

Caring from a distance



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Looking after a person with dementia can be challenging – and if you care for someone from a distance, you may experience a different set of challenges. For example, you may not be able to pop in regularly, and it may be harder to respond to issues quickly.

Nevertheless, you can still play an important part in supporting the person you care for, even if you don't live nearby.

What is caring from a distance?

Caring from a distance is when you support and help someone from afar – whether that's an hour away, elsewhere in the country, or even in a different country.

Whether the person living with dementia lives alone, with someone else, in a care home, or is currently in a hospital or hospice, there are lots of things you can help them with.

This could include:

- speaking to them on the phone to offer companionship, support and reassurance

- paying their bills
- handling their utility accounts eg council tax, gas, electricity and water
- managing their daily household matters, such as food shopping deliveries, or arranging for their rubbish to be put out
- co-ordinating their medical appointments and/or visits from health and social care professionals
- arranging for their prescriptions to be fulfilled and delivered
- arranging transport to and from hospital or other appointments
- helping them apply for benefits

Lasting power of attorney

Lasting power of attorney (LPA) is a legal process where a person appoints one or more people as their 'attorney' – that is, someone who can make decisions on their behalf if they lack the mental capacity to do so themselves.

If you have an LPA, you can make these decisions even if you are not there in person.



As dementia progresses, many people will lack the capacity to make informed decisions, so if the person you support hasn't yet made an LPA, it's important to do so as soon as possible. You should do this even if you are their next of kin, as this doesn't guarantee that you will be able to make decisions on their behalf.

There are two types of LPA, and the same person/people or different ones can be an attorney for each.

- If you have lasting power of attorney for property and financial affairs and are authorised to act on behalf of the person with dementia, you

may need to manage their bank and savings accounts, pensions and investments, pay bills, or make decisions about their living arrangements, including buying or selling property

- If you have lasting power of attorney for health and welfare and the person you care for no longer has capacity to make decisions, you may need to make decisions on their behalf about medical treatment, health and social care

See Sources of support on p14 for details of our information on making and using an LPA.

Collecting information about the person with dementia

It can be helpful to keep all the information you have about the person with dementia in one place, such as an A4 ring binder, a box file or a document on your computer. This will help you find all the information you need if there is a sudden change in circumstances – for example, if the person becomes unwell – and will also help you anticipate where future challenges might arise.

You could include:

Health needs

- What do you know about the person's dementia – eg what type do they have? When were they diagnosed? What are their main symptoms? How does it affect their daily living? Has there been a gradual or sudden deterioration in their condition?
- Do they have any other illnesses or conditions? If so, how does this affect them?
- Do they have any sight or hearing difficulties? Do they wear glasses or hearing aids?

- What medicines do they take? It's helpful to have a list of current medications and dosages
- Who is their GP? Which other health or social care professionals are involved in their care? Record these people's contact details
- Have they previously had a fall or hospital admission? When, and what for?

Care and support needs

- Does the person have a care plan? If so, keep a copy and ensure you update it if it changes
- Do they have a home carer? If so, is the carer provided by the local authority or employed by an agency? Write down contact details and the days/times they usually visit
- Do they require help with personal care – such as washing, getting dressed, preparing meals, taking medicines or attending appointments?
- Do they need help with general housework, laundry, shopping, etc?



- Does the person need help managing their finances – such as paying bills or applying/reapplying for benefits?
- Do they rely on independent living equipment like a walking stick, Zimmer frame, bath seats, personal fall alarm?
- What activities do they enjoy, and do they need help to attend or engage with them?
- What is their daily/weekly routine – eg do they go to a day centre on the same day each week?
- Do they have any help from volunteers/charities?

Social needs

- Can the person use the phone to call for help or just have a chat?
 - Who are their friends and neighbours? Are these people willing to visit, and to be called on for help? If so, make a note of their contact details
- Having a clear idea of the person's needs and how they are being met will help you offer support on a daily basis, and if a problem arises – even if you can't be there in person.

Caring from a distance – when the person lives at home

If possible, visit the person's home to ensure that it's as safe, secure and comfortable as it can be for them. If you can't visit, ask if another family member or friend can take a look.

You could make the following safety checks:

- Look for trip hazards such as loose carpets or rugs, excess

furniture that gets in the person's way, and clutter that could be moved

- Check the window and door locks work. Find out if someone locally, such as a trusted neighbour, could keep a spare key
- Consider installing a key safe with a code in case emergency access is needed
- Consider whether modifications such as ramps, a stairlift or grab rails might be useful – you can





ask the local Social Services team to carry out a Needs Assessment to identify what might help

- Think about assistive technology that could help the person in their day-to-day life, such as dementia-friendly clocks, electronic pill organisers, picture phones, personal fall alarms, etc
- Consider using the Lions Club ‘Message in a Bottle’ scheme – this is where a bottle containing the person’s basic personal information and medical notes is kept in their fridge so emergency services can access this

information quickly. See Sources of support on p15

- Look into signing up for the Herbert Protocol – a national scheme that allows the police, Social Services and other local services to share useful information about the person in case they go missing

Please see Sources of support on p15 for more details on all of the above.

There may come a time when the person needs professional support to keep living at home, or is no longer able to live in their home,

even with support. Please see Sources of support on p14 for our leaflets on finding care at home and choosing a care home.

Caring from a distance – when the person is in a care home, hospital or hospice

If the person with dementia is living in a care home, or is in hospital or a hospice, you can still support them even if you can't often visit in person.

- Find out the routine and hours of the care setting, such as mealtimes, bedtime, medication rounds and activities so that you can contact the person at the most suitable time
- Ask if you can be told what they have taken part in (eg a trip out, music activity or gardening), so that you can talk to them about it
- Find out the best way to contact the person – do they have their own phone, or should you phone a member of staff? If you're writing them letters, find out if someone can help read them if necessary. Many care homes will

support the person to make or receive video calls – ask if this is possible

- Talk to the staff about how you can give them information or feedback about the person's care and discuss any support plans. Is there a particular time when the health and social care team visit and review the person's care?
- Make sure the care setting knows if you have lasting power of attorney
- Check the procedure regarding consent to share information with you
- If other family members or friends live nearby, ask them to contact you after visiting to give you an update

Keeping essential records

If you are well organised with a system for recording important information about the person with dementia, you'll be able to help quickly if another family member or carer has questions, or if you need to make decisions in a crisis.

- Write down useful contact details, eg the person's doctor



- or nurse, dentist, optician, other relatives, neighbours, their utility providers, their solicitor. Keep these details in a safe place
- Ask the person with dementia – if appropriate – where they keep important documents, such as bank details, benefits statements and legal documents, including LPA documents and their Will. If you're the person's named attorney for health and welfare and/or property and financial affairs, it's advisable to have a notarised copy of these documents yourself
- Consider whether it's appropriate for you to be the person's 'proxy' for day-to-day health and social care matters. Signing a proxy agreement with their GP means that they can discuss the person's care and treatment with you. You may also be able to manage the person's appointments and repeat prescriptions online. Ask the Practice Manager how to arrange this
- Find out whether the person has made an Advance Statement, Advance Care Plan or Advance Decision to Refuse Treatment (ADRT). These are statements

of their wishes and decisions regarding future medical treatment and care – and an ADRT is legally binding if drawn up correctly. If so, keep a copy of these documents

Things to consider when you visit, or to discuss by phone/email

The additional distance between you and the person with dementia makes it all the more important that you have a local network of people to talk to about the person you care for. This could include neighbours, other relatives and friends.

Each time you visit the person with dementia, reassess their circumstances. Check in with the person themselves, as well as their other family, friends or health and social care professionals, to keep up to date with any changes. Some useful things to consider include:

- Are there any concerns, worries or changes in their medical condition?
- What appears to be working well or not so well?

- Do they appear to be their usual self in terms of appearance, weight and general wellbeing?
- Are there any signs that they're taking less care of themselves, or where they live, than before?
This could include neglecting their physical appearance; increasing untidiness in their home; out of date food in the fridge; an overgrown garden; missing appointments, etc

Staying connected to the person with dementia

Caring from afar often involves co-ordinating lots of tasks and jobs. But it's equally important that you and the person with dementia spend time connecting with each other and enjoying each other's company, no matter the distance.

Regular contact times may give the person with dementia something to look forward to. Some people say that having a set time to receive a phone call or visit helps to reduce feelings of isolation and anxiety.

Try to notice the positive things, and enjoy the time you do spend together, whether it's on the phone, by letter or in person.



You could send photos, cards or small gifts to let the person know you are thinking of them.

Supporting family carers who live nearby

Often, as well as having your support from afar, the person with dementia will have other family carers or friends living nearby who help out with their care.

These people often need support themselves. You could, for example:

- provide emotional support, by phone, email, letters or video calls
- help them arrange support for the person with dementia, such as befriending services, day centres or residential respite care. This will allow the day-to-day carers to have a break

Caring for yourself

Taking care of yourself is important when you're caring from a distance.

You might be juggling many things,

such as work and family life, as well as your caring responsibilities. You might be worried about what's happening in the life of the person with dementia, or feel guilty about not being nearby. You may feel overwhelmed, poorly equipped or isolated.

You're not alone – and there is a lot of information and advice to help guide and support you, including speaking to a dementia specialist Admiral Nurse (see Sources of support on p13).

It can be helpful for your own planning to think about the practicalities of the support you can offer, for example, the travel time involved and expenses incurred.

You could consider talking to your family and employer about the challenges of caring from a distance to see whether there is anything they can do to support you. If things are feeling overwhelming, you might want to talk to your GP about any support they can provide, or request a Carer's Assessment to discuss what would help you in your caring role – see Sources of support on p15.

Above all, be realistic about the support you can offer, and don't be afraid to ask for help from others – caring for a person with dementia is often a joint activity, and when you pull together, life is easier for everyone.



Sources of support



To speak to a dementia specialist Admiral Nurse about caring from a distance 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.

To pre-book a phone or video appointment with an Admiral Nurse, please visit dementiauk.org/get-support/closer-to-home/.

Dementia UK resources

Making the home safe and comfortable for a person with dementia

[**dementiauk.org/safe-comfortable-home**](https://dementiauk.org/safe-comfortable-home)

Choosing a care home

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

Lasting power of attorney

[**dementiauk.org/lasting-power**](https://dementiauk.org/lasting-power)

Advance Care Planning

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

Finding support and assistance at home

[**dementiauk.org/finding-help-assistance/**](https://dementiauk.org/finding-help-assistance/)

Looking after yourself as a carer

[**dementiauk.org/get-support/looking-after-yourself-when-you-care-for-someone-with-dementia/**](https://dementiauk.org/get-support/looking-after-yourself-when-you-care-for-someone-with-dementia/)

Practical guide to getting the most out of GP and other health appointments

[**dementiauk.org/practical-guide-to-getting-the-best-out-of-gp-and-other-health-appointments/**](https://dementiauk.org/practical-guide-to-getting-the-best-out-of-gp-and-other-health-appointments/)

Getting the most out of remote consultations

[**dementiauk.org/get-support/diagnosis-and-next-steps/getting-the-most-out-of-a-remote-consultation/**](https://dementiauk.org/get-support/diagnosis-and-next-steps/getting-the-most-out-of-a-remote-consultation/)

GP online services

dementiauk.org/get-support/diagnosis-and-next-steps/gp-online-services/

The Carer's Assessment

dementiauk.org/the-carers-assessment/

Other useful resources

Lions Club Message in a Bottle scheme

lionsclubs.co/MemberArea/knowledge/lions-message-in-a-bottle/

The Herbert Protocol

met.police.uk/advice/advice-and-information/missing-person/missing-persons/vulnerable-people-at-risk-of-going-missing/dementia-missing-risk-herbert-protocol/

The Needs Assessment

nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/getting-a-needs-assessment/

Independent Age – advice on independent living for older people

independentage.org/

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 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



dementiauk.org • **info@dementiauk.org**

Dementia UK, 7th Floor, One Aldgate, London EC3N 1RE
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