Respite care is any care arrangement designed to give rest or relief to unpaid carers. It aims to support carers to have a break from their caring responsibilities. This factsheet looks at what respite care is, the different types that are available, and how to pay for it. It also offers tips to help carers and people with dementia to get the most out of replacement care.

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

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What is respite care?

Everyone needs a break from time to time. Carers are no different, and it is important that they are able to have a rest, whether it is a short break to run errands or meet friends, or longer time spent away. Breaks are good for a carer’s physical and mental wellbeing and can enhance their relationship with the person they care for. The person with dementia may also benefit from the break. It could provide social interactions and opportunities to pursue hobbies and interests, remain involved and active, and form new relationships.

There are many different types of respite care (see ‘Types of respite care’). It may be possible to have a combination of different types. It can be helpful to speak to a professional (such as a social worker) about the options available. Different types of respite care may be available in different parts of the country. They include:

- day centres
- care and support at home
- a short stay in a care home
- Shared Lives (a scheme where a person needing support regularly visits an approved carer – see ‘Other useful organisations’)
- holidays or short breaks
- carers’ emergency respite care schemes
- direct payments to fund creative solutions.

These arrangements are covered in detail in this factsheet.
When considering respite care, it’s important to think about the type of care and support the person with dementia needs. Full-time nursing care is expensive and may not always be necessary. When arranging care and support with a homecare agency or care home, staff should talk to you about writing a care and support plan that aims to achieve good outcomes for the person with dementia.

Similarly, if the person with dementia has an assessment that focuses on their personal outcomes, this should help identify both their care needs, and the things that matter most to them. A professional, such as a social worker or dementia specialist nurse, can provide more information.

**How is respite care provided?**

The responsibility to help carers take a short break from caring lies with the local authority. In Wales, these duties are outlined in the Social Services and Well-being (Wales) Act 2014.

The local authority will need to assess a person’s needs before agreeing to provide care. In Wales, a needs assessment or a carer’s assessment is available to anyone if it appears that they may have care and support needs. It can be requested by the person with dementia, a carer or a professional (for example a GP, consultant or hospital social worker) by contacting the local authority.

It is important that both the carer and person with dementia are assessed, if possible. You and the person you care for can be assessed separately, or as a combined assessment. Your needs can still be assessed even if the person you care for refuses an assessment or is found not to have eligible needs after their assessment.
The assessment enables social services to identify what matters most to the carer and the person they support, including any needs they have. If you or the person you care for meet the criteria, this should be the start of a discussion with the local authority about how you want your needs to be met, including respite care.

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

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. A range of respite care options may be offered. This could include a stay in a care home, a place at a day centre or access to another type of break using a direct payment. Some local authorities or carers’ organisations will provide respite care to the person with dementia in an emergency (usually between 48 and 72 hours depending on the situation). The local authority or local carers’ centre can provide more information and say what is available in a certain area. They should provide clear information and advice from the earliest stage of this process.

Some people with dementia and carers choose to arrange and pay for respite care outside of any local authority arrangements. If you choose to do this, it is your responsibility to find and arrange the respite care either with an individual, a care agency or a care home.

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Types of respite care

Care at home

Respite care can be provided at home. Many people prefer this because they can stay in a familiar environment and maintain daily routines. Respite care at home can involve a personal assistant, support worker, volunteer or paid carer visiting the home. They may do any of the following:

- come in during the day to give you a break, allowing you time to do something you want to do – for example, go to the shops, visit friends or pursue education or a hobby
- spend time with the person with dementia and engage them in social activities both inside and outside of the home
- come in to the home to care for the person during the night to give you a chance to sleep
- stay with the person or make regular visits over a certain period of time so that you can go on holiday or have an extended break away from the home.

Respite care at home can be arranged through the local authority, or privately – either directly through a homecare agency, or sometimes through local voluntary organisations (such as carers’ centres). A carer from a homecare agency may be able to provide respite care for a few hours a day, make regular visits throughout the day, or provide 24-hour support for the person at home, depending on the person’s needs.

Some care agencies specialise in providing 24-hour live-in care. This is usually more expensive than a place in a care home. If the local authority is funding respite care there may be a limit on what they will fund. If they can meet the person’s needs in a cheaper way – for example, in a care home – then they are required to do so. However, these decisions cannot be based on cost alone and the local authority must discuss the arrangements with you and the person you care for.
Another option is to employ a personal assistant to provide care. If you or the person you care for are receiving a direct payment, you may want to use this to employ a personal assistant directly. For more information see factsheet 473, Personal budgets. This factsheet is mostly about the system in England, but the section on direct payments is relevant to Wales too.

Some local carers’ organisations may offer a respite care service. This usually involves a regular carer coming to spend time (usually a few hours) with the person with dementia. The local carers’ centre can provide information on what is available locally. Carers’ centres are independent charities that deliver support services for carers in local communities. Carers UK and Carers Trust can provide details of the nearest one (see ‘Other useful organisations’).

Friends and family
If the person you care for wants to stay at home, family and friends may be able to spend some time with them to give you a break. Alternatively, family and friends could have the person with dementia to stay with them, if you want to have a break at home.

You and the person you care for may be more comfortable with this arrangement because they will be spending time with someone familiar. Relatives may also be more familiar with the person’s routine and preferences.

However, family members and friends may not be able or willing to take on this responsibility. It can help to talk to them and try to find solutions that work for everyone.
Care away from home

Day centres
Day centres can provide a range of support for a person with dementia, including activities and social interaction. Some day centres specialise in supporting people with dementia, and some are run specifically for younger people with dementia. The local authority or local Alzheimer’s Society can provide details of day centres in your area. You can also go to alzheimers.org.uk/dementiaconnect to see what is available near you.

It may take the person a while to adjust to attending a day centre, and initially they may need support and encouragement to go. Some carers find accompanying the person for the first few visits helps. It’s important for staff at the day centre to get to know the person and treat them as an individual. This will mean they can help the person settle in and make sure that activities meet their needs.

Holidays and short breaks
Respite care can also take the form of a short break or a holiday. Some organisations provide specialist package holidays for people with dementia and their carers. They include support with caring tasks, and facilities that are accessible and dementia friendly. This means you can have a break from your caring role and focus on spending quality time with the person you care for. The local Alzheimer’s Society or carers’ centre can provide more information. You can also go to alzheimers.org.uk/dementiaconnect to see what is available near you.

Taking a holiday together may require a lot of planning. It’s important that arrangements are made with the provider in advance, if possible, so that you and the person you care for both know what to expect. The person with dementia may need extra support when coping with the new environment or changes to their routine. For more information and advice on travelling see factsheet 474, Travelling and going on holiday.
Care homes
Another option is for the person with dementia to stay in a care home to receive respite care. There are different types of care home, providing different levels of care in addition to accommodation.

- Some care homes provide assistance with personal care (such as washing and bathing). These are often referred to as ‘residential’ care homes.
- Some care homes provide nursing care as well as personal care. They provide care with a registered nurse on site 24-hours a day. These are often known as ‘nursing homes’.
- Some care homes are registered as dementia care homes. These specialise in caring for and supporting people with dementia.

Some care homes have beds set aside for people requiring respite care or short breaks. However, it can be difficult to get respite care in a care home when it is wanted or needed because it depends on a room being available. If possible it can help to plan ahead for when respite care will be needed.

Respite care can be provided at home. Many people may prefer this because they can stay in a familiar environment and maintain daily routines. Respite care at home can involve a personal assistant, support worker, volunteer or paid carer visiting the home.
How is respite care funded?

There are a range of options that may be appropriate when it comes to funding respite care.

Some respite care services may be provided free of charge by the local authority. Many are means-tested and because respite care is provided as a service to the person you are looking after, they may have to contribute towards the cost. The local authority will calculate the cost of the services to be provided and then financially assess the person, to see how much they should contribute to the cost of these services.

If a person with dementia is funding the respite care themselves, they should contact the organisation providing the respite care directly to ask about availability and to sort out the financial arrangements. It is important to gain a thorough understanding of what is included in any contract to provide care and support. This will help to avoid misunderstandings or unexpected costs.

Funding arrangements

Care homes
The local authority can charge the person with dementia for short-term stays in care homes (under eight weeks) in one of two ways.

- They can assess the amount they should pay based on their income and capital and according to national rules for financial assessment for temporary care.
- They can charge what they think is a ‘reasonable’ amount, although this should take account of individual circumstances and leave the person with enough money to run their household. There are national rules about how much the person should be left to live on. A financial assessment may be carried out to establish how much the person should pay.
Care in the community
If care is provided at home, the local authority can ask the person with dementia to pay a ‘reasonable’ amount toward the cost. As with temporary respite stays in care homes, the person must be left with enough money to run their home and to live.

Direct payments
After a needs assessment, an amount of money is identified as being necessary to meet the person’s needs. A person with dementia may decide to receive this in the form of a direct payment. This is a payment that goes directly to the person to pay for their care and support. Direct payments aim to give people greater flexibility and choice over how their needs are met. They can be used in a number of ways, such as employing a personal assistant, taking a break, or for respite care in a care home for up to four weeks in any 12-month period. However, the direct payment can only be spent as agreed in the person’s support plan.

As a carer you may also be entitled to a direct payment, depending on your need for support. Again, it must be used to meet the needs and achieve the goals identified in your support plan. You might want to hire a paid carer from an agency – for example, to help with shopping trips – or use the direct payment to pay for a supported holiday or for education. The local authority can give you information on direct payments and eligibility. See also factsheet 473, Personal budgets. The majority of this factsheet applies to England, but the ‘Direct payments’ section is also relevant to Wales.
Other funding
You may be able to get help with the cost of respite care or taking a break from a charity, grant-making trust or benevolent fund. Ex-service organisations, as well as those that support retired people in a particular type of work, may also help. The local carers’ centre or Alzheimer’s Society can advise on what is available locally. You can also go to alzheimers.org.uk/dementiaconnect to see what is available near you.

There may also be national organisations that can help. For more information see ‘Other useful organisations’ and factsheet W532, Paying for care and support in Wales.

Carer’s allowance
Carer’s allowance is a benefit paid to carers who meet certain criteria. One of these is that the person they care for receives Disability living allowance (DLA), Personal independence payment (PIP) or Attendance allowance (AA). These are sometimes known as ‘qualifying benefits’.

If someone with dementia goes into a care home or hospital, after 28 days they will usually stop receiving these qualifying benefits. This means that a carer would no longer receive Carer’s allowance. However, a short period of respite care (no longer than 28 days) would not affect a carer’s entitlement to Carer’s allowance. If the carer goes into hospital, Carer’s allowance can continue for up to 12 weeks in a 26 week time span.

Carer’s allowance can be complicated. To check if you are eligible for Carer’s allowance and other benefits, contact Citizens Advice or another local organisation such as Age Cymru for a full benefits check. For details see ‘Other useful organisations’.
Giving information to respite care providers

It is helpful to give as much information as possible to those providing respite care to the person with dementia. It may help to use a tool such as Alzheimer’s Society’s This is me. This allows the person with dementia to tell staff about their needs, preferences, likes, dislikes and interests so that they receive better, more person-centred care. You can download a copy from alzheimers.org.uk/thisisme or order a copy for free by phoning 0300 303 5933. It will be helpful to write things down for the carers, including information on:

- 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, any activities they enjoy doing throughout the day
- specific ways to support the person if they become upset or distressed
- any medicines they need to take
- any sensory or physical difficulties they may have
- dietary, religious and cultural needs
- any hobbies and interests the person has
- if the person is being looked after at home, details about the running of the home – for example, which key locks which door, how the washing machine works, which day the bins are collected
- important phone numbers – for example, the person’s GP
- emergency contact details – for example, the carer or another family member or friend.
Respite care: tips for carers

If you care for a person with dementia and are thinking of arranging respite care for them, there are some things it can help to do and think about.

- **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 use respite care in the early stages of the condition, or before they feel it is needed, rather than at the later stages or if a crisis or emergency situation arises. This can give you a feel for respite care, as well as a chance to try different types.

- **Consider short breaks or visits to start with** – This will mean you, the person and those providing respite care can get to know each other. It may help to build confidence before a longer visit.

- **Arrange a needs assessment** – If both you and the person have an assessment of your needs, it will help you both to know what you need and the options you have.

- **Talk about respite care** – Some people find openly talking about respite care helpful. It will give both you and the person with dementia a chance to discuss your options and your feelings. You know the person best, so will know the best way to talk to them.

- **Talk to paid carers** – It’s important for a paid carer to get to know the person and what works for them. Talking to them about their needs and their routine can help. For care at home, it can help for the person and the new carer to spend time together (possibly with you to start with) so they get to know each other and build a relationship before the respite care starts.
Visit the care home or day centre – Ask carers about their training and experience, and what care and support they can provide. The quality of care the person will receive is important. You may feel more confident with the respite care arrangement if you know what training and skills the staff have.

Talk to others – Talking to other carers about your feelings can help. They may be able to give tips and suggestions. However, it’s important to remember what works for one person may not work for another. You may also want to talk to a professional (for example a support worker) about how you’re feeling.

Focus on the benefits – You may be worried that a respite care arrangement won’t provide the same level of care as you can, or that the person will become unsettled. It is natural to be concerned, but try to focus on how the break will support you in your caring role.

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. Another type of respite care or another location may be more successful. You may need to try different options to find what works best for you and the person.

It is helpful to give as much information as possible to those providing respite care to the person with dementia.
Adapting to respite care

When you and the person you care for access respite care, you may experience difficulties. You may also 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.

You should find out if there are certain things worrying the person. If you know what they’re worried about, you will be better able to support and reassure them. It may also mean you can look at ways to address their worries. For example, if the person is concerned about being in an unfamiliar environment, you could ensure they take a few favourite items and some photographs with them. Following some of the tips mentioned earlier in this factsheet might help to address some concerns. Experiencing difficulties is not unusual, and it is normal for you to feel nervous about the experience. However, these feelings shouldn’t discourage you from taking a break.

Caring for a person with dementia is a complex and challenging job. There are positive and negative aspects, and each carer will cope with their situation in different ways.

Taking a break 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 up to your standards. However, it’s important to know that having a break will do both you and the person you care for good in the long term. It may ultimately mean that you can carry on caring for longer.

For more information see factsheet 523, Carers: looking after yourself.
Other useful organisations

Age Cymru
Tŷ John Pathy
13/14 Neptune Court
Vanguard Way
Cardiff CF24 5P

08000 223 444 (advice line)
enquiries@agecymru.org.uk
www.agecymru.org.uk

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

Citizens Advice
Various locations
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 (above). Opening times vary.

Care and Social Services Inspectorate Wales
Welsh Government office
Rhydycar Business Park
Merthyr Tydfil CF48 1UZ

0300 7900 126
cssiw@wales.gsi.gov.uk
www.cssiw.org.uk/

Regulates, inspects and reviews all adult social care services in the public, private and voluntary sectors in Wales.
Carers Wales
Unit 5
Ynys Bridge Court
Cardiff CF15 9SS

0808 808 7777
advice@carers.uk
www.carers.uk/wales

Provides information and advice about caring, alongside practical and emotional support for carers.

Carers Trust Wales
Third Floor
33–35 Cathedral Road
Cardiff CF11 9HBT

02920 090087
wales@carers.org
www.carers.org/wales

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.

Shared Lives Plus
G04 The Cotton Exchange
Old Hall Street
Liverpool L3 9JR

0151 227 3499
www.sharedlivesplus.org.uk

UK network for family-based and small-scale ways of supporting adults through Shared Lives carers.
**Turn2us**
0808 802 2000 (helpline, 9am–8pm weekdays)
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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