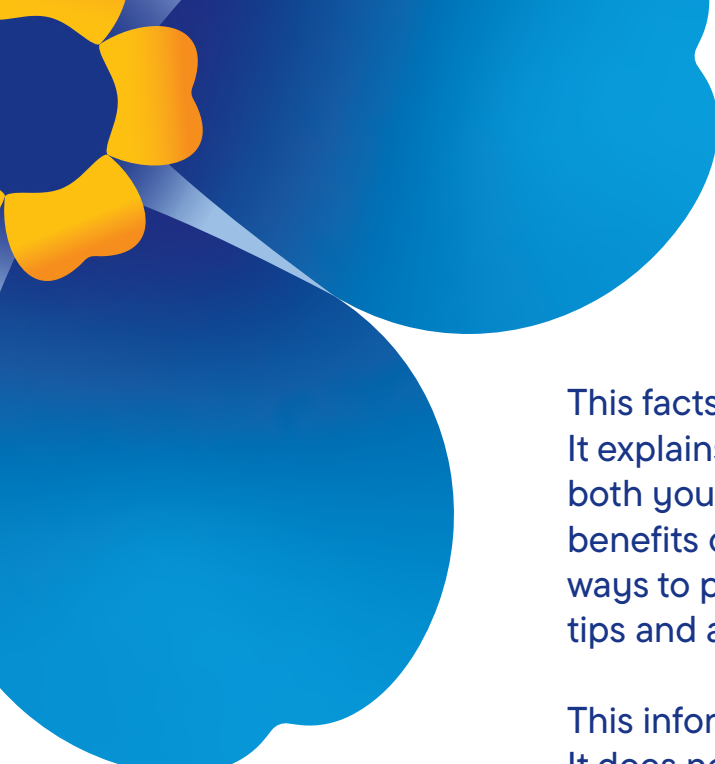


Respite care in Northern Ireland



**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 Northern Ireland. It does not cover England or Wales, where the systems are different. See factsheet 462, **Respite care in England** or W462, **Respite care in Wales**.

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1 What is respite care?

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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 break from a daily task, such as someone else helping the person to wash and dress. Or it can give you 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 work 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 they go outside 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.

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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 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 or 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 section 5 'Adapting to respite care' on page 19.

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 trust. 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 a budget given to the person by the trust. See 'Understand funding' on page 10.

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.

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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 day centres are owned by health and social care trusts (HSCTs). Others can be run by charities, such as Age NI, or privately owned. Use our Dementia Directory to see what is available in your area – **alzheimers.org.uk/dementiadirectory**

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.

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 trust or the Shared Lives scheme will be able to provide more information. See 'Other useful organisations' on page 23.

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 in case a permanent move is needed in the future. 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. This includes 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.

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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. Ask your trust or carers' centre how they can support you. They may provide local emergency card schemes.

Emergency card schemes involve detailing 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 be given an emergency card. It's useful to carry this 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. Carer's NI have a downloadable template on their website that you can use.

Some local authorities will provide emergency respite care. Your trust or local carers' centre can provide more information about what is available in your area.

3 Making arrangements

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If you have no experience of respite, it can be helpful to think of the process as a series of steps, taking each one in turn. These steps are described in more detail in this section:

- involve the person with dementia
- request an assessment of need 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 are able to consent or refuse respite services, it is their decision to make. Some people may lack the ability (mental capacity) to consent. In these cases, a best-interest decision can be made for them.

When discussing respite care with the person with dementia:

- **Focus on the benefits that a break can bring you both.** You could say, 'If you attend daycare, you can socialise and try something new while I do housework. We can then spend the rest of the week together.'
- **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.** You could say, 'Are you willing to try daycare or would you prefer someone staying at home with you? If you aren't sure after a few weeks, we could try something different.'
- **If they are resistant to respite care, ask what their concerns are.** They may feel worried about something that you could reassure them about. If they are worried about missing a part of their routine, such as going to their place of worship or a social group, you can avoid respite at those times.
- **If they are still resistant, revisit the conversation another time.** Try to find a time that is best for the person. 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 you could ask them to discuss it with the person instead.

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Request an assessment of need for the person with dementia

Anyone with dementia can have an assessment of need by the trust. It is also sometimes referred to as a 'community care assessment' or 'care needs assessment'. Professionals carry out these assessments using a 'Single assessment tool'.

An assessment should identify what the person's needs are, even if they are currently being met. It should also include what support is needed. This helps the trust decide if they will arrange or pay towards meeting these needs.

The HSC trust will compare the person's needs with eligibility criteria set by the Department of Health and Social Care. These criteria consist of four bands of risk. The HSC trust will try to establish which risk band the person falls into. They will then use this to decide whether the person will receive services.

The bands of risk are critical, substantial, moderate and low.

The HSC trust is responsible for meeting a person's care needs for the critical and substantial risk bands. The trust can choose to meet needs in the moderate and low risk bands, but legally do not have to.

So if a person is assessed as having low or moderate needs, the trust may not provide a respite service for the person. This means the person may need to arrange and fund the respite themselves.

However, it is worth checking if the trust will arrange respite following a carer's assessment to meet your needs. See 'Request a carer's assessment for yourself' on page 9.

As a carer, 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 day-to-day care, but need respite to help you take time out from your caring role, let the assessor know.

The person with dementia can ask for an assessment of need – even if they think they may not meet the criteria. It may still be helpful to them. The trust cannot refuse to carry out an assessment.

If the trust does not meet the person's needs, the information in the assessment can still be helpful. It can be used to discuss care and support needs with respite providers you may choose to fund yourself.

For more information on the assessment process and how to prepare for it, see factsheet NI418, **Assessment for care and support in Northern Ireland**.

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 and 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 a hobby or another commitment. Ask whether anything is available to support you with that.

A carer's assessment is often carried out at the same time as an assessment of need for the person with dementia. The Single assessment tool contains a carer's assessment. 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 trust 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 trust to arrange this.

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Understand funding

To understand your respite options, you need to know if you can access funding through the trust. 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 either one of the following:

- an **assessment of need** 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.

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 receiving the respite service.

Trusts have the power to charge for care and support provided at home. But they don't usually use this power. This means that services provided while a person lives at home, are usually provided free of charge. This includes respite care, such as sitting services and day care.

However, this may change in the future and trusts may start to charge more frequently. If this happens, services would still be free for anyone aged 75 and over. It would also include anyone claiming means-tested benefits, such as pension credit (guarantee credit). Anyone else would receive a means test to check what they could afford to pay.

For residential respite in a care home, the trust will decide whether to carry out a financial assessment, or just charge a reasonable amount for the person to pay.

If the person with dementia needs to pay the total cost of residential respite, they may be known as a 'self-funder'. As they are paying for all their care, they can choose the provider that suits them best, with what they want to spend.

If the person can receive some support with funding, there may be limited choice because of the available budget. If you have a service or home in mind, the trust 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 trust, 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.

Direct payments can't usually be made to pay close relatives for care if they live in the same house as the person. But trusts can make exceptions for this.

For respite costs, see section 4 'Charges for respite care' on page 15.

Carer's personal budget

A carer's personal budget may be available to you – whether the person with dementia has care funding or is a self-funder. 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.

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Decide on the right type of respite care

There are things to consider when looking for the right care option for the person with dementia and also for your needs. An assessment of need may 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 take into account their current staffing levels and other service users.

When considering your options, it can help to think about:

- **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.
- **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 trust may mean that some options may not be available to you. Some may feel too expensive for self-funders. The trust should be able to give you more information about services in your area. If you are receiving funding, they can tell you what is available for the budget. There are usually care choice directories available in print or online.

Ask the trust 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.
- **The Regulation and Quality Improvement Authority (RQIA)** has more information about homecare providers and care homes in your local area.

If you are considering hiring a personal assistant, you can get more guidance from <https://www.nidirect.gov.uk/articles/employing-professional-carer-or-personal-assistant>

You can find contact details for these organisations in 'Other useful organisations' on page 23.

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/dementiadirctory**
- Read **Regulation and Quality Improvement Authority (RQIA)** inspection reports and quality ratings on their website.
- Ask friends and family who have had similar experience.
- 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 has?
- Is there a trial period, and how long is it?

If you're choosing homecare, 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 respite in a care home, see booklet 690, **Choosing a care home for a person with dementia.**

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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 section 5 'Adapting to respite care' on page 19.

4 Charges for respite care

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Charges for respite care vary. Some respite care services may be free of charge through the Health and Social Care trust. Other services may have a cost that will be charged to the person with dementia. The trust 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 trust 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 available assets the person has. This includes savings and investments. It does not include the person's main home.

A financial assessment will only need to take place if the trust decides to charge for a service.

Care at home

Currently, trusts don't usually charge for services provided in a person's home. This may change in the future. If they do decide to charge, the means test for home help is complicated. Home help may include respite sitting services. Ask the trust for details if they provide and charge for this locally.

Any charges are based on a person's ability to pay. If a trust decides a person must contribute, they will take into account:

- savings over £6,000 if a person is over 60 years old
- savings over £3,000 if a person is under 60 years old
- weekly income
- any outgoings a person has.

Anyone who is over 75 or claiming a means-tested benefit, such as Pension credit guarantee credit, cannot be charged.

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Residential respite in care homes

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

Charges for short-term residents, who are eligible for trust funding, depend on the trust. The trust has the power to charge, but it may not choose to. Therefore, a financial assessment may not take place to assess a person's ability to pay.

The trust can either decide to:

- charge, based on the financial assessment (see 'Capital limits'). This is dependent on a person's available income and capital. This may mean they pay the full amount.
- charge an amount it feels reasonable for the resident to pay. For example, they may charge for the 'hotel costs' of the stay such as meals, but not the care costs.
- decide not to charge for stays up to eight weeks. It cannot do this for longer stays.

You should ask for your trust's policy on this. If the trust does decide to charge and carry out a financial assessment, it will consider the person's capital and income.

Capital limits

In Northern Ireland, the 2024 capital limits are:

- upper capital limit – £23,250
- lower capital limit – £14,250.

If the person's capital is:

- **above the upper capital limit:** the trust will compare their available capital to the capital limits. The person can be expected to pay all their own residential respite costs.
- **between the upper and lower capital limits:** they will pay a means-tested contribution from their capital.
- **below the lower capital limit:** they won't have to pay any contribution from their capital. This means that they can keep any savings below £14,250 to use as they wish. However, they will still pay what they can afford from their income.

The person will always be allowed to keep a certain amount of protected income for living costs. This is income that can't be used to pay for care costs, including respite. This is called the Personal expenses allowance (PEA).

In Northern Ireland, the 2024 Personal expenses allowance rate is £30.44 weekly. The person may be able to keep more than this. The trust must ignore any means-tested benefits provided for home commitments.

Extra costs might include:

- a fixed heating charge
- mortgage payments, rent or service charges not met by Income support/Pension credit and Housing benefit
- housing support charges
- insurance premiums.

If someone is arranging and funding their own care, they should agree a rate with the care home in advance. In some cases, a short-term stay may become a permanent one. Care homes should therefore also provide key information on 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/dementiadirectory**. There may also be national organisations that can help. Turn2Us can give you more information on this. See 'Other useful organisations' on page 23 for details.

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Carer's allowance during residential respite

If the person with dementia receives respite care in a care home, Carer's allowance entitlement can continue for up to four weeks. However, it may end sooner than this, for example, if they have recently been in hospital.

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 they are funding their own respite stay, those benefits will usually be suspended 28 days after they enter a care home. Your Carer's allowance will continue until their entitlement to the qualifying benefit stops.

You should speak to the Disability and Carers Service to discuss any change of circumstances that could affect your Carer's allowance. You can now report changes for carers allowance online at www.nidirect.gov.uk/services/carers-allowance-report-changes-online

For information about types of benefits in Northern Ireland, use the Make the Call service. See 'Other useful organisations' on page 23 for details.

5 Adapting to respite care

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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
- areas they have lived
- people who are important to them
- experiences that have shaped the person's interests.

This is me[®] 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**.

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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. An 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 the toilet?'

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 trust 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 can provide cognitive stimulation and 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 they are 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.

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your notes

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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?' 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

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Regulation and Quality Improvement Authority (RQIA)

028 9536 1111

info@rqia.org.uk

www.rqia.org.uk

The RQIA is the independent body responsible for monitoring and inspecting the availability

NI Direct

0800 587 0912 (Monday- Friday, 9am – 4pm)

Email Attendance Allowance and Disability Living

Allowance: dcs.post@dfcni.gov.uk

Email Carers Allowance: belfastcastlecourt.caenquiries@dfcni.gov.uk

www.nidirect.gov.uk

NI Direct is the official Government website for Northern Ireland residents, providing a single point of access to public sector information and services.

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.

Carers Northern Ireland

0808 808 7777 (helpline, 9am–6pm Monday–Friday)

advice@carersni.org

www.carersuk.org/northernireland

Carers Northern Ireland gives information, advice and support about caring.

GOV.UK

www.gov.uk

On the GOV.UK website you can find information and services from the UK government, including paying for care.

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Shared Lives Plus

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.

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.



Factsheet NI462

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Next review due: November 2027

Our publications are 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)

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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

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