

Replacement care (respite care) in England

Factsheet LP462
April 2015



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

This factsheet is for people living in England and is not intended for Wales and Northern Ireland, where the systems are different. For information on respite care in these countries please see factsheet W462, **Respite care in Wales** or NI462, **Respite care in Northern Ireland**.

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Replacement care (respite care) in England

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

What is replacement care?

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

- day centres
- care at home
- a short stay in a care home
- Shared Lives
- holidays or short breaks
- carers' emergency replacement care schemes.
- These arrangements are covered in detail in this factsheet.

When considering replacement care, it's important for a carer to think about the type of care the person with dementia needs. Full-time nursing care is expensive and may not always be necessary. When arranging care with a homecare agency or care home, staff should talk to the carer about writing a care plan around meeting the needs of the person with dementia. Similarly, if the person with dementia has a needs assessment, this should help identify their care needs (see 'How is replacement care provided?').

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A professional, such as a social worker or dementia specialist nurse, can provide more information.

How is replacement care provided?

The responsibility to help carers take a short break from caring lies with the local authority. The needs of a person and their carer are assessed. This needs assessment enables social services to identify what a person's care needs are. If they meet the criteria, this should be the start of a discussion with the local authority about how the person or their carer want their needs to be met.

In England a needs assessment or a carer's assessment is available to anyone if it appears that they may have care and support needs. It can be requested by the person, their carer, or a professional (eg a GP, consultant or hospital social worker) by contacting the local authority.

When considering replacement care, it's important for a carer to think about the type of care the person with dementia needs. Full-time nursing care is expensive and may not always be necessary.

In some areas, replacement care for a person with dementia is provided as a result of a carer's assessment, while in others it's provided after a needs assessment for the person themselves. It is important that both the carer and person with dementia are assessed if possible. They can be assessed separately, but joint assessments are available if both parties consent. A carer's needs can still be assessed if the person they care for refuses an assessment or is found not to have eligible needs after their assessment. See 'How is replacement care funded?' below.

The local authority should provide clear information and advice from the earliest stage of this process.

A range of replacement care options may be offered. This could include a stay in a care home, a place at a day centre or access to another type of break using a direct payment.

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

For more information see factsheet 418, **Assessment for care and support in England**.

Types of replacement care

Care at home

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

- come in during the day to give the carer a break, with the carer using the time to do something they want to do (eg go to the shops, visit friends or pursue education or a hobby)
- spend time with the person and engage them in social activities both inside and outside of the home
- come in to the home to care for the person during the night to give the carer a chance to sleep
- stay with the person or make regular visits over a certain period of time so that the carer can go on holiday or have an extended break away from the home.
- Replacement care at home can be arranged through the local authority, or privately, directly with a homecare agency. A carer from a homecare agency may be able to provide replacement care for a few hours a day, regular visits (eg three times a day) or 24-hour support for the person at home, depending on their needs.

Some care agencies specialise in providing 24-hour live-in care. This is usually more expensive than a place in a care home. If the local authority is funding replacement care there may be a limit on what they will fund. If they can meet the person's needs in a cheaper way, for example in a care

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home, then they will do so. However, these decisions cannot be based on cost alone and the local authority must discuss the arrangements with the person and their carer.

Another option is to employ a personal assistant to provide care. If the carer or person with dementia is receiving a direct payment, they may want to use this to employ a personal assistant directly. For more information see factsheet 473, **Personal budgets**.

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

Friends and family

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

The person with dementia and their carer may be more comfortable with this arrangement because the person will be spending time with someone familiar. Relatives may also be more familiar with the person's routine and preferences. However, family members and friends may not be able or willing to take on this responsibility. It can help to talk to them and try to find solutions that work for everyone.

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Care away from home

Day centres

Day centres can provide a range of support for a person with dementia, including activities and social interaction. Some day centres specialise in supporting people with dementia, and some are run specifically for younger people with dementia. The local authority or local Alzheimer's Society office can provide details of day centres in a particular area.

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

Holidays and short breaks

Replacement care can also take the form of a short break or a holiday. Some organisations provide specialist package holidays for people with dementia and their carers. They include support with caring tasks, and facilities that are accessible and dementia friendly. This means the carer can have a break from their caring role and focus on spending quality time with the person they care for. The local Alzheimer's Society office or carers' centre can provide more information.

Taking a holiday together may require a lot of planning. It's important that arrangements are made with the provider in advance, if possible, so that the person with dementia and their carer both know what to expect. The person with dementia may need extra support when coping with the new environment or changes to their routine. For more information and advice on travelling see factsheet 474, **Travelling and going on holiday**.

Care homes

The person with dementia can stay in a care home for replacement care. There are different types of care home, providing different levels of care in addition to accommodation.

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

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

Other options

Shared Lives

Shared Lives is an alternative to homecare and care home arrangements. It is a national scheme where the person with dementia can spend time in the home of another carer and give their own carer a break. Availability may depend on the local area. The local authority or local Shared Lives organisation can provide more information.

Carers' emergency replacement care scheme

Some local authorities or carers' organisations will provide replacement care to the person with dementia in an emergency (usually between 48 and 72 hours depending on the situation). The local authority or local carers' centre can provide more information and say what is available in a certain area.

How is replacement care funded?

Replacement care services can sometimes be provided free but are usually means-tested. The Care Act 2014 means that replacement care is now recognised as a service to the person with dementia, who may have to pay, and that the carer should not be charged. However, if the person with dementia has a needs assessment but is found not to have eligible support needs, the carer can be asked to pay for replacement care, subject to a financial assessment that the local authority will carry out.

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

Some replacement care services may be provided free of charge by the local authority. Many are means-tested, which means the person with dementia may have to contribute towards the cost. The local authority will calculate the cost of the services to be provided and then financially assess the person, to see how much the person should contribute to the cost of these services.

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

Funding arrangements

Care homes

The local authority can charge the person with dementia for short-term stays in care homes (under eight weeks) in one of two ways. They can assess the amount they should pay based on their income and capital and according to national rules. Alternatively, they can charge what they think is a 'reasonable' amount, although this should take account of individual circumstances and leave the person with enough money to run their household. There are national rules about how much the person should be left to live on. A financial assessment may be carried out to establish how much the person should pay.

Care in the community

If care is provided in the person's own home, the local authority can ask the person with dementia to pay a 'reasonable' amount toward the cost. As with temporary replacement stays in care homes, the person must be left with enough money to run their home and to live.

Vouchers

Instead of organising services directly, some local authorities may give people vouchers that can be used with local services. For more information contact the local authority or local carers centre.

Direct payments

After a needs assessment, the amount of money identified as being necessary to meet the person's needs is called a personal budget. A person with dementia may decide to receive their personal budget allocation in the form of a direct payment. A direct payment is paid directly to the person, to pay for their care and support. They aim to give people greater flexibility and choice over how their needs are met. They can be used in a number of ways, such as employing a personal assistant, taking a break with a carer, or replacement care in a care home for up to four weeks in any 12-month period. However, the direct payment can only be spent as agreed in the person's support plan and it will be agreed in advance how it will be used to meet their needs.

Carers may also be entitled to a direct payment depending on their need for support. Again, it must be used to meet the needs and achieve the goals identified in their support plan. A carer may hire a paid carer from an agency, for example to help with shopping trips, or they may use the direct payment to pay for a supported holiday or for education. The local authority can give information on personal budgets and eligibility. See also factsheet 473, **Personal budgets**.

Other funding

A person may be able to get help with the cost of funding replacement care or taking a break from a charity, grant-making trust or benevolent fund. Ex-service organisations, as well as those that support retired people in a particular type of work, may also help. The local carers centre or Alzheimer's Society can advise on what is available locally. There may also

be national organisations that can help. For more information see 'Other useful organisations' and factsheet 532, **Paying for care and support in England**.

Carer's allowance

For someone receiving Carer's allowance, their entitlement continues for a period of up to 12 weeks inside a 26-week time span, or until Disability living allowance (DLA), Personal independence payment (PIP) or Attendance allowance entitlement for the person they care for, stops. Consequently, a short period of replacement care, within these limits, should not affect their entitlement to Carer's allowance.

It is helpful for carers to give information to those providing replacement care. This can support them while they care for the person with dementia.

Giving information to replacement care providers

It is helpful for carers to give information to those providing replacement care. This can support them while they care for the person with dementia. It may help to use a tool such as **This is me**, which people with dementia and their carers can use to tell staff about their needs, preferences, likes, dislikes and interests. You can download a copy from alzheimers.org.uk/thisisme or order a copy for free by phoning **0300 303 5933**.

It will be helpful to write things down for the carers, including information on:

- what the person with dementia likes and dislikes; this could range from food preferences to a favourite jumper
- details of their routine: what time they get up, what time they like to eat, any activities they enjoy doing throughout the day
- specific ways to support the person if they become upset or distressed
- any medicines they need to take
- any sensory or physical difficulties they may have

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- dietary, religious and cultural needs
- any hobbies and interests the person has
- if the person is being looked after at home, details about the running of the home, eg which key locks which door, how the washing machine works, which day the bins are collected
- important phone numbers, eg the person's GP
- emergency contact details, eg the carer or another family member or friend.

Replacement care: tips for carers

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

- **Plan ahead** – New environments can be challenging for a person with dementia. It can help to set up a regular replacement care routine, to help both you and the person adjust. Some people find it helpful to use replacement care in the early stages of the condition, or before they feel it is needed, rather than at the later stages or if a crisis or emergency situation arises. This can give you a feel for replacement care, as well as a chance to try different types.
- **Consider short breaks or short visits to start with** – This will mean you, the person and those providing replacement care can get to know each other. It may help to build confidence before a longer visit.
- **Arrange a needs assessment** – If both you and the person have an assessment of your needs, it will help you both to know what you need and the options you have.
- **Talk about replacement care** – Some people find openly talking about replacement care helpful. It will give both you and the person with dementia a chance to discuss your options and your feelings. You know the person best, so will know the best way to talk to them.

- **Talk to paid carers** – It's important for a paid carer to get to know the person and what works for them. Talking to them about their needs and their routine can help. For care at home, it can help for the person and the new carer to spend time together (possibly with you to start with) so they get to know each other and build a relationship before the replacement care starts.
- **Visit the care home or day centre** – Ask carers about their training and experience, and what care and support they can provide. The quality of care the person will receive is important. You may feel more confident with the replacement care arrangement if you know what training and skills the staff have.
- **Talk to others** – Talking to other carers about your feelings can help. They may be able to give tips and suggestions. However, it's important to remember what works for one person may not work for another. You may also want to talk to a professional (eg support worker) about how you're feeling.
- **Focus on the benefits** – You may be worried that a replacement care arrangement won't provide the same level of care as you can, or that the person will become unsettled. It is natural to be concerned, but try to focus on how the break will support you in your caring role.
- **Keep trying** – Replacement care is an adjustment for everyone. If something doesn't work or doesn't go to plan, try not to give up. Another type of replacement care or another location may be more successful. You may need to try different options to find what works best for you and the person.

Adapting to replacement care

When carers and people with dementia access replacement care they may experience difficulties. The carer may also have some worries, for example about how the person is settling in, whether they are being well cared for, or if their routine is being disrupted.

The carer should find out if there are certain things worrying the person. If they know what they're worried about they will be better able to support and reassure them. It may also mean carers can look at ways to address the worry. For example, if the person is concerned about being in an

unfamiliar environment, the carer could ensure they take a few favourite items and some photographs with them. Following some of the tips mentioned earlier in this factsheet might help to address some concerns. Experiencing difficulties is not unusual, and it is normal for a carer to be nervous about the experience. However, these feelings shouldn't discourage them from taking a break. Caring for a person with dementia is a complex and challenging job. There are positive and negative aspects, and each carer will cope with their situation in different ways.

Taking a break is not always an easy decision to make, and carers may feel worried or guilty. They may feel that replacement care will create more stress and that the quality of the care will not be up to their standards. It's important to know that having a break will do both the person with dementia and the carer good in the long term. It may ultimately mean that the carer can carry on caring for longer.

For more information see factsheet 523, **Carers: looking after yourself**.

Other useful organisations

Care Quality Commission

CQC National Customer Service Centre
Citygate
Gallowgate
Newcastle upon Tyne NE1 4PA

0300 061 6161
enquiries@cqc.org.uk
www.cqc.org.uk

Regulates, inspects and reviews all adult social care services in the public, private and voluntary sectors in England.

Carers UK

20 Great Dover Street
London SE1 4LX

0808 808 7777
advice@carersuk.org
www.carersuk.org

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

Carers Trust

32–36 Loman Street
London SE1 0EH

0844 800 4361
info@carers.org
www.carers.org

Works to improve support services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

Shared Lives

G04 The Cotton Exchange
Old Hall Street
Liverpool L3 9JR

0151 227 3499
www.sharedlivesplus.org.uk

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

Turn2us

0808 802 2000 (helpline, 9am–8pm weekdays)

info@turn2us.org.uk

www.turn2us.org.uk

Turn2us helps people in financial need gain access to welfare benefits, charitable grants and other financial help. They also provide information on grants that may be able to support people to access help and support.

Factsheet LP462

Last reviewed: April 2015

Next review due: April 2018

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

A list of sources is available on request.

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

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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.

