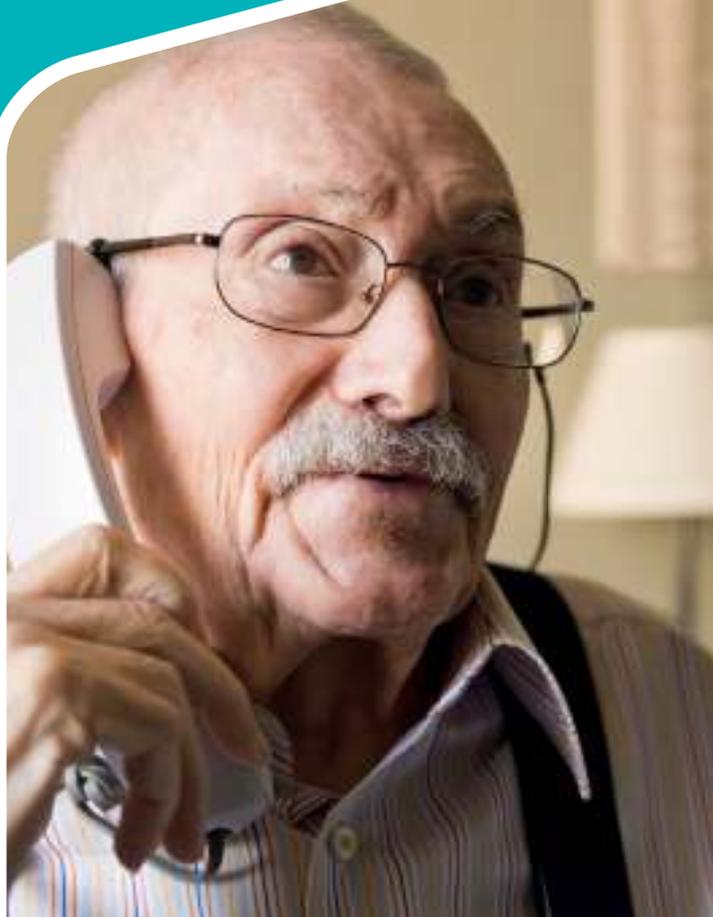




DementiaUK

Helping families face dementia

**Caring for
someone with
dementia from a
distance, during
the coronavirus
outbreak**



Looking after someone with dementia can be challenging especially in these uncertain times. At Dementia UK, we know how challenging it can be, which is why we provide dementia specialist Admiral Nurses, who give families the compassionate one-to-one support, expert guidance and practical solutions that help them face dementia with more confidence.

This leaflet has been written by Admiral Nurses, to offer guidance to those caring for someone from a distance as well as for those who are unable to visit due to COVID-19. Looking after someone from a distance has its own challenges, as you cannot pop in regularly, and it is harder to respond to issues quickly.

What is caring from a distance?

Caring from a distance is when you support and help someone from afar. It could be a mile away, ten miles, the next county or another country. Alternatively, you may have been visiting someone but no longer can due to COVID-19.

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

If you are supporting a person with dementia, this could include:

- speaking to them on the phone, to offer companionship, support and reassurance
- paying their bills
- handling their utilities accounts
- 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

Lasting Power of Attorney

If you are the registered Lasting Power of Attorney (LPA) for Property and Affairs and authorised to act on their behalf, then you may need to manage their bank and savings accounts, investments, pay bills or make decisions about their living arrangements.

If you are the registered Lasting Power of Attorney (LPA) for Health and Welfare, and they have been found to no longer have capacity to make decisions, then you may need to make decisions on their behalf about their health and medical treatment or day to day care (see

Sources of support at the end of this leaflet for the Dementia UK leaflets on LPA and Capacity).

If you are supporting someone from a distance, who themselves is caring for someone with dementia, you might be:

- providing emotional support, by phone, email, letters or maybe video calls
- helping them to arrange support for the person with dementia, such as befriending services, day centres or residential respite care



Keeping information about the person with dementia

It can be helpful to assemble all of the information you have about the person with dementia, and useful contact details, in one place, such as an A4 ring binder or box file. This will help you if there is a sudden change in circumstances, such as the onset of illness – and will also help you anticipate where future challenges might arise.

You could consider:

- What do you know about the progress of their dementia? For instance, what diagnosis do they have? When did they get the diagnosis? Has there been a gradual or sudden deterioration?
- What other illness do they have and how does it affect them? What medicines do they take? It's very helpful to have a list of current medications and dosage
- Who is their GP? What other clinical or social professionals are involved in their care?
- Have they previously had a fall or hospital admission? When? What happened?
- What help do they require with personal care, such as getting dressed, preparing meals, taking medicines, attending appointments or generally getting about?
- Is help needed with general housework, laundry, shopping and paying the bills?
- Can they use the phone to call for help or just have a chat?
- What activities do they enjoy, and do they need help to attend them?

Having a clear idea of what help is needed – and wanted – will help you prepare a plan together.

Caring from a distance – when the person lives at home

If possible, visit the person's home, to see that it is as safe, secure and comfortable as it can be for them.

Here are some things to consider:

- Are there trip hazards such as loose carpets or rugs? Clutter that could be moved? Excess furniture?
- Check that smoke alarms work and have working batteries
- Check the window and door locks work. Is there a person locally who could keep a spare key?
- Consider installing a key safe with a code, so that emergency access can be gained
- Would modifications such as ramps, or grab rails be useful?
- Could assistive technology help the person in their day-to-day life? You could consider dementia friendly clocks, electronic pill boxes, picture phones, pendant alarms, sensors that monitor for falls etc.

Please see Sources of support for our leaflet on Making the home safe and comfortable for a person with dementia, as well as resources on assistive technology.

There may come a time when the person is not able to continue living in their home anymore. Please see Sources of support for our leaflets on finding care at home, or on choosing a care home.



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

There are still ways that you can support a person with dementia when they are living in other places such as a care home, hospital or hospice. Some ways include:

Finding out the routine and hours of the care setting, such as mealtimes, bedtime, activities, so that you can contact the person at the most suitable time.

Ask if you can know what they have taken part in (e.g. a creative writing group or choir), so that you can talk to them about it.

Find out how best to contact them: by direct phone? By calling a

member of staff? If you are writing them letters – is there someone who can help read them to them if necessary? Many care homes will support you to make video calls, so you can see each other. Ask them about this.

Talk to the staff about how you can feedback to them about care or discuss the medical or support plan. Is there a particular time when the health and social care team visit and review care?

It is also useful to check what the arrangements are for consent to share information with you.

Being organised

Consider what other useful contact and telephone numbers you might need and keep these in the same place, for instance: their doctor or nurse, other relatives, neighbours, their solicitor etc. Ask the person with dementia – if appropriate – where they keep important documents, such as their financial documents, bank statements; and legal documents, including LPA documents, and their Will.

If you are the person's named attorney, for either their health or finances, it is advisable to have a notarised copy of these documents yourself.

Consider whether it is appropriate for you to be a proxy for the person, in their day-to-day health and social care needs. Signing a proxy agreement with the person's GP means that they can discuss the person's care and treatment with you. The person's GP surgery will be able to advise you about this. You may also be able to manage the person's appointments and repeat prescriptions online (please see Sources of support for Dementia

UK and the Royal College of GPs' leaflet on Online GP Services – an internet portal giving you access to this information).

Find out whether the person with dementia has made any Advance Statements, Advance Care Plans or Advance Decisions to Refuse Treatment. These are statement of their wishes and decisions regarding future medical treatment and care. If so, keep a record of where these statements, with all of your other information.

You could suggest to the person, or help them to use the Lions Club 'Message in a bottle' scheme – a bottle which sits in their fridge, containing their basic personal information and medical notes (see Sources of support).

Consider signing the person up for the Herbert Protocol, a national scheme linking the Police with social services and other local services, to share useful information about the person, in case they go missing.

Things to consider when you visit, or to discuss with those who do

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

Each time you visit, reassess the situation. Check in with the person living with dementia, as well as their other family, friends or clinical professionals to keep updated 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 are taking less care of themselves, or where they live, than before? This could include increasing untidiness, in their physical appearance, or in their home; out of date food in the fridge; rubbish building up etc.





Staying connected to the person with dementia

Caring from a distance might feel like it involves a lot of coordination of tasks and jobs. It may well do! However, connecting with each other, no matter the distance, can be enjoyable and helpful for all of you.

Regular contact times may give the person living with dementia something to look forward to.

Some people say that having a set time to receive a phone call helps to reduce feelings of isolation and anxiety. Try to notice the positive things, and enjoy the time you do spend together, whether it is on the phone or by letter.

Caring for yourself

Taking care of yourself is important. Caring from a distance can mean juggling many things; maybe you are working or have a family of your own. Perhaps you are worried or feel guilty about what you can or can't do. You may feel overwhelmed, poorly equipped or on your own. However, you are not alone. There is a lot of information and advice to help guide and support you.

It can be helpful for your own planning to think about the practicalities of the support you offer, for example, the travel time involved, and expenses incurred. You could consider talking with your family and employer about what it means to be a carer from a distance, to see whether there is anything they can do to support you. Be realistic about what you can provide, and don't be afraid to ask for help from other people.

If you have any other questions or concerns about dementia or caring for someone from a distance, you can call the dementia specialist Admiral Nurses on our Helpline, free of charge, on 0800 888 6678 or helpline@dementiauk.org

The Helpline is open Monday to Friday, 9am-9pm and on the weekends, 9am-5pm.

Sources of support

Dementia UK leaflet on A safe and comfortable home for a person with dementia

Dementia UK leaflet on Finding care at home

Dementia UK leaflet on Choosing a care home

Dementia UK leaflet on Lasting Power of Attorney

Dementia UK resource on Advance Care Planning

Other useful organisations

The Lion's Club Message in a Bottle scheme

<https://lionsclubs.co/MemberArea/message-in-a-bottle/>

Live Better with Dementia – assistive technology

<https://dementia.livebetterwith.com/>

The Metropolitan Police – the Herbert Protocol

www.met.police.uk/herbertprotocol

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 www.dementiauk.org/donate or call **0300 365 5500**.

Publication date: Feb 2020
Review date: Feb 2022
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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.



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Saturday and Sunday, 9am – 5pm

www.dementiauk.org • info@dementiauk.org