



DementiaUK
Helping families face dementia

Changes in care Finding help and assistance at home



Caring for a person with dementia can be emotionally and physically challenging. There are various options open to you to get some additional support, and it's important that you find the right type of help for you and the person with dementia.

Making the decision to have someone help you care for a family member with dementia at home can be a difficult step to take. Inviting someone into your home to provide support can also be hard after many years of independence.

But it's very important that you do get help, if and when you need it. If your health begins to suffer because of lack of sleep, or no time to yourself, because of the physical impact of helping the person to move or get dressed, then you won't be able to care for them as well as you would like. It's important that both you and the person with dementia get appropriate support so you can have the best quality of life possible.

What is help and assistance at home?

Having support at home can be organised in a number of different ways. For example, it could mean getting a little bit of extra help with vacuuming or gardening, or paid carers visiting in the morning to help get the person with dementia up, washed and dressed or even 24 hour live-in care.

You and the person you're caring for, may feel that you're managing and don't need any help. However, there are some things that you could seek support with, that will help both you and the person with dementia to stay as well as possible for longer. These 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
- dealing with incontinence; helping the person get to the toilet and cleaning them if they have an accident



- help with late day confusion or sundowning; the sense of fear or of being in the wrong place that some people with dementia experience at dusk
- support with activities, such as exercise, reading, games or socialising in the home
- having a paid carer to support the person with dementia during the night so you can get a good night's sleep
- coping with distressed behaviour, such as pacing, shouting or anger

Offers of help from family and friends

You might feel uncomfortable taking your friends and family members up on offers to help out, or actively asking them for support. But people are often prepared to help – it might just be that they're not sure how. Tell your friends and family if there is anything they can do which will make your life a bit easier.

This could include:

- picking up some shopping for you, or prescriptions
- coming around to do some

cooking, if you find it tricky to leave the person with dementia in another room

- sitting with the person with dementia for a while; or taking them out shopping, to a café, or another activity to maintain interests, so you can do something else or go out

It's 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 bad situation worse.

Community schemes and services

There might be local services that can help you. These include:

- befriending services; church or community centre volunteer schemes; local day centres. These local groups can sometimes arrange for someone to come to your home and sit with the person with dementia for a while or to take them out for a few hours. Speak to your social worker about these, if you have one; or contact the Admiral Nurse

Dementia Helpline to find out about support in your local area

- local Memory Cafes or dementia support groups can offer services and support to people living with dementia and their family carers
- telecare services; your local council may offer monitoring and alarm systems that will alert you or a care centre to certain things, such as if the person has fallen. Or they may provide you with a button to summon help when you need it. Ask your local council about their telecare provision. Private telecare companies also operate around the UK

Home care

As the person's dementia progresses, you might be eligible for funding for some help at home. The amount of funding that a person you're caring for is entitled to, will depend on their income and savings. However, all people with a disability for which they require care are entitled to claim Attendance Allowance, a weekly payment that you can use towards paying for your care. Find out more here:

www.gov.uk/attendance-allowance

The first thing you'll need to do is contact your local council and request a needs assessment and a carer's assessment. If you're in England or Wales, you'll find details of how to do this on the government website: www.gov.uk/apply-needs-assessment-social-services.

In Scotland, this is called the Assessment of your Care Needs and is available from Care Information Scotland: www.careinfoscotland.scot/topics/how-to-get-care-services/assessment-of-your-care-needs.

In Northern Ireland, your health and social care assessment will be carried out by the social services department of your local trust. More information can be found on the Northern Ireland government website, here: www.nidirect.gov.uk/articles/arranging-health-and-social-care.

Alternatively, you can call the Admiral Nurse Dementia Helpline for assistance in finding the right phone number to call.

Once the assessment has been carried out, you'll receive a care

package report detailing what healthcare, equipment, help in your home or residential care the council will provide. You might be offered the choice between accepting council-provided support or receiving a direct payment to source your own care.

Choosing a carer to help you at home

If you're self-funding or would prefer to choose care yourself, you can find out what care agencies provide care in your area by visiting the website of the United Kingdom Homecare Association (UKHCA).

This is the professional association for homecare providers, and it has a postcode search facility: www.ukhca.co.uk

You could also speak with other family carers in your position, and ask them who they use and how they would rate them. In addition, you may find the following hints and tips useful:

- Ensure the care agency is Care Quality Commission regulated if in England. In Wales, this is the Care Inspectorate. In Northern

Ireland, this is the Regulation and Quality Improvement Authority. In Scotland, this is the Care Inspectorate (see Sources of support at the end of this leaflet). You can request the latest report from the care agency

- Make sure the care agency employs staff that are dementia trained
- Ask whether the care staff have had Disclosure and Barring Service (DBS) checks to ensure they're suitable for working with vulnerable adults
- Prepare a short profile of the person you care for, to include 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. Please see Dementia UK's leaflet on Life Story work for more information (see Sources of support)
- Think about the time of day and for how long you would like the person to help you for

Paid care can usually be bought hourly, or can be arranged in shifts, up to arranging for 24 hour live-in care. It's worth considering that the person's needs might increase as their dementia progresses. You might then find that you'll need to pay for more time or request additional types of help from your carer.

Why should you consider care at home?

Having extra help in the home can:

- reduce the person with dementia's agitation and distress
- help focus the day for the person with dementia, by ensuring someone living alone receives good nutrition and hydration and keeps them connected to the community
- give some much needed respite time for the family carer
- provide social interaction for the person with dementia and their family carer
- reduce isolation
- keep the person with dementia in their own home for longer

Sources of support

The Live in Care Hub

www.liveincarehub.co.uk

Government site on needs assessment

www.gov.uk/apply-needs-assessment-social-services

Care Information Scotland website on assessment of care needs

www.careinfoscotland.scot/topics/how-to-get-care-services/assessment-of-your-care-needs

Northern Ireland Direct Government Services website on the health and social care assessment

www.nidirect.gov.uk/articles/arranging-health-and-social-care

Care Information Scotland

www.careinfoscotland.scot

0800 011 3200

United Kingdom Homecare Association (UKHCA)

www.ukhca.co.uk

The Care Quality Commission (England)

www.cqc.org.uk

The Care Inspectorate (Wales)

www.careinspectorate.wales

The Regulation and Quality Improvement Authority (NI)

www.rqia.org.uk

The Care Inspectorate (Scotland)

www.careinspectorate.com

Dementia UK leaflet on the Carer's Assessment

www.dementiauk.org/the-carers-assessment

Dementia UK leaflet on Life story work

www.dementiauk.org/life-story

Dementia UK leaflet on Sources of support

www.dementiauk.org/sources-of-support-for-families

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

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

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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



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