

# Respite care in Northern Ireland

Northern Ireland  
factsheet  
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Respite care is the term for types of temporary care that give anyone with a main responsibility for caring for someone else the chance to take a rest or a short break.

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

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

This information is for people living in Northern Ireland and does not cover England and Wales, where the systems are different. For respite care in England see factsheet 462, **Replacement care (respite care) in England**, and for Wales see factsheet W462, **Respite care in Wales**.

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# Respite care in Northern Ireland

## What is respite care?

Respite care is temporary care that means the person's main carer can have a break from caring. Respite care can be arranged for a short time, for example while you go to the shops or meet friends. It can also be arranged for a longer time, for example if you want to have a break for a few days, or spend some time away.

## Types of respite care

The right type of respite care for the person with dementia will depend both on their needs and yours. Respite care can include:

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

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

For example, if you want to attend a class for a couple of hours a week you might choose to have care at home, or a day centre. If either you or the person with dementia needs a longer break, a short stay in a care home might be more suitable.

For information on the different ways you can access respite care see 'Arranging respite care' on page 7.

### Care at home

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

### Care agencies and other care providers

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

Some local carers' organisations offer a respite care service. This often involves a regular carer coming to spend a few hours with the person with dementia. Your local carers' centre can give you information on what is available locally. Carers' centres are independent charities that deliver support services for carers in local communities. Carers NI, Carer's Trust or your local Health and Social Care (HSC) trust can provide details of your local carers' centre (see 'Other useful organisations' on page 15 for more details).

### Support workers (personal assistants)

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

- come during the day to give you time to do something you want to do (such as going to the shops, visiting friends or attending a class)
- help with personal care such as washing and dressing
- spend time with the person with dementia doing things they enjoy, either inside or outside their home
- come into the person's home to provide care and support during the night, so that you can get some sleep
- stay with the person or make regular visits so that you can go on holiday or have a break away from home.

### Friends and family

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

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

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

### Care away from home

#### Day centres

Day centres can be a good way for people with dementia to take part in activities and meet other people. Some day centres specialise in supporting people with dementia, and some are run specifically for younger people with dementia. Ask your local HSC trust or go to **[alzheimers.org.uk/dementiadirectory](https://alzheimers.org.uk/dementiadirectory)** to find out what is available in your area.

If the person's needs assessment identifies that day centres are something they and you both need, then the HSC trust must arrange this for you.

It may take the person with dementia some time to adjust to attending a day centre, and initially they may need support and encouragement to go. You might find it helps to go with the person for their first few visits. It's important for staff at the day centre to get to know the person and their likes, dislikes and support needs. This will mean they can help the person settle in and make sure that activities meet their needs. See 'Giving information to respite care providers' on page 11 for more advice on how you can help with this.

### Holidays and short breaks

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

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

The person with dementia may need extra support to cope with a new environment or changes to their routine, such as leaving the bathroom light on and door open at night. Finding a holiday company that caters for people with dementia can make things easier and mean you both have a more enjoyable holiday. For more information and advice on travelling, including details of specific providers, see factsheet 474, **Travelling and going on holiday**.

### Care homes

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

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

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

### **Shared Lives**

The Shared Lives scheme is another option for respite care. The idea is usually that someone with care needs can live or stay in the home of someone who is an approved Shared Lives carer.

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

The scheme is not available everywhere but it is expanding. Your local trust or Shared Lives Plus will be able to provide more information about whether this is currently available near you. See ‘Other useful organisations’ on page 15 for more information.

### **Arranging respite care**

You can arrange respite care through your Health and Social Care (HSC) trust or you can contact a personal assistant, homecare agency or care home directly. These options are explained in more detail below.

#### **Arranging respite care through the HSC trust**

Your HSC trust is responsible for helping you to find different types of respite care. They will work out how they can support you and the person you care for by assessing your care and support needs. If you have an assessment this is a ‘carer’s assessment’. If the person with dementia has an assessment this will be a ‘health and social care assessment’. To request an assessment you, the person with dementia, or a professional (for example, your GP) should contact your HSC trust.



During the assessment, the trust will work out what care and support needs you both have. If you meet certain criteria, a social worker will discuss with you, and the person with dementia, how you want these needs to be met and what options are available – including different types of respite care.

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

The HSC trust may provide the person with dementia with respite care, but the person may be asked to contribute towards the cost. The HSC trust can charge them for short stays in care homes (of under eight weeks) in one of two ways. They can either assess the amount they should pay, based on their income and capital (such as property and savings) and follow national rules. Or they can charge what they think is a 'reasonable' amount, although this should take account of individual circumstances.

If care is provided in the person's own home, the HSC trust can ask the person with dementia to pay 'a reasonable amount' towards the cost. HSC trusts can decide whether to allow direct payments to be used for respite care. Ask your local HSC trust to find out.

If the person with dementia chooses not to have a health and social care assessment, or if they are found not to be eligible for care and support after an assessment, you can still have a carer's assessment. HSC trusts can provide carers with services to help maintain their health and wellbeing. This may include help with short-term care either in the person's own home or in a care home. However, in some cases, your income may be assessed and you may be asked to contribute towards the cost of care.



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

For more information about health and social care and carers assessments see factsheet NI418, **Assessment for care and support in Northern Ireland**.

### Arranging respite care yourself

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

The person with dementia can still have a health and social care assessment even if they are paying for the care themselves (see 'Arranging respite care through the HSC trust' on page 7). This will help to establish what kind of care they need.

The Regulation and Quality Improvement Authority (RQIA) regulates all care providers in Northern Ireland, including care homes and care delivered in the person's home. Lists of care providers and inspection reports are available. For more information see 'Other useful organisations' on page 15. You can also search our dementia directory for services in your area. Go to **[alzheimers.org.uk/dementiadirectory](https://alzheimers.org.uk/dementiadirectory)**

### Charities

If you are having difficulty paying for respite care or for a holiday for the person with dementia, you may be able to get financial help from a charity. Organisations such as Turn2us can give you information and support. See 'Other useful organisations' on page 15 for details.

## Choosing a respite care provider

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

- What training do the staff have? Does it include dementia care training? What experience do they have of working with people with dementia?
- Will there be a care plan to meet the needs of the person with dementia?
- How often do they assess the person and their needs?
- Are they able to meet any religious or cultural needs the person with dementia has?
- Do they keep notes, and can you see these?
- How are relatives and those close to the person supported?
- How do they manage unexpected events, such as staff sickness?
- Are there any additional charges?
- Is there a trial period, and how long is it?
- What insurance is in place and what does it cover?
- What is their complaints process?

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

- Will the person always have the same carers?
- Can the person change carers?
- Are their costs based on an hourly charge?
- Do they charge more for weekends, evenings/nights 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 means that you can get a better understanding of how they cope with different situations.

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

## Giving information to respite care providers

It is important to give information about the person with dementia to anybody providing respite care. This can make it easier for the person to adjust to a change of environment or carer. It can also help anyone providing respite care to support the person and meet their needs.

This information can be used to write a care plan with you and the person you care for. It will help everyone to know what care and support has been agreed and should be reviewed regularly.

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

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

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

- important phone numbers, such as the GP
- emergency contact details, for example for you or another family member or friend.

## Adapting to respite care

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

The person you care for may also be worried about respite care. It can help to talk to them and find out if they are worried about certain things. If you know what they're worried about, it will be easier for you to find ways to support them. It may also mean that you can look at ways to address the issue. For example, if the person is concerned about being in an unfamiliar environment, you could make sure they take a few favourite items with them, such as photographs, to make it feel more familiar.

Following some of the tips on page 13 may help. Care providers can find it helpful to know if there are any concerns or anything worrying the person. It means they can put things in place to address these and tailor the support they provide.

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

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

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

## Respite care: tips

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

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

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

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

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

## Other useful organisations

### Age NI

0808 808 7575 (advice line, 9am–5pm Monday–Friday)  
advice@ageni.org  
www.ageuk.org.uk/northern-ireland

Age NI provides information and advice for older people in Northern Ireland.

### 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.

### Carers Trust

0300 772 9600  
info@carers.org  
www.carers.org

Carers Trust can help with advice on personal wellbeing, benefits and support, and can signpost for assistance with finance. (Only available to carers of people living in the Southern Health and Social Care Trust area.)

### Citizens Advice

www.citizensadvice.org.uk

Citizens Advice can provide information and advice about legal and financial issues, including benefits. It can also suggest ways to get more legal and financial advice. See website for local contact details.



### **Law Centre NI**

028 9024 4401

[admin@lawcentreni.org](mailto:admin@lawcentreni.org)

[www.lawcentreni.org](http://www.lawcentreni.org)

Law Centre NI offers free legal advice and support on social security, health and social care and employment.

### **Regulation and Quality Improvement Authority (RQIA)**

028 9536 1111

[info@rqia.org.uk](mailto:info@rqia.org.uk)

[www.rqia.org.uk](http://www.rqia.org.uk)

The RQIA is the independent body responsible for monitoring and inspecting the availability and quality of health and social care services in Northern Ireland.

### **Shared Lives Plus**

0151 227 3499

[info@sharedlivesplus.org](mailto:info@sharedlivesplus.org)

[www.sharedlivesplus.org.uk](http://www.sharedlivesplus.org.uk)

Shared Lives Plus is a network that links voluntary carers with people needing care across the UK.

### **Turn2us**

[www.turn2us.org.uk](http://www.turn2us.org.uk)

Turn2us is a charity that provides information and support about accessing welfare benefits, grants and other financial help.

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

Reviewed by: Catherine Harper, Community Care Legal Officer, Law Centre NI; Michael Graham, Director, Cleaver Fulton Rankin Solicitors and member of Solicitors for the Elderly

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

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

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

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

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

For support and advice, call us on **0333 150 3456** or visit [alzheimers.org.uk](https://alzheimers.org.uk)



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