Finding help and support at home
Looking after a person with dementia can be emotionally and physically demanding and at some stage, many people find they need some additional support to continue to provide care.

**Why should you consider having help and support at home?**

Making the decision to get help at home for a person with dementia can be a difficult step to take. You and the person with dementia may feel that you’re managing and don’t need any help. You might feel that you are letting the person down or failing in your caring role by seeking and accepting help and support.

Inviting someone into your home to provide support can be hard after many years of independence, and you may also have to think carefully about any financial cost that this may incur.

But it’s very important that you do get help if you need it. If your health begins to suffer because of exhaustion, lack of sleep or time to yourself, or because of the physical impact of helping the person wash, get dressed and move around, you won’t be able to care for them as well as you would like.

While it might feel like you’re admitting defeat, having the support of a carer may mean that the person with dementia can remain at home for longer.

Having help in the home can also:

- reduce agitation and distress for the person with dementia
- help provide a daily routine
- improve your relationship by having someone else take over tasks that you both find stressful or frustrating
- ensure that a person who lives alone receives good nutrition and hydration
- keep the person connected to the community, eg by taking them out to groups and other activities
- give the family carer some much needed respite
- provide social interaction for the person with dementia and their family carer
- reduce isolation
Are you a carer?

Many family members and friends of a person with dementia don’t consider themselves to be carers.

You might, for example, think that the tasks you are carrying out are simply what is expected within a relationship. Or your caring responsibilities might have become routine, meaning you rarely reflect on how much you are doing and the impact this may have on your health and lifestyle.

However, you are considered to be a carer if you help with:

- personal care like washing and dressing
- managing the person’s medications
- shopping, cleaning, cooking and laundry
- travelling to doctors’ and other health appointments
- helping them get out and about
- looking after their bills and finances
- providing company by sitting with them
- watching over them if they cannot be left alone

If you help with any or all of these, it’s important to have a Carer’s Assessment and apply for all the benefits that you are entitled to – see p6 for more information.
Types of help and support at home

There are various ways of getting support at home, and it’s important to find the right type of help for you and the person with dementia. For example, you could have:

- informal help from other family members and friends
- a cleaner or gardener to help with household and garden chores
- a befriender (often a volunteer) who visits to provide companionship and/or take the person out to groups and activities
- paid carers who help with personal care and daily living activities – they may visit a few times a week, every day, or several times a day
- 24-hour live-in care

Tasks that a volunteer or paid carer may help with include:

- physically moving the person with dementia – for example helping them in and out of the shower or into bed
- preparing and eating meals
- managing medication
- personal care eg washing, dressing, toileting and dealing with incontinence
- helping with sundowning: the sense of fear, confusion or of being in the wrong place that many people with dementia experience at dusk
- support with activities such as exercise, reading, games or socialising in or out of the home
- supporting the person with dementia overnight so you can sleep
- managing distressed behaviour, such as pacing, shouting or anger

Help from family and friends

Family members and friends can be a great help in providing informal care and support for the person with dementia. You might feel uncomfortable accepting their offers or asking them for support.
Finding help and support at home

But people are often prepared – and keen – to help.

Family and friends might be unsure how they can support you and the person you care for, so it’s best to be upfront about anything they could do to make your life a bit easier.

This could include:

- picking up shopping or prescriptions
- helping with preparing meals – especially if you find it tricky to leave the person with dementia in another room while you cook – or dropping off meals that they have prepared at home
- helping with household tasks like cleaning, gardening or DIY
- sitting with the person with dementia for a while, or taking them out shopping, to a café or to activities – this will help provide companionship and an opportunity to maintain their interests while you have some time to yourself

It’s also important that you maintain relationships with your own friends and family, even when it seems difficult to fit them in. Isolation and loneliness can make a difficult situation worse, so try to make time for your own social relationships.

If it’s hard to leave the person with dementia alone or organise...
respite, you could ask family and friends to come to you – although bear in mind that some people with dementia find visitors or changes in routine unsettling.

**Community schemes and services**

There might be local services that can help you in your caring role. These include:

**Befriending services:** these may be church or community volunteer schemes, or local charities. They can arrange for someone to sit at home with the person with dementia for a while or to take them out for a few hours.

**Support groups:** local memory cafés or dementia support groups can offer services and support to people living with dementia and their family carers (including educational workshops for carers and activities for people with dementia to stimulate the brain). Some take place remotely over apps like Zoom so you can access them from home.

There are also young carers’ groups specifically for children and young people with caring responsibilities.

**Telecare services:** your local council may offer monitoring and alarm systems that will alert you or a call centre in certain circumstances, such as if the person has fallen. These are often personal alarms that are worn on a cord around the neck, with a button to press to summon help. Private telecare companies also operate around the UK.

To find out about any of the services above, you can speak to the person’s social worker or the local council Social Services team or call our free Dementia Helpline – see Sources of support on p10 for details.

**Funding home care**

As the person’s dementia progresses, you might need to pay for a professional home carer. You or the person you care for might be eligible for funding to help with this. The amount will often depend on their income and savings.

To establish the support needs of you and the person with dementia, you will need to ask Social Services
Finding help and support at home

to carry out a **Carer’s Assessment** (for you) and a **Needs Assessment** (for the person you care for).

The Carer’s Assessment looks at what support you need to carry out your caring role. This might include some sort of help at home. The Needs Assessment looks at what support the person with dementia needs, which again may include help at home or a home carer.

Once the assessments have been carried out, you’ll receive a care package report detailing what healthcare, equipment, help at home or residential care is recommended. You will also need a financial assessment to see how much you will have to contribute to the cost of any support recommended.

If you are eligible for financial support, this is called a personal budget. You can ask the council to manage the budget for you – this means that they will choose the care provider and pay them on your behalf. Alternatively, you can have the funding paid directly to you, so you can choose the person’s carers and pay them yourself from your budget. This is called a direct payment.

Other types of benefit/funding to help with care costs include:

- **Attendance Allowance**: this is for adults of state pension age
(67) with a disability who have had care or supervision needs for at least six months, and can go towards paying for home care

- **Personal Independence Payment (PIP):** financial help with extra living costs for people aged 16 to state pension age who have a long-term physical or mental health condition or disability that causes difficulty with everyday tasks or getting around

- **NHS continuing healthcare (CHC) funding:** this covers the cost of care for people with long-term, complex health needs

To find out more about all of these, along with our information on financial and legal sources of support, please see p10.

The information above applies to England and Wales. For information on benefits in Scotland and Northern Ireland, please see Sources of support on p11.

**Choosing a carer to help you at home**

If you are self-funding home care or have decided to receive direct payments from the local council so you can choose care yourself, you can find out which care agencies provide care in your area using the postcode search tool of the UK Homecare Association (UKHCA): please see Sources of support on p11.
Finding help and assistance at home

You could also speak to other local families who use home carers for a person with dementia and ask them who they use and how they would rate them.

You may find the following tips useful:

• Ensure the care agency is regulated by the Care Quality Commission (England), the Care Inspectorate (Wales), the Regulation and Quality Improvement Authority (Northern Ireland), or the Care Inspectorate (Scotland) – see Sources of support on p10 for contact details. You can request the latest report from the care agency

• Make sure the care agency employs staff who are dementia trained

• If the person has young onset dementia, ask if the carer has experience in caring for a younger person with the diagnosis and understands their different needs

• Check that the care staff have had Disclosure and Barring Service (DBS) checks to ensure they’re suitable for working with vulnerable adults

• Ask for references or testimonials from other families who use the agency

• Think about when you would like the carer to visit, and for how long

• Think about what tasks you would like the carer to help with

• Prepare a short profile of the person you care for, including their likes, dislikes and facts about their life, to share with the care provider. This will enable a relationship to be built up and help prompt conversations. See Sources of support on p10 for our information on Life Story work

• Find out whether the same carers will attend the person with dementia every day, or whether there may be several different people

• Find out what will happen if the person’s regular carers are ill or on holiday

• Ask if you can have a trial period to see how the carer and the person with dementia get on
Sources of support

If you would like to speak to a dementia specialist Admiral Nurse about finding help and support at home or any other aspect of dementia, please call our free Helpline on **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email **helpline@dementiauk.org**

If you would prefer to pre-book a phone or video call with an Admiral Nurse, please visit **dementiauk.org/closer-to-home**

Dementia UK resources

The Carer’s Assessment  
[dementiauk.org/the-carers-assessment](dementiauk.org/the-carers-assessment)

Life Story work  
[dementiauk.org/life-story](dementiauk.org/life-story)

Advance Care Planning  
[dementiauk.org/advance-care-planning](dementiauk.org/advance-care-planning)

Guide to NHS continuing healthcare (CHC)  
[dementiauk.org/guide-to-continuing-healthcare-funding](dementiauk.org/guide-to-continuing-healthcare-funding)

Financial and legal sources of support and advice  
[dementiauk.org/sources-of-support-and-advice](dementiauk.org/sources-of-support-and-advice)

Considering a care home for a person with dementia  
[dementiauk.org/choosing-a-care-home](dementiauk.org/choosing-a-care-home)

Care quality inspectors

The Care Quality Commission (England)  
[cqc.org.uk](cqc.org.uk)

The Care Inspectorate (Wales)  
[careinspectorate.wales](careinspectorate.wales)

The Regulation and Quality Improvement Authority (Northern Ireland)  
[rqia.org.uk](rqia.org.uk)

The Care Inspectorate (Scotland)  
[careinspectorate.com](careinspectorate.com)
### Benefits
- **Carer’s Allowance**
  [gov.uk/carers-allowance](https://www.gov.uk/carers-allowance)
- **Attendance Allowance**
  [gov.uk/attendance-allowance](https://www.gov.uk/attendance-allowance)
- **Personal Independence Payment (PIP)**
  [gov.uk/pip](https://www.gov.uk/pip)
- **NI Direct: arranging health and social care**
- **Scotland: Carer’s Allowance**
- **Benefits calculators**
  [gov.uk/benefits-calculators](https://www.gov.uk/benefits-calculators)
- **Financial support if you’re disabled**

### Other resources
- **NHS guide to help at home from a paid carer**
- **NHS guide to care and support you can get for free**
- **Independent Age: impartial advice to help older people live independently**
  [independentage.org](https://www.independentage.org)
- **Find your local council**
  [gov.uk/find-local-council](https://www.gov.uk/find-local-council)
- **The Live-In Care Hub**
  [liveincarehub.co.uk](https://www.liveincarehub.co.uk)
- **Care Information Scotland**
  [careinfoscotland.scot](https://www.careinfoscotland.scot)
- **UK Homecare Association (UKHCA)**
  [homecareassociation.org.uk](https://www.homecareassociation.org.uk)
The information in this booklet is written and reviewed by dementia specialist Admiral Nurses.

We are always looking to improve our resources, to provide the most relevant support for families living with dementia. If you have feedback about any of our leaflets, please email feedback@dementiauk.org

We receive no government funding and rely on voluntary donations, including gifts in Wills.

For more information on how to support Dementia UK, please visit dementiauk.org/donate or call 0300 365 5500.

Publication date: June 2022
Review date: June 2024
© Dementia UK 2022

If you’re caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

Call 0800 888 6678 or email helpline@dementiauk.org

Open Monday-Friday, 9am-9pm
Saturday and Sunday, 9am-5pm

dementiauk.org • info@dementiauk.org

Dementia UK, 7th Floor, One Aldgate, London EC3N 1RE
Dementia UK is a registered charity in England and Wales (1039404) and Scotland (SCO47429).