

# Finding care 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 help with caring for them at home. The progressive nature of dementia means that a person's care needs will increase over time, and it often becomes extremely difficult to meet them without support.

### **Why should you consider having help at home?**

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

Inviting someone into your home to provide support can be hard after many years of independence, and you may also have to consider the financial cost that it may incur.

But it is 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 the physical impact of helping the person wash, get dressed and move around, it will become increasingly difficult to care for them.

And while it might feel like you are admitting defeat, having the support of a carer may mean that the person with dementia can remain at home for longer, in familiar surroundings.

Having help in the home can also:

- relieve you of some of the stress and worry of caring
- reduce agitation and distress for the person with dementia
- provide a daily routine



- improve your relationship with the person you care for by having someone else take over tasks that you both find stressful or frustrating
- ensure the person eats and drinks well
- 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 and time to themselves
- provide social interaction for the person with dementia and their family carer
- reduce isolation

## Are you a carer?

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Many family members and friends of a person with dementia do not think of themselves as carers. You might, for example, think that you are simply doing what is expected within a relationship. 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. Or if your parent has dementia – particularly young onset dementia (where symptoms develop before the age of 65) – you may feel you are too young to be considered a carer.

However, you are a carer if you help with:

- personal care like washing and dressing
- managing the person's medications
- shopping, cleaning, cooking and laundry
- taking them 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 is important to have a carer's assessment and apply for all the benefits that you are entitled to – see p16 for more information.



### Types of care and support at home

There are various ways of getting support at home, and it is important to find the right sort 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
- ‘meals on wheels’ – these may be provided by the local council, but there are also private companies offering home delivery of prepared meals
- 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 (where a paid carer lives in the person's home with them to provide assistance day and night)

### Help from family and friends

Family members and friends can be a great help in providing informal care and support. You might feel uncomfortable accepting their offers or asking for support, but people are often prepared – and keen – to help.

For example, they could:

- pick up shopping or prescriptions
- help with preparing meals – especially if you find it tricky to cook while supervising the person with dementia – or drop off meals that they have prepared at home
- take children to school and pick them up afterwards; or take them to after-school activities
- give the person lifts to healthcare and other appointments
- help with household tasks like cleaning, gardening or DIY
- sit with the person at home or take them out shopping, to a café or activities – this will provide companionship and opportunities to maintain their interests while you have some time to yourself

Family and friends might be unsure how they can support you and the person you care for, so be specific about how they can help. This will ensure the support they provide is helpful for both you and the person you care for; enable them to say if they do not feel they can assist in that way; and ensure there are no misunderstandings about what they are doing.

It is also important to maintain your own relationships with family





and friends and make sure you have time together separately from your caring duties. If it is hard to leave the person with dementia alone or organise respite care, you could ask family and friends to visit you rather than socialising outside the home – although bear in mind that some people with dementia find visitors or changes in routine unsettling.

### **Befriending services and other community schemes**

There might be local services that can help you in your caring role. For example, befriending services may be offered by church/fait h groups, community volunteer schemes or local charities. They can arrange for someone to visit the person with dementia at home or to take them out for a few hours. These services are often free, but some charge a fee to cover the befriender's time and expenses – although considerably less than professional home care.

To find out about community or local council support services, you can speak to the person's GP or social worker or your local Social Services, or call our free Helpline – see Sources of support on p16 for details.

### **Paid home carers**

Many people hire a home carer to support the person with dementia, particularly as their condition progresses. Home carers often have training and experience in supporting people with dementia and other health and care needs. They are also a good option if you do not live nearby, do not have other family members who can help, or are finding it hard to juggle work with caring.

Tasks that a carer may help with include:

- physically moving the person with dementia – for example helping them into and out of the shower or into bed
- preparing meals and supporting the person to eat and drink
- managing medication
- personal care eg washing, dressing, going to the toilet and helping with incontinence
- supporting the person with sundowning: the sense of fear, confusion or disorientation that many people with dementia experience at dusk
- supporting them with activities such as exercise, reading, games or socialising in or out of the home
- providing supervision and care overnight so you can sleep
- helping to reduce distressed behaviour, such as pacing, shouting or anger

If you are self-funding home care or have decided to receive direct payments from the local council so you can choose care yourself (see p13), you will need to decide how to find and hire a carer. There are three main options:





**1. Using a care company:** this is where the carer is employed and supplied by a company that manages all the employment matters, such as:

- recruitment
- Disclosure and Barring Service (DBS) checks to ensure they are suitable for working with vulnerable adults
- training
- tax and National Insurance
- sickness/holiday cover

A manager will write the person's care plan with you and be your point of contact for any issues that arise.

Care companies must be 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 p17 for contact

details. You can view their latest reports on the relevant care inspectorate's website or request them directly from the companies you are considering.

You can look up care companies in your area using the UK Homecare Association's search tool at [homecareassociation.org.uk](https://homecareassociation.org.uk)

**2. Through an introductory agency:** this is where an agency maintains a register of self-employed carers and, for an upfront fee, matches them with the person who needs care. This may be cheaper than using a care company, but you will then be responsible for paying the home carer directly and dealing with any employment matters like contracts, holidays, sickness cover etc. There will be no ongoing contact with or support from the agency once the carer is in place.

Introductory agencies and the carers on their register are not inspected or regulated so you will need to do your own checks of the carer's suitability and ensure they have had a DBS check and taken out public liability insurance.

**3. Employing an independent carer:** some people prefer to find their own self-employed carer, for example through adverts in local papers, community groups or social media, or word of mouth. Independent carers are not regulated or inspected so you will need to carry out your own interviews and assessments. Again, you will be responsible for paying the carer directly and dealing with employment issues, including ensuring they have a valid DBS certificate and insurance.

If you need advice on deciding which home care option is right for you, please contact our dementia specialist Admiral Nurses – see Sources of support on p16.



### Tips for choosing home care

- Speak to other local families who use home carers for a person with dementia and ask for recommendations
- Check that the carer has had DBS checks – particularly if you are using an introductory agency or an independent carer
- Find out what dementia training the carer has had, and whether they have experience of caring for a person with dementia
- Ask for references or testimonials from other families who use the company/carers
- If the person has young onset dementia (where symptoms develop before the age of 65), find out whether the carer has experience of supporting younger people
- Think about when you would like the carer to attend, and for how long
- Think about what tasks you would like the carer to help with
- Prepare a profile – often known as a life story – of the person you care for, including their likes, dislikes and facts about their

life, to share with the care provider and help them build a relationship. See Sources of support on p17 for our information on life story work

- If you have a choice of carers, consider who would suit the person best in terms of their age, sex and personality. It can be particularly beneficial if they have some shared interests, eg music, sport or gardening
- If the person has a care plan, ensure you share it with the care company/carer and discuss how they will implement it
- If you are using a care company, find out whether the same carer will attend the person every day, or whether there may be several different people
- Find out what will happen if the person's regular carer is ill or on holiday – if you are hiring a carer directly or through an introductory agency, it is particularly important to think about back-up cover
- Ensure the carer has public liability insurance
- Ask if you can have a trial period to see how the carer and the person with dementia get on
- Consider your budget and how you will meet the cost of care in the short- and long-term – you may need to increase the amount of care as the person's dementia progresses. For more information on funding care, please see p13
- Be aware that you may reach a stage where it proves too difficult to care for the person at home, even with paid support, and a move into a care home may be necessary – please see Sources of support on p16 for information on choosing a care home



### Funding home care

If you wish to hire a paid home carer, the person you care for might be eligible for funding from the local council. The amount they receive will depend on their income and savings – if they are above a certain level, they will not qualify for financial support.

The first step is to ask Social Services 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 in 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.

Following the assessments, you will receive a report detailing what healthcare, equipment, home help or residential care is recommended. The person with dementia will also need a financial assessment to see if they qualify for funding towards the cost of any support recommended.

If the person is eligible for financial support, this is called a personal

budget. You can ask the council to manage the budget for you – this means that the council 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 people with a disability who have had care or supervision needs for at least six months, and can go towards paying for home care
- **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 p16.

The information above applies to England and Wales. For information on benefits in Scotland and Northern Ireland, please see Sources of support on p18.







## Sources of support

To speak to a dementia specialist Admiral Nurse about finding care and assistance at home or any other aspect of dementia, please call **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25<sup>th</sup> December), or email [▶ helpline@dementiauk.org](mailto:helpline@dementiauk.org)

If you prefer, you can book a phone or video appointment with an Admiral Nurse at a time to suit you: visit [▶ dementiauk.org/book](https://dementiauk.org/book)

### Dementia UK resources

#### Advance care planning

[▶ dementiauk.org/advance-care-planning](https://dementiauk.org/advance-care-planning)

#### Attendance Allowance

[▶ dementiauk.org/attendance-allowance](https://dementiauk.org/attendance-allowance)

#### The carer's assessment

[▶ dementiauk.org/the-carers-assessment](https://dementiauk.org/the-carers-assessment)

#### Choosing a care home for a person with young onset dementia

[▶ dementiauk.org/young-onset-dementia-choosing-a-care-home](https://dementiauk.org/young-onset-dementia-choosing-a-care-home)

#### Choosing a care home for a person with dementia

[▶ dementiauk.org/choosing-a-care-home](https://dementiauk.org/choosing-a-care-home)

#### Financial and legal sources of support and advice

[▶ dementiauk.org/financial-and-legal-sources-of-support](https://dementiauk.org/financial-and-legal-sources-of-support)

### **Guide to NHS continuing healthcare (CHC)**

➤ [dementiauk.org/guide-to-continuing-healthcare-funding](https://dementiauk.org/guide-to-continuing-healthcare-funding)

### **Life story work**

➤ [dementiauk.org/life-story](https://dementiauk.org/life-story)

### **Life story template**

➤ [dementiauk.org/wp-content/uploads/dementia-uk-my-life-story-template.pdf](https://dementiauk.org/wp-content/uploads/dementia-uk-my-life-story-template.pdf)

### **Looking after yourself as a carer**

➤ [dementiauk.org/looking-after-yourself-as-a-carer](https://dementiauk.org/looking-after-yourself-as-a-carer)

## **Care quality inspectors**

### **The Care Quality Commission (England)**

➤ [cqc.org.uk](https://cqc.org.uk)

### **The Care Inspectorate (Wales)**

➤ [careinspectorate.wales](https://careinspectorate.wales)

### **The Regulation and Quality Improvement Authority (Northern Ireland)**

➤ [rqia.org.uk](https://rqia.org.uk)

### **The Care Inspectorate (Scotland)**

➤ [careinspectorate.com](https://careinspectorate.com)

## **Benefits**

### **Attendance Allowance**

➤ [gov.uk/attendance-allowance](https://gov.uk/attendance-allowance)

### **Benefits calculator**

➤ [gov.uk/benefits-calculators](https://gov.uk/benefits-calculators)

### **Carer's Allowance**

➤ [gov.uk/carers-allowance](https://gov.uk/carers-allowance)

### **Carer Support Payment (Scotland)**

➤ [mygov.scot/carers-support-payment](https://mygov.scot/carers-support-payment)

### **Financial support if you're disabled**

➤ [gov.uk/financial-help-disabled/disability-and-sickness-benefits](https://gov.uk/financial-help-disabled/disability-and-sickness-benefits)

### **NI Direct: arranging health and social care**

➤ [nidirect.gov.uk/articles/arranging-health-and-social-care](https://nidirect.gov.uk/articles/arranging-health-and-social-care)

## **Other resources**

### **Care Information Scotland**

➤ [careinfoscotland.scot](https://careinfoscotland.scot)

### **Find your local council**

➤ [gov.uk/find-local-council](https://gov.uk/find-local-council)

### **Independent Age: impartial advice to help older people live independently**

➤ [independentage.org](https://independentage.org)

### **The Live-In Care Hub**

➤ [liveincarehub.co.uk](https://liveincarehub.co.uk)

### **Meals on wheels**

➤ [gov.uk/meals-home](https://gov.uk/meals-home)

### **NHS: financial assessment (means test) for social care**

➤ [nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/financial-assessment-means-test/](https://nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/financial-assessment-means-test/)



### **NHS guide to care and support you can get for free**

➤ [nhs.uk/conditions/social-care-and-support-guide/care-services-equipment-and-care-homes/care-and-support-you-can-get-for-free](https://www.nhs.uk/conditions/social-care-and-support-guide/care-services-equipment-and-care-homes/care-and-support-you-can-get-for-free)

### **NHS guide to help at home from a paid carer**

➤ [nhs.uk/conditions/social-care-and-support-guide/care-services-equipment-and-care-homes/homecare](https://www.nhs.uk/conditions/social-care-and-support-guide/care-services-equipment-and-care-homes/homecare)

### **NHS: paying for your own care (self-funding)**

➤ [nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/paying-for-your-own-care-self-funding](https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/paying-for-your-own-care-self-funding)

### **UK Homecare Association (UKHCA)**

➤ [homecareassociation.org.uk](https://homecareassociation.org.uk)

**To speak to a dementia specialist Admiral Nurse  
about any aspect of dementia:**

Contact our Helpline:  
**0800 888 6678 or [helpline@dementiauk.org](mailto:helpline@dementiauk.org)**

Book a virtual appointment:  
**[dementiauk.org/book](https://dementiauk.org/book)**

**Our charity relies entirely on donations to fund our  
life-changing work. If you would like to donate to help us  
support more families:**

- Call **0300 365 5500**
- Visit **[dementiauk.org/donate](https://dementiauk.org/donate)**
- Scan the QR code

**Thank you.**



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