

# Respite care in Northern Ireland

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Respite care is short-term care used as a temporary alternative to a person's usual care arrangements. People who care for someone with dementia often carry on without realising how tired or tense they have become. A break or holiday can help them relax and recharge their batteries. It is important that carers have regular breaks and make time for their own needs. Respite care may also be needed in other situations. For example, the carer might have to go into hospital, or might have other important commitments. This factsheet outlines some of the different options available.

Please note that this information is valid in Northern Ireland only.

For respite care in England, see factsheet 462, **Replacement care (respite care) in England**. For information about respite care in Wales, see factsheet W462, **Respite care in Wales**.

## Managing feelings about respite care

Whatever the reasons for respite care, it can affect people who care for someone with dementia in different ways. Some may feel worried or guilty about taking a break and leaving the person they are supporting, even for a short period. It is important to remember the following points:

- If a carer stretches themselves too far and becomes ill or depressed, life may become more difficult both for them and the person with dementia.

- Carers are entitled to time to themselves, in order to do what they want to do.
- Many carers find it helpful to discuss their concerns with a professional who has knowledge of dementia, with other carers or with someone on the Alzheimer's Society National Dementia Helpline.

If possible, they should also discuss the situation with the person with dementia. They may prefer one sort of arrangement to another.

It is natural to prefer to stay in familiar surroundings, especially for someone living with dementia. The person may not fully understand why they have to go away and may feel confused, or may say they don't want to go. This can make the person who normally cares for them feel guilty about wanting or needing some time alone. However, it is important to remember that taking an occasional break is good both for the carer and the person with dementia, as time apart will enable the carer to 'recharge' their batteries and feel refreshed.

### **Tips: avoiding distress**

- Avoid discussing arrangements too far ahead of the planned date.
- When the time for the break comes, be positive in your explanation. It might be helpful to talk about the break in the context of a 'little holiday'.
- Reassure the person with dementia that they will be well cared for and that they will be coming home again.
- Remember that any insecurity or uncertainty you show may cause the person with dementia to feel afraid, so try to stay calm and give information in a clear and simple manner.
- Remember that it is not selfish to want or need a rest.

## Care at home

Arranging temporary care in the home of the person with dementia has some advantages – for example, the person may find it reassuring to remain in familiar surroundings. However, any regular carers might have to spend considerable time and effort making arrangements to ensure that the person is well cared for and that the home runs smoothly while they are away.

The easiest solution might be to arrange for a friend or relative to stay. If this isn't possible there are a number of other options. It is important to think carefully about the type of care required. Full-time nursing care is usually very expensive, and may not be necessary.

The options for finding someone to provide care at home include:

- **Personal recommendations** – perhaps another carer or the GP surgery may know of someone suitable.
- **Advertising** – advertising locally is often best because the person with dementia and those who care for them can get to know the person beforehand.
- **Homecare agencies** – these can find people to provide respite care, but will probably be more expensive. The local health and social care (HSC) trust may have a list of local homecare agencies.
- **Care packages** – if the person does not need support 24 hours a day, a care package involving family, friends or neighbours, social services, voluntary agencies and even some private care might be the answer.
- **The local HSC trust** – some local HSC trusts arrange homecare, although they vary in this respect (see 'Community care assessments' below).

## Checklist: setting up respite homecare

- Always interview the applicant personally, and take up references.
- Ask whether the applicant has any experience or training in dementia care.
- Introduce the applicant to the person with dementia to ensure that everyone is comfortable with the situation.
- Check with your home insurance company that the person with dementia is covered for someone working in their home (in case of accident or theft).
- Ask the applicant about their employment status. If they are not self-employed, the carer might be responsible for their tax and national insurance. The local Citizens Advice Bureau may be able to advise (see 'Other useful organisations').
- Make sure that you agree with the applicant exactly what their role will be. For example, you need to make it clear if you expect them to do certain household tasks, or to take the person out each day.
- Make sure that everyone is clear about the hours and fees, and put this in writing.

## Instructions

It is essential to leave very clear explanations and instructions for whoever is caring for the person with dementia, preferably in writing. This means that there is less possibility of them forgetting, or of there being a misunderstanding. Instructions should include:

- details of the usual routine and activities of the person with dementia, their likes and dislikes and any dietary, religious or cultural practices that should be respected
- clear instructions about the running of the home – for example, which keys lock which doors, and how the washing machine operates
- important phone numbers – for the GP surgery, for example
- the contact details of carers or family members, or of someone else to contact in an emergency.

## Tip: using life history books

Life history books or personal profiles can be an invaluable toolkit for any third party spending time with the person you care for. These should include key facts about the person's life experiences, where they have worked, important people in their life, their interests and any particularly sensitive subjects. Try to include photographs that interest the person with dementia, with clear information about the photograph to stimulate conversation.

Alzheimer's Society produces a tool called **This is me** to record key background information about a person. See [alzheimers.org.uk/thisisme](http://alzheimers.org.uk/thisisme)

## Care away from home

If short-term care is arranged away from home, the person with dementia may take some time to settle into their new environment. It may also take them some time to readjust when they get home. The person with dementia may not understand why they need to go somewhere else, so those around them need to give calm reassurance that this is only for a short time and carers need to be firm about the fact that they need a break.

The carer should visit the place beforehand, preferably with the person with dementia, to ensure that it is suitable and can cater for individual needs. They should also check that staff have enough information to enable them to relate to the person with dementia as an individual, to reassure them when necessary and to avoid any unnecessary distress. Life history books or personal profiles can help to give vital information about the person with dementia (see 'Tip: using life history books' above). These will aid staff to understand their needs and interests.

## Travelling and going on holiday

Some forms of holiday accommodation may be able to cater for people with dementia travelling alone or taking a break with their carer. For more information see factsheet 474, **Travelling and going on holiday**.

## Short-term care schemes

Another option is short-term care provided by residential care homes, nursing homes or hospitals. This is not always easy to arrange, as it depends on a place being vacant at a specific time. However, some homes and hospitals put aside a number of places for short-term care, enabling carers to plan ahead.

- A home providing residential care only will probably be suitable if the person with dementia is mobile and has fewer care needs. Staff usually provide support with washing, dressing and going to the toilet and will assist at mealtimes, if necessary, but they do not provide nursing care.
- A home providing nursing care is likely to be suitable if the person with dementia has difficulty moving, has continence problems or nursing care needs.

Factsheet 476, **Selecting a care home**, explains what to look for when choosing a care home.

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. (See 'Other useful organisations' for contact details.)

## Paying for short-term care

If the person with dementia or someone they know wants to pay for the total cost of short-term care (they don't have to do this), they can make their own arrangements. Care homes providing nursing care are generally more expensive than homes providing residential care only. However, fees for either vary greatly.

The person with dementia should have a community care assessment (see below) even if they are paying for the care themselves. This will help to establish what kind of care they need. HSC trusts can choose

whether to charge for respite care – most do. If they charge, the cost must be ‘reasonable’. If a person feels that the fee is unreasonable, they can request a financial assessment.

## **Community care assessments**

If the person with dementia and their carer need help with the cost of care, at least one of them (see ‘Carers’ assessments’ below) will need a community care assessment. The local HSC trust arranges these. HSC trusts differ in their procedures and the services they consider to be priorities. (See factsheet NI418, **Community care assessment.**)

## **Carers’ assessments**

Carers are eligible for an assessment of their own needs in relation to their caring role. If someone is caring for a person with dementia and has not had an assessment of their needs, they should ask their HSC trust for one.

HSC trusts can provide carers with services in their own right, 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, the person’s income may be assessed and they may be asked to contribute towards the cost of care.

## **HSC trusts arrangements**

If a person has been assessed as needing and qualifying for short-term care, the HSC trust may provide it. However, the person with dementia may be asked to contribute towards the cost.

The HSC trust can charge the person with dementia for short-term 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 and according to 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 have discretion to allow direct payments to be used for respite care. Consult your local HSC trust to find out.

## **Charities**

If a carer is having difficulty financing a holiday for the person with dementia, or paying for respite care, they may be able to get financial help from a charity. Organisations such as Turn2us can point carers in the right direction (see ‘Other useful organisations’ for details).

## **Other useful organisations**

### **Age NI**

3 Lower Crescent  
Belfast BT7 1NR

T 0808 808 7575  
W [www.ageuk.org.uk/northern-ireland](http://www.ageuk.org.uk/northern-ireland)

Provides information and advice for older people in Northern Ireland.

### **Carers NI**

58 Howard Street  
Belfast BT1 6JP

T 0808 808 7777 (Adviceline, Monday–Friday 10am–4pm)  
E [advice@carersuk.org](mailto:advice@carersuk.org)  
W [www.carersuk.org/northernireland](http://www.carersuk.org/northernireland)

Charity that provides information and advice to carers about their rights, and how to access support.



## **Citizens Advice Bureau (CAB)**

Various locations

W [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

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

Your local CAB can provide information and advice in confidence or point you in the right direction. To find your nearest CAB look in the phone book, ask at your local library or look on the Citizens advice website (above). Opening times vary.

## **The Law Centre**

Belfast Office

124 Donegall Street

Belfast BT1 2GY

T 028 9024 4401

028 9023 9938 (textphone)

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

Western Area Office

9 Clarendon Street

Londonderry BT48 7EP

T 028 7126 2433

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

The Law Centre provides a legal service in specific areas of law to people on low incomes who live or work in Northern Ireland.

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

9th Floor Riverside Tower  
5 Lanyon Place  
Belfast BT1 3BT

T 028 9051 7500  
E [info@rqia.org.uk](mailto:info@rqia.org.uk)  
W [www.rqia.org.uk](http://www.rqia.org.uk)

The RQIA is the independent regulator of health and social care in Northern Ireland. The RQIA carries out inspections of care services which can be accessed via their website.

### **Turn2us**

T 0808 802 2000 (helpline 9am–8pm Monday to Friday)  
E [info@turn2us.org.uk](mailto:info@turn2us.org.uk)  
W [www.turn2us.org.uk](http://www.turn2us.org.uk)

Charity that provides information and support about accessing welfare benefits, grants and other financial help.

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Alzheimer's Society National  
Dementia Helpline

England, Wales and Northern Ireland:  
**0300 222 1122**

9am–8pm Monday–Wednesday  
9am–5pm Thursday–Friday  
10am–4pm Saturday–Sunday

[alzheimers.org.uk](http://alzheimers.org.uk)

Alzheimer's Society is the UK's  
leading support and research charity  
for people with dementia, their  
families and carers.



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