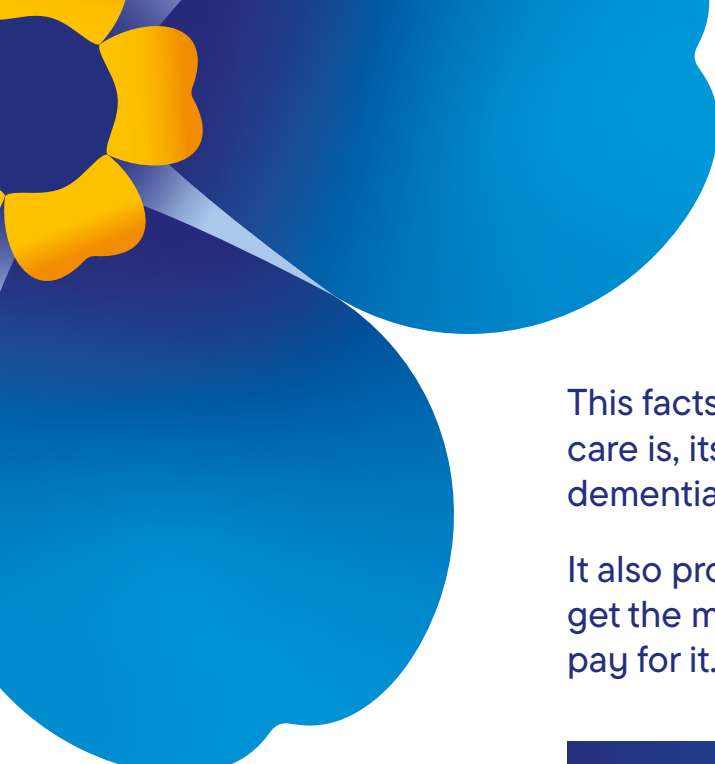


Replacement care (respite care) in England



**Alzheimer's
Society**

Together we are help & hope
for everyone living with dementia



This factsheet explains what replacement (respite) care is, its benefits for those caring for a person with dementia and the different options available.

It also provides practical tips and advice on how to get the most from replacement care and ways to pay for it.

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1 What is replacement care?

Replacement care is temporary care that means the person's main carer can have a break from caring. Replacement 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.

Replacement care can include:

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

The right type of replacement care for the person with dementia will depend both on their – and your – needs. 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.

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 information on the different ways you can access replacement care see 'Arranging replacement care' on page 6.

The next section has more information on different types of replacement care.

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

Partner of a person with dementia.

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2 Types of replacement care

Care at home

Many people prefer care provided in the person's 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 replacement 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 replacement 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 UK or your local authority can provide details of your local carers' centre (see 'Other useful organisations' on page 16 for more details).

Support workers (personal assistants)

Replacement 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 do any of the following:

- come in 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 inside or outside their home
- come in to 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.

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 authority or local Alzheimer's society what is available in your area, or go to [alzheimers.org.uk/dementiadirectory](https://www.alzheimers.org.uk/dementiadirectory)

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 replacement care providers' on page 12 for more advice on how you can help with this.

Holidays and short breaks

Another form of replacement 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.

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

Partner of a person with dementia.

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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 them 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, **Going on holiday when a person has dementia**.

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 replacement 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 replacement care will be needed can be difficult, but it can be helpful to make arrangements for the future if you can.

Other options

Shared Lives

The Shared Lives scheme is another option for replacement 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 in the country but it is expanding. Your local authority or the Shared Lives scheme will be able to provide more information about whether this is currently available near you. See 'Other useful organisations' on page 16 for more information.

Carers' emergency replacement care

There may be times when you are unable to care for the person you support. For example, if you are suddenly taken ill or have an urgent issue to deal with at home. In these situations, some local authorities or carers' organisations will provide emergency replacement care for the person with dementia. They will usually provide care lasting between 48 and 72 hours, depending on the situation. Your local authority or local carers' centre can provide more information and let you know what is available in your area.

It's a good idea to carry a 'Carers Emergency Card' if these are available in your area. The schemes work differently in different areas. They are free, identify you as a carer and mean the person you care for has support if something happens to you. Check with your local authority or local carers' centre to see if these are available in your area. You may be offered one after you have had a carer's assessment.

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3 Arranging replacement care

You can arrange replacement care through your local authority or you can contact a personal assistant, homecare agency or care home directly. This section has more information on these options.

Arranging replacement care through the local authority

Your local authority's social services team is responsible for helping you to find different types of replacement 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 'care needs assessment'.

During the assessment, social services 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 replacement 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 social services for a reassessment, also known as a review. This will show whether yours or the person's needs have changed and may lead to extra care and support being provided, including replacement care.

If the person with dementia chooses not to have a care needs 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.

To request an assessment you, the person with dementia, or a professional can contact your local authority's Social Services team.

Social services must provide clear information and advice about the services available in their 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 local authority 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 needs and carers assessments, see factsheet 418, **Assessment for care and support in England**.

Arranging replacement care yourself

If you choose to arrange replacement care without any help from the local authority, it is your responsibility to find and arrange the replacement 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 replacement 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 Care Quality Commission (CQC) regulates and inspects adult social care services (including providers of replacement care) and has more information (including quality ratings) about homecare providers and care homes in your local area. For more information see 'Other useful organisations' on page 16. You can also search our Dementia Directory for services in your area. Go to alzheimers.org.uk/dementiadirectory

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4 Paying for replacement care

Charges for replacement care vary. With local authorities, some replacement care services may be provided free of charge. Other services may have a cost that will be charged to the person with dementia. The local authority will assess the person's financial situation to decide whether or not they should pay, and if so, how much. This is called a 'financial assessment'.

The Care Act 2014 recognises replacement care as a service to the person with dementia. This means that they may have to pay for replacement care and the carer should not be charged. However, even if the person with dementia has a care needs assessment, but is found not to have eligible support needs, you can still access replacement care. You may have to pay for this yourself. This will also be determined by a financial assessment from your local authority.

If after a financial assessment a person with dementia is paying for the replacement care themselves, they can contact the organisation providing replacement care directly. They should ask questions about availability and cost. You may be able to support them with this, by making sure that they know the questions to ask.

It is also helpful to make a written record of the information provided by the organisation to refer to later. It may be necessary to sign a legal contract with the care provider. Make sure you check all the details of this carefully so you understand what's included and avoid misunderstandings or unexpected costs.

If the local authority is funding the replacement care there may be a limit on what they will pay. Their priority will be to meet the person's needs at the lowest cost. For example if a care home is cheaper than 24-hour live-in care, the local authority is likely to choose this option. However, any decision cannot be based on cost alone. It must be based on the needs and choices of you and the person you care for, and the local authority must discuss the arrangements with you both.

The next section tells you more about the payment or funding arrangements for different replacement care options.

Care homes

There are two ways the local authority can charge for a short-term stay in a care home (up to eight weeks).

- 1 The local authority can assess the amount the person should pay based on their income and capital and according to national rules. This is called a financial assessment.
- 2 The local authority can charge what they decide to be a 'reasonable' amount.

In both cases the amount should take account of the person's circumstances such as their income and any costs related their condition (for example extra heating or laundry costs). The local authority must always leave the person with enough money to run their household.

Care at home

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

For more information on various ways to pay for replacement care, and the amounts you might be expected to pay, see factsheet 532, **Paying for care and support in England**.

Personal budgets and direct payments

If the person with dementia has had a care needs assessment, the local authority's social services team will work out the amount of money that will meet the person's needs. This is called a personal budget amount.

A person with dementia who is receiving funding from the local authority may decide to receive their personal budget as a direct payment. A direct payment aims to give people greater choice over how they spend the money to meet their needs.

Some examples of what a direct payment can be used for include:

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

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As a carer, your support needs can also be paid for by the local authority as a direct payment, depending on a financial assessment. You could use the direct payment in a number of different ways, such as hiring a paid carer from an agency (for example to help with shopping trips) or paying for a supported holiday or for education.

Your local authority can give you information on personal budgets, direct payments and eligibility. For more information see factsheet 473, **Personal budgets**.

Vouchers

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

Other types of funding

You, or the person you care for, may be able to get help with replacement care funding from a charity, grant-making trust or benevolent fund. Ex-service organisations, as well as organisations that support people who have been employed in certain jobs or industries may also help. Your local Alzheimer's Society or carers' centre can advise on what is available locally. There may also be national organisations that can help. Turn2Us can give you more information on this – see 'Other useful organisations' on page 16 for details.

Carer's allowance

If you receive Carer's allowance, your entitlement to this may continue for up to 12 weeks if you choose to use replacement care. Any benefits the person receives will stop 28 days after they go into a care home. This includes Disability living allowance (DLA), Personal independence payment (PIP) or Attendance allowance (AA). Your Carer's allowance will continue until their entitlement to the benefit they get stops. You should speak to the Carer's Allowance Unit to discuss any change of circumstances that's likely to affect your benefit or if you need more information about Carer's allowance. The benefits system is complicated and so it is helpful to have a full benefits check. Your local Citizen's Advice or Age UK will be able to help you with this – see 'Other useful organisations' on page 16 for details.

For more information about different types of benefits see factsheet 413, **Benefits for people affected by dementia**.

5 Choosing a replacement care provider

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It can feel daunting to find the right care option for the person with dementia and also your needs. 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 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 home care, 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 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 replacement 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.

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6 Giving information to replacement care providers

It is important to give information about the person with dementia to anybody providing replacement care. This can make it easier for a person with dementia to adjust to a change of environment or carer. It can also help anyone providing replacement care to support the person and meet their needs. This information can be used to write a care plan with you and the person with dementia. 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 or order a copy for free by phoning **0300 303 5933**.

The information you provide to replacement 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
- their hobbies and interests
- if the person will be staying at home during the replacement 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.

7 Adapting to replacement care

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Replacement 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 with dementia may also be worried about replacement 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, such as photographs, with them to make it feel more familiar. Following some of the tips on page 14 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 replacement 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 replacement 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.

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8 Replacement care: tips

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

- **Talk about it** – It can help to talk openly about replacement 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 replacement care routine, to help both you and the person adjust. Some people find it helpful to arrange replacement care early on, rather than waiting for an emergency or things to become hard to manage. This can support you to carry on caring, be an opportunity to try different types of replacement 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 replacement 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 replacement care provider (possibly with you to start with) before the replacement care starts or as part of a trial.
- **Focus on the positives** – You may be worried that replacement 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 replacement care – for example, by meeting new people or taking part in hobbies and activities.
- **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. 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

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.

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I need to be able to read other peoples stories, because very often you feel very lonely.

Family member
of a person with
dementia.

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Other useful organisations

Carer's Allowance Unit

0800 731 0297

www.gov.uk/carers-allowance-unit

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

Care Quality Commission (CQC)

03000 616161

enquiries@cqc.org.uk

www.cqc.org.uk

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

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 UK

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

advice@carersuk.org

www.carersuk.org

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

GOV.UK

www.gov.uk

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

Shared Lives

0151 227 3499

info@sharedlivesplus.org.uk

www.sharedlivesplus.org.uk

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

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 462

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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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