0151 227 3499

info@sharedlivesplus.org.uk

www.sharedlivesplus.org.uk

Shared Lives Plus is a UK network for family-based and small-scale ways of supporting adults through Shared Lives carers.

Turn2us

0808 802 2000 (helpline, 9am–5pm Monday–Friday)

info@turn2us.org.uk

www.turn2us.org.uk

Turn2us helps people in financial need gain access to welfare benefits, charitable grants and other financial help. They also provide information on grants that may be able to support people to access help and support.

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Our information is based on evidence and need, and is regularly updated using quality-controlled processes. It is reviewed by experts in health and social care and people affected by dementia.

Reviewed by: Nick Andrews, Research and Practice Development Officer, Wales School for Social Care Research, Swansea University, and Valerie Billingham, Health and Care Lead Older People's Commissioner for Wales

This factsheet has also been reviewed by people affected by dementia.

To give feedback on this factsheet, or for a list of sources, please contact publications@alzheimers.org.uk

People affected by dementia need our support more than ever. With your help we can continue to provide the vital services, information and advice they need.

To make a single or monthly donation, please call us on **0330 333 0804** or go to alzheimers.org.uk/donate

Alzheimer's Society is the UK's leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia.

For support and advice, call us on **0333 150 3456** or visit alzheimers.org.uk



Alzheimer's Society operates in England, Wales and Northern Ireland. Registered charity number 296645.

