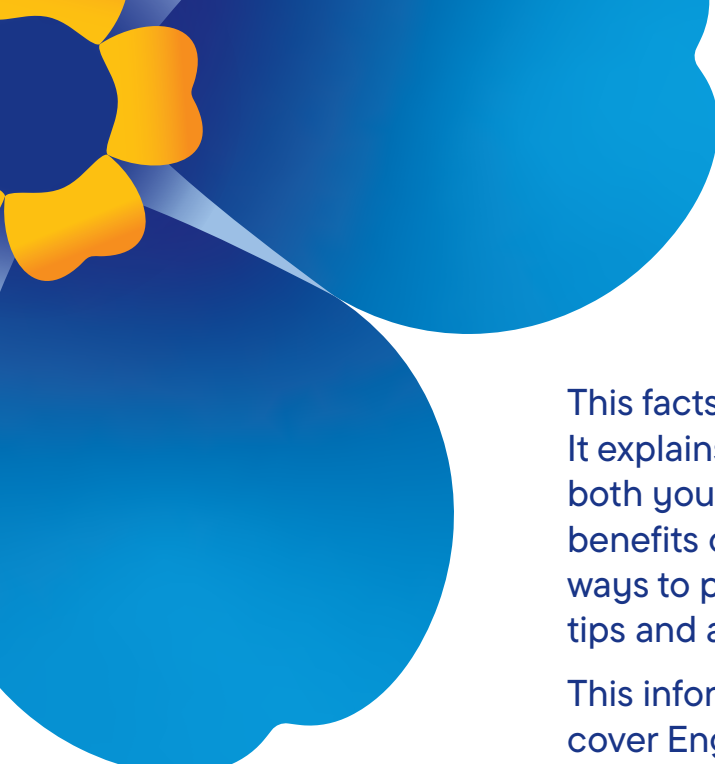


Respite care in Wales



**Alzheimer's
Society**

Together we are help & hope
for everyone living with dementia



This factsheet is for carers of a person with dementia. It explains what respite care is and how it can support both you and the person you care for. It lists the benefits of respite, the different options available and ways to pay for them. This factsheet also gives practical tips and advice on how to adapt to respite care.

This information is for people living in Wales. It does not cover England and Northern Ireland, where the systems are different. See our other **Respite care** factsheets 462 (England) or NI462 (Northern Ireland).

Contents

1	What is respite care?	1
2	Types of respite care	2
3	Making arrangements	6
4	Charges for respite care	12
5	Adapting to respite care	15
	Other useful organisations	19

1 What is respite care?

Respite care is temporary care that helps you, as a carer, to look after your own health and wellbeing. It is often put in place to give carers like you a break from your usual caring routine.

Many people think of respite care as a substantial period, such as a stay in a care home for a number of nights. However, it can be any amount of time that gives you some kind of break.

Respite care can be provided inside or outside of the home. It can give you a planned break from a daily task, such as someone else helping the person to wash and dress. Or it can be a break from your ongoing routine, such as supported holidays or daycare. In some cases, respite may be unplanned. This could be due to poor health, a hospital stay or other responsibilities.

Respite care can help you to:

- balance other commitments, such as employment or education
- feel less overwhelmed in your caring role and prevent burnout
- maintain your relationship with the person you care for
- maintain your other relationships and keep a healthy social life.

Respite care can give the person with dementia opportunities to:

- try new activities, which can help cognitive stimulation
- socialise with others
- have a change of environment – if outside of the home
- feel less guilty about relying on their main carer.

You might also hear the term ‘replacement care’. This is where someone else helps with a certain task, for example, staff from a care agency helping with meals. This can enable you to go to any appointments of your own. It can also help you with physical tasks you can’t manage or don’t feel comfortable doing.

Caring for a person with dementia isn’t easy. You may be feeling stressed and tired. Please remember that this is completely normal and you are not alone. It’s important that you look after yourself too. For more guidance on this, see factsheet 523

Carers – looking after yourself.

Space for your notes

“

I’ve been sole carer for my husband for five years, not had a break or holiday, in all that time, feeling totally drained.

Partner of a person with dementia

”

Space for your notes

2 Types of respite care

Some people with dementia prefer to receive care and support in their own home. This is so they can stay in a familiar environment and maintain their daily routine. This can work well if you are taking a break away from the home, going out for the day or on holiday.

However, some carers who live with the person they care for may prefer respite to be provided away from home. As well as giving the person with dementia a change of environment, this can give you the chance to do things you might not otherwise normally be able to do. This could be maintenance jobs around the home or having visitors.

This section outlines different options for respite care.

Friends and family

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

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

If you do have someone you can ask, let them know how they can help. For example, they could spend time with the person so you can go to a class or meet friends.

It is not always possible for friends or family to provide care, or you may not wish to ask them. Don't worry, familiarity can also be built with professional carers. See 'Adapting to respite care' on pages 15–18.

Care agencies and other care providers

Care agencies can provide different types of respite (replacement) care in the person's own home. Usually, this will involve a short visit to do a set task, such as helping the person to get washed and dressed.

However, if asked, care agencies may also provide:

- **a sitting service** – where they stay with the person with dementia for a short period of time, so you can leave the home
- **a befriending service** – where they support the person to take part in an activity they enjoy, such as art or reminiscence
- **nighttime care** – so that you can get some sleep
- **24-hour care** – to allow the person to remain at home while you take a break away or go on holiday.

Personal assistants

Personal assistants support people who need help with a range of tasks in their own home. They may work for a care agency organised by the local authority. They can also be employed directly by you, the person you care for or another appropriate person on their behalf.

This support can be self-funded or through a 'direct payment'. This is money given to the person by the local authority. See 'Understand funding' on pages 8 and 9.

Personal assistants can in some cases provide greater flexibility with care. If there are limits to what an available care agency can offer with task-based care, a personal assistant can be a good alternative.

You can personalise the job description and the care required to suit the person with dementia. For example, this can include activities such as taking the person on country walks, watching sporting events or going shopping. You might be able to employ a friend or someone familiar to the person, who you feel more comfortable leaving them with.

Day centres

Day centres can be good places for people with dementia to take part in activities and meet other people. Different centres offer different opportunities. For example, some will offer transport to and from the venue, day trips or meals, and others will not.

All day centres should provide the chance to socialise and take part in activities, such as quizzes, games or yoga. If the centre supports people with dementia, they may include activities such as reminiscence.

Day centres can provide a welcome break for people who want to leave the house but need to remain well-supported and safe. Some local social services run day centres, sometimes with involvement from the local health board. Others can be privately owned. See what is available in your area.

Holidays and short breaks

Another form of respite care is for you and the person to take a short break or holiday together. This can give you a break from your usual caring routine with extra support for you.

Some organisations provide specialist holidays for people with dementia and their carers. They include support with care and facilities that are accessible. You might find that being away from your normal environment means you can focus on spending quality time with the person.

Space for your notes

“

We tried a day centre once a week, but realised mum preferred a one-to-one at home. Mum enjoys this, they go for walks and bake cakes together.

Daughter of a person with dementia

”

Space for your notes

“
We were going
on holiday but
my husband
doesn't want to
go. I am desperate
for a break.

Partner of a
person with
dementia

”

When arranging a holiday or short break, it's important to make arrangements with the holiday company well in advance. This means you and the person know what to expect. It also gives the holiday company time to organise support for you both.

The person you care for may need help to cope with a new environment or changes to their routine. If there are things that give them comfort at home, try keeping them as similar as possible on holiday if you can. This might include leaving the bathroom light on or keeping the bedroom door open at night.

Finding a holiday company that caters for people with dementia can make things easier. This can mean you both have a more enjoyable holiday. For more information and advice on travelling, see factsheet 474 **Going on holiday when a person has dementia**.

Shared Lives

The Shared Lives scheme involves someone with care needs living or staying in the home of an approved Shared Lives carer.

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 may provide daytime support – either in their own home or the home of the person.

Your local authority or the Shared Lives scheme will be able to provide more information. See 'Other useful organisations' on pages 19 and 20 for more information.

Care homes

Some care homes offer opportunities for people with dementia to stay for a short period of time. This is sometimes known as 'short-break care' or 'residential respite'.

This can work well if you are going on holiday as it can give you peace of mind that the person is safe. It can also help you and the person with dementia to 'trial' a care home before deciding to move in permanently. This helps staff to get to know the person, and helps the person become familiar with the place. See booklets 690 **Choosing a care home for a person with dementia** and 691 **Supporting a person with dementia in a care home**.

There are two types of care home. These provide different levels of care. The right type of home for a person with dementia will depend on their individual health and care needs:

- **Residential care homes** – these can help people who need prompting, supervision or support when doing daily tasks. These include eating, dressing, going to the toilet, washing and bathing.
- **Nursing homes** – these are for people with nursing care needs. For example, they may have difficulty moving, issues with continence or medical needs. Nursing homes have a registered nurse on site during the day and at night. This means that they can provide nursing care as well as support with daily living needs.

Arranging respite care in a care home depends on a room being available. If possible, plan ahead. Some homes reserve rooms for short-term residents that are pre-bookable. Other homes may only offer short-notice bookings.

Even if you aren't considering respite in a care home now, explore what options are available. This can help if there's a sudden change that affects how much support the person needs.

Carers' emergency replacement care

It can be difficult to think about being unable to care for the person you support. But you could be taken ill suddenly or another crisis situation could arise. If you register as a carer, this can provide valuable reassurance for you.

Your local authority may operate an emergency card scheme. This usually involves giving them details of the care you provide and who for. You can then set out a contingency plan, in case you are not able to care for the person. This can include other people to contact.

You'll usually be given an emergency card to carry around with you. If you have an accident or emergency, anyone who helps you will then know someone is relying on you. There is usually a number on the card if you need help. The call centre may contact one of your emergency contacts and ask if the contact can help the person with dementia.

If there are no local emergency card schemes in your area, you could consider making your own card and keeping it with you. This can make other people aware that the person needs support if there is an emergency. You could include someone to contact in this situation.

Your local authority or local carers' centre can provide more information about what is available in your area. They can advise how you can plan care in case of an emergency.

**Space for
your notes**

Space for your notes

“
My dad has advanced dementia and my mum is starting to struggle.

Daughter of a person with dementia

”

3 Making arrangements

If you have no experience of respite, it may feel difficult to know where to turn for help. It can be helpful to think of the process as a series of steps, taking each one in turn. Throughout this section, you will find advice about the following steps:

- involve the person with dementia
- request a care assessment for the person with dementia
- request a carer's assessment for yourself
- understand funding
- decide on the right type of respite care
- research the service
- getting started.

Involve the person with dementia

As the person with dementia will be the one using the respite service, they need to be involved. If they have mental capacity, it is their decision whether they use a respite service or enter residential respite. If they don't have the mental capacity to decide, a best-interest decision can be made on their behalf. For more information on supporting a person with a decision, see factsheet 460 **Mental Capacity Act 2005**.

The following may help when discussing respite care with the person with dementia:

- **Focus on the benefits that a break can bring you both.**
For example, you could say, 'If you attend daycare, you can socialise and try something new while I do chores at home. We can then focus on spending time together the rest of the week without me worrying about housework.'
- **Be clear about the need for some support or a break.**
Try not to highlight all the things you do to care for them. This may make them feel guilty or blamed. Discuss together what the right length of time for a break should be.
- **Talk through which options would and would not be acceptable to them and help them feel in control.**
For example, you could say, 'Would you be willing to try daycare or would you prefer someone staying at home with you? If you aren't comfortable after a few weeks, we could stop and try something different.'

- **If they are resistant to the idea of respite care, ask what their concerns are.** They may feel worried about something that you could reassure them about. For example, if they are worried about missing a part of their routine, such as going to their regular place of worship or a social group, you can tailor the respite to avoid those times.
- **If they are still resistant, revisit the conversation another time.** Try to find a time to do this that is best for the person. For example, if they experience 'sundowning' later in the day (which can increase confusion), have the conversation in the morning. If the person is more likely to respond to a professional or family member, you could ask them to discuss it with the person instead.

Request a care assessment for the person with dementia

Anyone with dementia can have an assessment of their needs by the local authority. This is called a care assessment (and is also referred to as a 'care needs assessment').

A care assessment should identify what the person's needs are – even if they are currently being met. It should also include what support is needed. It helps the local authority decide if they will pay towards meeting these needs.

Make it clear which of the person's needs you are currently meeting. Think about what you're happy to continue with and what you would like some help with. If you are happy to continue but need respite to help you take some time out from your caring role, let the assessor know.

The local authority cannot refuse to carry out an assessment, even if they think the person will have to pay for their own support and care. If the local authority does not pay towards the care and support, the information in the assessment can still be helpful. You can use it to discuss care and support needs with providers.

For more information on the care assessment process and how to prepare for it, see factsheet W418 **Assessment for care and support in Wales**.

Space for
your notes

Space for your notes

Request a carer's assessment for yourself

Anyone who cares for a person with dementia is entitled to an assessment of their needs as a carer. This is carried out by the local authority or an organisation on their behalf. This is called a carer's assessment.

A carer's assessment should identify what your needs are and what type of support would help you. Let the assessor know what you want to continue doing. For example, this could be sport or hobbies. Ask whether anything is available to support you with that.

A carer's assessment is often carried out at the same time as a care assessment for the person with dementia. This can be helpful as your needs could be met by support given to the person you care for. For example, if you wish to travel abroad for a family or work commitment, the local authority may provide respite for this period.

You can ask for a carer's assessment at another time if you want to. You may feel you could be more open about your feelings and needs if the person you care for is not at the assessment. Speak to the local authority to arrange this.

Understand funding

To understand your respite options, you need to know if you can access funding through the local authority. Finding out about funding can seem complicated as there are a few steps involved.

The purpose of respite is usually to give the carer a break. However, respite may be put in place after one of the following:

- a **care assessment** for the person with dementia
- a **carer's assessment** for the carer.

Even if the person with dementia is assessed as having no eligible care needs, respite can still be provided following the carer's assessment.

Local authorities may choose not to charge for all types of respite. If the care does need to be paid for, it is always the person with dementia who will have their finances assessed. A carer must not be charged for respite costs. This is still the case even if the respite is for the benefit of the carer. This is because it is the person with dementia who will be directly receiving the service.

Respite is usually charged according to the rules for home care. This means that no matter what capital or income a person has, they will not be asked to pay more than the maximum weekly charge. This is currently set at £100 per week as of 2024. This includes respite outside of the home, such as daycare or a short stay in a care home.

If the local authority agrees to fund respite in order to meet the person's needs, there may be limited choice. If you have a service or home in mind, the local authority may not fund it if a cheaper option can meet the person's needs. Ask which options are within budget.

If a person with dementia does get funding from the local authority, they may decide to receive it as a 'direct payment'. A direct payment gives people greater choice over how they spend the money to meet their needs.

A direct payment can be used for the following examples of respite:

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

Local authorities can agree to direct payments being used to pay close relatives for care. This is even if they live in the same house as the person.

For respite costs, see 'Charges for respite care' on pages 12–14.

Local authorities can provide financial support to eligible carers. This is to help your own health and wellbeing and meet your needs as a carer. For example, it may cover gym membership or a laptop to maintain contact with friends. It cannot be used for services for the person you care for. This means it cannot be used to fund respite care.

Decide on the right type of respite care

It can feel daunting to find the right care option for the person with dementia and also for your needs. The local authority assessment will be useful when you talk with providers about the care the person requires. The provider should also assess if they can meet the person's needs. They should consider their current staffing levels and other service users.

When considering your options, it can help to think through the following questions:

- **What is available near me?** This factsheet explains the main types of care available. But each local area will have its own services and providers
- **What do I want to do with the time?** If you need respite so that you're able to do a specific activity, it may be better to search for a sitting service or daycare. If you are planning a much-needed break, you may need to explore options that provide longer support, such as a short stay in a care home.

**Space for
your notes**

Space for your notes

- **Which options am I comfortable with now?** This may change over time. But if right now you wouldn't consider a certain type of care, it is best to focus on alternatives.
- **What would the person be most comfortable with?** This will depend on their character. For example, if the person you care for is sociable and outgoing, a day centre might work better than respite at home. Also, think about the age of the person. If they have young-onset dementia, they may feel happier in a dementia group for younger people. Other considerations include cultural, language and disability needs. Check what is available in your area.
- **What is the budget?** Funding from the local authority may mean that some options may not be available to you. The local authority should be able to give you information about services in your area with a range of costs. They can tell you what is available within their budget. You may wish to fund your own respite or arrange additional care that the local authority won't fund. If so, there are usually care choice directories available in print or online. It can help to tailor your search so you see the most relevant options.

Ask the local authority for a list of the type of service you are looking for. This could be day centres, pre-bookable respite beds or nighttime care agencies. You can also search the following:

- **Housing Care** can help you find homecare or residential care services.
- **Care Inspectorate Wales** has more information about homecare providers and care homes in your local area. It regulates and inspects adult social care services (including providers of respite care).

If you are considering hiring a personal assistant, you can get more guidance from Skills for Care. They can help if you are using a direct payment from the local authority or if the person is paying the total cost. They have an information hub with a range of resources for people employing their own care and support.

You can find contact details for these organisations in 'Other useful organisations' on pages 19 and 20.

Research the service

Social care workers can support you and give you options. However, they usually won't recommend a particular service. This is because everyone's needs and preferences vary. For example, a day centre that provides lots of opportunities for physical activity may suit one person, but not another. Instead, you could:

- Attend a local group for people with dementia or carers and see if there are any word-of-mouth recommendations. You can search our Dementia Directory for services in your area. Go to **www.alzheimers.org.uk/dementiadirectory**

- Read Care Inspectorate Wales inspection reports and quality ratings on their website.
- Ask friends and family who have had similar experiences.
- Read online reviews.

Remember, services can also improve and change since their last inspection or review.

It's a good idea to meet with care providers to find out more about how they work and how you feel about them. The following are some ideas of questions you might want to ask:

- What is the minimum length of stay and how far in advance do they need a place booked?
- What training do the staff have? Does it include dementia care?
- What experience do they have of working with people with dementia?
- Are they able to meet any religious or cultural needs the person with dementia has?
- Is there a trial period and how long is it?

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

- Will the person always have the same carers?
- How do they manage unexpected events, such as staff sickness?
- Are their costs based on an hourly charge?
- Do they charge more for weekends or bank holidays?

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 can give you a better understanding of how they cope.

If you are looking at residential respite in a care home, see booklet 690 **Choosing a care home for a person with dementia**

Getting started

Change can be difficult. If you have been providing all of the person's care, any outside help may feel like a big step for you both. It may be difficult for you to trust others to provide the care, and for the person you care for to accept help.

Starting with something short-term may be helpful. Then perhaps work up to something longer or more frequent. There may be some trial and error in finding what works well for you both.

Respite is something you may feel you want to put off. However, it can be beneficial for you both in the long term, especially if respite becomes necessary rather than optional. For instance, if you need an operation and can't provide care for some time, it's best to think about possible challenges and solutions. Try to focus on the positives a successful respite arrangement can bring. See 'Adapting to respite care' on pages 15–18.

**Space for
your notes**

Space for your notes

4 Charges for respite care

Charges for respite care vary. With local authorities, some respite care services may be 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 if they should pay, and if so, how much. This is called a 'financial assessment'.

Financial assessment

The person with dementia (or their carer or relative) will be asked to complete some forms about their finances. Someone from the local authority may visit to help the person fill in the forms.

In these forms, the person with dementia will have to report on two things:

- **income** – this refers to any money the person receives regularly. For example, this could be a pension or certain benefits (such as Universal credit or the Guarantee credit element of Pension credit)
- **capital** – this refers to any other assets the person has. This includes savings and investments. It does not include the person's main home.

Care at home

Respite care can be provided in the person's own home, or in the community such as a day centre. In this case, the local authority can ask the person to pay an 'affordable' amount towards the cost. This will never be more than the maximum weekly charge, which is currently set at £100 per week (2024).

If the person has over £24,000 (2024 rate) in available capital, they will either pay:

- the maximum weekly charge, or
- the amount the services actually cost if they cost less than the maximum weekly charge.

If the person has less than £24,000 (2024 rate) in available capital, they will not be expected to use any of their capital to cover care costs, including respite. They must also be left with enough income to cover living costs. This is known as their minimum income amount (MIA). This is comprised of:

- **Basic entitlement** – this can be the amount of Pension credit guarantee Credit that a person receives. Or, if they are not getting this benefit, the amount worked out by the local authority based on their age, level of disability and personal circumstances.

- **35% buffer of their basic entitlement** – this is the minimum buffer, but the local authority may allow more.
- **10% allowance for Disability related expenditure (DRE)** – this covers additional costs related to the person's disability needs not met by the social care package. Examples include community alarms, extra laundry costs and food for a specialist diet. Local authorities may allow more than this.

This means that if someone has less than £24,000 in available capital, they may pay less than the maximum weekly charge for their care. This is to allow them to cover any living costs with their income.

Residential respite in care homes

Most people entering respite in a care home are classed as short-term residents. This is because their stay should be no longer than eight weeks.

Short-term residents who are eligible for local authority respite funding have the same rules for respite at home. This means that regardless of whether they have above or below the £24,000 capital limit, the maximum they can be charged for respite care in a residential care home is £100 per week (2024 rate). If they have less than £24,000 they may be charged less.

If a person goes into a care home for more than eight weeks, they are usually known as a 'temporary resident'. This means their financial assessment for respite care will be different. It will follow similar rules to an assessment for permanent care.

If they have over the capital limit for residential care, which is set higher at £50,000 (2024 rate), they will need to self-fund their residential respite costs. There is no maximum weekly charge for residential care, so they may be expected to pay the full cost of the respite fees.

If they have below £50,000 (2024 rate) in available capital, they will not be expected to use any of this for residential respite care costs. A contribution from their income will still be expected, but they must retain their minimum income amount. In addition to this, they must:

- be left with enough income to cover any of the housing costs stated in the regulations. This includes 'mortgage repayments, payments of rent or ground rent, council tax [and most] service charges'
- have their partner's needs considered, if they have one
- retain any ongoing Disability related expenditure costs.

Whether the person is classed as a short-term or temporary resident, their property will not be included. This is because the person intends to return home when respite ends.

Space for
your notes

Space for your notes

If you, or the person with dementia, is funding all of your own respite costs, you should agree a rate with the care home in advance. In some cases, a short-term stay may become a temporary or permanent one. Care homes should therefore inform you of charges if that were to happen.

Other types of funding

You, or the person you care for, may be able to get help with respite care funding. This could be from a charity, grant-making trust or benevolent fund. This includes ex-service organisations that support people who have been in certain jobs or industries.

Your local carers' centre can advise on what is available in your area. To find your local carers' centre, you can visit our Dementia Directory at alzheimers.org.uk/find-support-near-you. There may also be national organisations that can help. Turn2Us can give you more information on this. See 'Other useful organisations' on pages 19 and 20 for details.

Carer's allowance during residential respite

If the person with dementia receives respite care while staying in a care home, Carer's allowance entitlement can continue for up to 12 weeks. However, it may end sooner than this.

For you to be eligible for Carer's allowance, the person you care for must be receiving a 'qualifying benefit'. This includes:

- Disability living allowance (DLA)
- Personal independence payment (PIP)
- Attendance allowance (AA).

Unless you or the person with dementia are funding the whole cost of respite yourselves, these benefits will usually stop 28 days after the person goes into a care home. Your Carer's allowance will continue until their entitlement to the qualifying benefit stops.

You should speak to the DWP to discuss any change of circumstances that could affect your benefits, or any benefit of the person you care for. This includes stays in hospital and respite in care homes. For information about types of benefits, see factsheet 413 **Benefits for people affected by dementia**.

5 Adapting to respite care

Space for your notes

Introducing any type of extra care can be a big support for you and the person you care for. However, it can be difficult to adjust to. It is very common to be nervous about potential changes. But these feelings shouldn't stop you from using respite if you feel it would help. This section outlines some common concerns about respite care and suggests ways to help overcome them.

Introducing new people

When we know someone well, we have insight into how best to communicate with them. We often have a good idea about what makes them feel confused or settled, upset or happy, anxious or content. This familiarity, along with mutual trust, is usually built over time.

To build familiarity between the person with dementia and anyone new, it can help to share information. It is often easier to develop rapport if we have common interests with others. So if staff know a little about the person's interests, this can be a good conversation opener.

Knowing other details about the person can help to build a relationship. These include:

- their preferred names or nicknames
- topics of conversation they enjoy, or try to avoid
- their hobbies or interests
- their religious faith or other beliefs
- previous jobs or volunteering, or areas they have lived
- people who are important to them
- experiences that have shaped them.

This is me® (and Welsh version **Dyma fi**®) is a simple leaflet that supports a person with dementia receiving professional care. It can be used to record details about a person who can't easily share information about themselves. You can download a copy from alzheimers.org.uk/thisisme or order a copy for free by phoning **0300 303 5933**.

Space for your notes

How will respite providers know what to do?

As the one who provides most of the person's care, you will usually know the best way to support them. The provider should put together a support plan. A care assessment could provide a good starting point for this. Be sure to share:

- details of the person's routine, such as what time they get up and what time they like to eat or have a nap
- 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
- what the person with dementia likes and dislikes – this could range from food preferences to a favourite jumper
- details about the running of the home, if staying at home. This may be 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.

Don't be afraid to share as much detail as possible, even if you aren't asked for it. For example:

- A provider may ask, 'Do they prefer a bath or a shower?'

Add the detail:

'They prefer a shower with lukewarm water on a low setting, without getting their hair wet.'

- A provider may ask, 'Do they need help with toileting?'

Add the detail:

'Yes, they need help to and from the toilet. But they wish to be left alone when they are in the bathroom to respect their privacy.'

- A provider may ask, 'Can they eat independently at mealtimes?'

Add the detail:

'They struggle with cutlery, making them feel uncomfortable eating in front of others. They reject support. Could you provide finger foods instead?'

The more comfortable the person feels and the more prepared the provider feels, the more likely it is that the respite will be successful.

Disrupting the person's routine

Routine is important to most people with dementia. It can help them to feel comforted and calm, reducing stress and anxiety. It is possible that changing a routine could impact that.

If they are being supported at home, consider arranging it on a day when they have no other commitments. If you have the choice, arrange it at a time of day that suits them best. For example, if they have a regular morning routine, it may be more successful introducing something in the afternoon. The distress of interrupting their routine could cause problems with the respite arrangement.

Unfamiliar environments

As well as sticking to a routine, it can be helpful for someone with dementia to stay in a familiar environment. However, this may not always be possible for respite. This may be because the carer needs some time at home alone. Or the local authority budget may be enough for a short break in a care home but not live-in care.

It may also be more beneficial for the person to have respite outside the home. New experiences could provide cognitive stimulation, and also help them to feel less isolated or withdrawn.

To reduce confusion in a new environment, consider small changes. This can make it feel more familiar. For example, if they are going to daycare:

- **See if you can begin with visiting together.** Start by just having a chat with staff and a cup of tea. Then next time, try an activity and then work up to them spending half a day on their own and eventually a full day. Ask the provider what is possible, without being disruptive to other service users.
- **Look for daycare where they may know someone else** who attends and ask the provider if they can sit together.
- **Look for services that already have familiar features to the person.** These could be faith groups, daycare for military veterans or culturally-based services.
- **Have someone they know drop them off** and pick them up to begin with. They may be able to stay with the person until they feel settled.

If the person is having a short break in a care home, see if they can take some of their own items they may find comforting. Photos in frames and personal objects can also become conversation starters. There may be some things they can change with the room layout to reflect what they are used to. This could include having the bedside table on the left or right, the curtains left open or closed, and the lamp on a certain setting.

Space for
your notes

Space for your notes

“

I look forward to my few hours to myself every week and dad likes the company. It took some time for me to relax when I was out, but now I don't worry.

Daughter of a person with dementia

”

There can be many benefits to good quality respite care but it is important to manage expectations of what the break will do for you both. It is also important to determine in advance how involved you will be during the period of the respite break. You might like to think about how often you will visit the care home (if you choose this) or how many times you will ring or be on hand for a telephone call.

Is respite worth it?

Caring for a person with dementia is complex and challenging. There are positive and negative aspects, and everybody will cope with their situation in different ways. Some people feel they lose their identity when they become a carer, often feeling guilty if they do take time for themselves. It can help to remind yourself why people find respite helpful and the benefits it can bring.

When it works well, respite can:

- improve family relationships
- reduce loneliness
- help maintain a sense of identity for both the person with dementia and the carer
- help with anxiety and depression
- support those providing care to meet other commitments and maintain relationships
- provide longer term benefits to carer health
- mean that you can carry on caring for longer, if you choose to.

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 both.

Talking to other carers about your feelings can help. They may be able to give you tips and suggestions, and it can be reassuring to speak to other people in a similar situation.

The Dementia Support Forum 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 **forum.alzheimers.org.uk**

You might also find it helpful to speak to a counsellor about your feelings. For more information, see 'How can talking therapies help carers?' on page 18 in factsheet 444 **Supporting a person with dementia who has depression, anxiety or apathy**.

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

Space for
your notes

Care Inspectorate Wales

0300 7900 126 (9am–5pm Monday–Thursday;
9am–4.30pm Friday)
CIW@gov.wales
www.careinspectorate.wales

Care Inspectorate Wales is the independent regulator of social care in Wales. They register, inspect and take action to improve the quality and safety of services.

Carer's Allowance Unit

0800 731 0297 (8am–6pm Monday–Friday)
www.gov.uk/carers-allowance-unit

The Carer's Allowance Unit deals with claims for Carer's allowance and handles enquiries about any change of circumstances or entitlement to the benefit.

Carers Trust

0300 772 9600
info@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 UK

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

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

GOV.UK

www.gov.uk

On the GOV.UK website you can find information and services from the UK government, including information about paying for care. You can also use it to search for details of your local authority at gov.uk/find-local-council

Shared Lives

0151 227 3499
info@sharedlivesplus.org.uk
www.sharedlivesplus.org.uk

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

Space for your notes

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.



Factsheet W462

Last reviewed: March 2024

Next review due: March 2027

Reviewed by: Dr Kritika Samsi, Senior Research Fellow, The Policy Institute, King's College London, Chris Barrett, Strategic Lead for Adult Social Care and Hospital Integration, Gloucestershire County Council, and Karan Jarvis Keysell, Care Sector Workforce Officer, Adult Social Care at Kent County Council

This factsheet has been reviewed by people affected by dementia.

To give feedback on this factsheet, or for a list of sources, please email [**publications@alzheimers.org.uk**](mailto:publications@alzheimers.org.uk)

This publication contains information and general advice. It should not be used as a substitute for personalised advice from a qualified professional.

Alzheimer's Society does not accept any liability arising from its use. We strive to ensure that the content is accurate and up to date, but information can change over time. Please refer to our website for the latest version and for full terms and conditions.

© Alzheimer's Society, 2025. All rights reserved. Except for personal use, no part of this work may be distributed, reproduced, downloaded, transmitted or stored in any form without the written permission of Alzheimer's Society.

At Alzheimer's Society we're working towards a world where dementia no longer devastates lives. We do this by giving help to everyone who needs it today, and hope for everyone in the future.

We have more information on **Needing greater support with care.**

For advice and support on this, or any other aspect of dementia, call us on **0333 150 3456** or visit **alzheimers.org.uk**

Thanks to your donations, we're able to be a vital source of support and a powerful force for change for everyone living with dementia. Help us do even more, call **0330 333 0804** or visit **alzheimers.org.uk/donate**



Together we are help & hope
for everyone living with dementia

Alzheimer's Society
43-44 Crutched Friars
London EC3N 2AE

0330 333 0804
enquiries@alzheimers.org.uk
alzheimers.org.uk

Registered charity no 296645. A company limited by guarantee and registered in England no 2115499. Alzheimer's Society operates in England, Wales and Northern Ireland.