

Caring from a distance



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 or respond to issues quickly.

However, you can still play an important part in supporting the person – whether you live an hour away, elsewhere in the country, or even in a different country. This could include:

- speaking to them by phone or video call to offer companionship and support
- managing their bills and benefits
- handling their utility accounts eg council tax, gas, electricity and water
- managing their daily household matters, such as food shopping deliveries, meals on wheels (you can ask your local social services if this is available) or arranging for their rubbish to be put out by a neighbour
- coordinating 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

Lasting power of attorney

Lasting power of attorney (LPA) is a legal process where a person appoints one or more trusted people – known as the ‘attorney’ – to make decisions on their behalf, in their best interests, if they lack the mental capacity to do so themselves.

Many people with dementia will eventually lose capacity, so it is



important that the person you care for makes an LPA as soon as possible. They should do this even if you are their next of kin, as this does not guarantee that you will be able to make decisions on their behalf.

There are two types of LPA:

- A property and financial affairs LPA authorises the attorney to look after matters such as managing the person's bank accounts, savings accounts, pensions and investments; paying bills; and buying or selling property
- A health and welfare LPA enables the attorney to make decisions about the person's medical treatment, health and social care

Please see Sources of support on p14 for details of our information on LPA.

Collecting information about the person with dementia

It is helpful to keep all the information you have about the person with dementia in one place, such as a ring binder, a box file or a file

on your computer. This will help you find the details 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?

- 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, what?
- How does this affect them?
- Do they have any sight or hearing difficulties?
- Do they wear glasses or hearing aids?

Medication and health records

- What medications do they take (if any) and what are the doses?
- Who is their GP?
- Which other health or social care professionals are involved in their care?
- Have they had any falls or hospital admissions? 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, are they provided by the local authority or an agency?
- What are their contact details?
- When do they usually visit?

Do they require help with personal care? For example:

- washing
- dressing
- preparing meals, eating and drinking
- taking medicines
- attending appointments

Does the person need help with general housework, laundry, shopping, etc?

Do they rely on independent living equipment? For example:

- walking stick
- walking frame
- bath seat
- personal fall alarm

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 be called on for help? If so, note their contact details.

Do they have any help from volunteers/charities?

What is their daily/weekly routine?

- Do they go to a day centre, support or activity group, place of worship? If so, record their contact details and the day/time they go
- How do they get to activities outside the home? Do they walk/drive themselves, or use public transport, a taxi, a friend, or volunteer transport?
- Do they need help attending appointments such as the hairdresser or chiropodist? If they find it difficult to attend these appointments, find out if they could be visited at home

Does the person drive? If so:

- Have they informed the DVLA (DVA in Northern Ireland) and insurance company of their dementia diagnosis? This is a legal requirement
- Keep a record of their driving licence number, car registration number, insurance and breakdown policies
- Are they eligible for a Blue Badge so that they, or the people who give them lifts, can use disabled parking? Please see Sources of support on p14 for more information

Caring from a distance – when the person lives at home

If possible, visit the person's home to ensure that it is as safe, secure and comfortable as possible. If you cannot visit, ask a more local family member or friend to take a look.

You could make the following checks:

- Look for trip hazards such as loose carpets or rugs, trailing wires and excess clutter



- 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 carers/ emergency services need to access the home
- Consider if modifications such as ramps, a stairlift or grab rails might be useful. Social services can carry out a needs assessment to identify equipment that might help (please see p15)
- Check that the person is managing to look after their home. Is the washing up being done and bins emptied? Are worktops, floors and bathrooms clean?
- Check for problems like damp, leaks and breakages
- Contact the person's local fire service to request a home fire safety check (do not call 999 for this)
- Think about assistive technology that could help the person in their day-to-day life, such as dementia clocks, electronic pill organisers, picture phones, a memo board and voice reminders on a smart device like Alexa: please see p14 for more information

- A personal fall alarm that connects directly to you or to a care line could offer reassurance and ensure that help is arranged quickly
- Ask if a trusted neighbour would be willing to let you know if they have any concerns, and help out in an emergency if you cannot get to the person quickly
- Make sure the person has a list of important numbers – including details of who they can call for help – saved in or kept near their phone

If you are concerned about the person's safety if they leave home alone, you could think about using a form of tracking so the person can be located if they go out, such as a phone app, smartwatch or tag attached to their handbag, purse or wallet.

You could also sign up for:

- 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
- 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 of these.

There may come a time when the person needs professional support to keep living at home, or can no longer live in their own home, even with support. Please see Sources of support on p14 for our leaflets on finding care at home, choosing a care home, and living alone with dementia.



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

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

Find out about the care setting's routine, such as mealtimes, bedtime, medication rounds and activities, so that you can contact the person at the most suitable time.

Ask to be kept informed about activities they have taken part in (eg an outing, music activity or gardening) so that you can talk to them about it. You could also tell the care home about activities that the person might enjoy, such as pet therapy or visits from local nurseries or school choirs, and help to arrange these.

Find out the best way to contact the person – do they have their own phone, or should you phone a member of staff? Many care homes will also support the person to make or receive video calls. If you write them letters, find out if someone can help read them if necessary.

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 LPA and check the procedure regarding consent to share information with you. What records do they keep, and will they contact you if there is an incident like a fall?

If other family members or friends live nearby, ask them to contact you after visiting to give you an update.

Keeping essential records

To ensure you can help quickly if another family member or carer has questions about the person with dementia, or in an unplanned or emergency situation, write down useful contact details and keep them in a safe place, as well as saving them in the person's phone or leaving a list near their home phone. For example:

- GP surgery
- dentist
- optician
- chiropodist
- carer/care agency
- social worker
- mental health team
- other relatives and friends
- neighbours
- utility providers
- solicitor
- employer, if the person is in paid/voluntary employment
- school/college/university of any dependent children

Ask the person with dementia – if appropriate – where they keep important documents such as their LPA and Will. If you are named on the person's LPA, keep a notarised copy yourself.

It is also a good idea to find out how to access their bank/building society/investment accounts, insurance policies and utility accounts, including mobile phone and broadband. Ask the person if they are willing to share these details with you, including login details and passwords, and if so, keep them in a safe place.

Consider asking the person's GP to name you as their 'proxy', which allows the GP to discuss their care and treatment with you. You may also be able to manage their appointments and repeat prescriptions online. Ask the Practice Manager how to arrange this – the person with dementia must agree.

Find out whether the person has made an advance statement, advance care plan (ACP), advance decision to refuse treatment (ADRT) or do not attempt CPR (DNACPR) instruction. These are statements of their wishes and decisions regarding future medical treatment and care – and ADRTs and DNACPRs are legally binding if drawn up correctly. If so, keep a copy of these documents. For more information, please see Sources of support on p14-15.

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

Whenever you visit the person with dementia, reassess their circumstances. Ask the person themselves, as well as their local family, friends or health and social care professionals, if they have any concerns about their health, living arrangements or ability to cope.

- 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 signs that they are 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
- Are they missing appointments, regular activities, etc?
- Are they managing matters like paying bills and renewing insurance policies on time?

Staying connected to the person with dementia

Caring from afar often involves coordinating lots of tasks and jobs. But it is 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 – whether for a call or visit – may give the person with dementia something to look forward to and reduce feelings of loneliness and anxiety. You could write this on their calendar or set an alert on their phone or a smart device.

Try to notice the positive things, and enjoy the time you do spend together. You could also send photos, cards, postcards or small gifts to show the person you are thinking of them.

Supporting family carers who live nearby

If the person with dementia has other family carers or friends living nearby who help with their care, these people may need support themselves. You could, for example:

- provide emotional support, by phone, video call, email or letter
- 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

- arrange to visit the person yourself if possible – whether for a day or a short stay – to give their usual family carers some time off
- set up a WhatsApp group where you can share information about the person and support each other

Caring for yourself

Looking after yourself is important when you are 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 not knowing what is happening in the life of the person with dementia, or feel guilty about not being nearby. You might have concerns about your finances if you are paying – fully or in part – for the person's care.

Take some time to think about the practicalities of the support you can offer, for example, the travel time involved and expenses incurred. If you work, consider talking to your employer so they can support you, for example by allowing flexible working so you can visit the person with dementia.

If you are feeling overwhelmed, talk to your GP about any support available, including details of carers' groups, or request a carer's assessment to discuss what would help you in your caring role. You could also speak to a dementia specialist Admiral Nurse for support and advice: please see Sources of support on p13.

Above all, be realistic about the support you can offer, and do not be afraid to talk to other family members and friends and ask for help – 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 Helpline on **0800 888 6678** (Monday to Friday 9am-9pm, Saturday and Sunday 9am-5pm) or email [▶ helpline@dementiauk.org](mailto:helpline@dementiauk.org)

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

Dementia UK resources

Advance care planning

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

Blue Badge parking

[▶ dementiauk.org/blue-badge-parking](https://dementiauk.org/blue-badge-parking)

The carer's assessment

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

Considering a care home

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

Finding help and support at home

[▶ dementiauk.org/finding-help-and-support-at-home](https://dementiauk.org/finding-help-and-support-at-home)

GP online services

[▶ dementiauk.org/gp-online-services](https://dementiauk.org/gp-online-services)

Lasting power of attorney

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

Living aids and assistive technology

- dementiauk.org/living-aids-and-assistive-technology

Living alone with dementia

- dementiauk.org/living-alone-with-dementia

Making the home safe and comfortable for a person with dementia

- dementiauk.org/making-the-home-safe-and-comfortable

A stay in hospital

- dementiauk.org/changes-in-care-a-stay-in-hospital

Other useful resources

Advance decisions to refuse treatment/do not attempt CPR (DNACPR)

- nhs.uk/conditions/end-of-life-care/planning-ahead/advance-decision-to-refuse-treatment/

Find your local social services

- nhs.uk/service-search/other-health-services/local-authority-adult-social-care

The Herbert Protocol

- safeguardinghub.co.uk/dementia-the-herbert-protocol/

Lions Club Message in a Bottle scheme

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

The needs assessment

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

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

Contact our Helpline:
0800 888 6678 or helpline@dementiauk.org

Book a virtual appointment:
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**
- Scan the QR code

Thank you.



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