



## Supporting you to make decisions while caring for someone living with dementia during Coronavirus (COVID19) and beyond

Name of person completing this document:

Relationship to the person living with dementia:

Name of person living with dementia:

Use this section to keep important phone numbers for example, care home, GP, pharmacy, district nurse, home care agency

Name	Name of key contact	Number



Economic and Social Research Council

NIHR | School for Primary Care Research



DementiaUK  
Helping families face dementia



Care and support through terminal illness

# SUMMARY

## WHAT IS THE DECISION AID?

- Your friend/relative may become unwell with coronavirus and you might need to make decisions quite quickly about their care.
- This decision aid is a guide to support you when making decisions. It covers some of the common challenges and decisions you may face. It also gives you information about your options and how to make a decision.

## WHO IS IT FOR?

- This decision aid is for you as a family member or friend caring for someone living with dementia who may not have the capacity or ability to make their own decisions.

## WHAT DECISIONS MIGHT YOU NEED TO MAKE?

- How to manage care at home
- How to support your friend/relative in a care home
- What to do if they became more ill
- Should they go to hospital?
- How to keep in touch if you can't visit

## WHAT DOES IT INCLUDE?

- Information on the common signs and symptoms of Coronavirus
- Important points about the legal aspects of decision making
- Information on what support is available at home or in the community
- Benefits and disadvantages of going into hospital
- Learning points about care homes during coronavirus
- Opportunity to consider the wishes and preferences – what is important to you? What is important to the person with dementia
- Key tips on how to look after yourself as a carer

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# Introduction

What is a decision aid?

A decision aid is a guide to support you when making decisions. It covers some of the common challenges and decisions you may face. It also gives you information about your options and how to make a decision. This includes seeking advice from health and social care professionals and other carers, like yourself.

Who is this decision aid for?

This decision aid is for you as a family member or friend caring for someone living with dementia who may not have the capacity or ability to make their own decisions. They may live with you at home, in their own home or in a care home. We have developed this decision aid to help you if you need to make decisions when the person you are caring for has or is suspected to have coronavirus (COVID19). You may need to revisit some decisions as things change and perhaps revise them. We hope it will be relevant to other times too, beyond coronavirus.

You may find thinking about these decisions upsetting: if so, please speak to other members of your family, friends, your GP and other professionals and ask them to support you.

# Coronavirus and beyond

How might coronavirus and government advice affect you and your family member/friend living with dementia?

- Your friend/relative may become unwell with coronavirus and you might need to make decisions quite quickly about their care.
- You may not be able to get the same support services because of changes to the availability of health and social care.
- Your friend/relative may not live with you and you may not be able to see them in person due to restrictions on travel and visiting.
- You may not be able to care for them – either because you become ill yourself, because you might be at increased risk or other consequences.

What decisions might you need to make?

You may need to make some decisions if your friend/relative becomes unwell with coronavirus such as:

- How could they be cared for at home?
- How could I support them in a care home?
- What should I do if they became more ill?
- Should they go to hospital?
- How would I keep in touch with them if I could not visit them?

What are some of the common symptoms of coronavirus?

The common symptoms of coronavirus include high fever, a new and continuous cough and loss of smell or taste. But some older people do not have these symptoms, instead they may have some of the following symptoms which may be mild and difficult to identify:

- Fatigue
- Delirium (sudden or worsening confusion)
- Dizziness
- Diarrhea
- Loss of appetite
- Feeling weak
- Vomiting/nausea
- Rash
- Falls
- Headache
- Stuffy or runny nose
- Conjunctivitis
- Abdominal pain
- Coughing blood

# Thinking about any existing Advance Care Plans

Your friend/relative may already have a care plan. A care plan details their needs and the care they wish to receive to meet these needs. They may have also made an Advance Care Plan, sometimes called an Anticipatory Care Plan. This is a record of care the individual would like to receive in the future.

**Does your relative have an Advance Care Plan?**

Yes  No

If yes, consider this plan or discussions you may have had with them about their care wishes.

Use this box to write down the important information to remember when making decisions about care and treatment (for example, going to hospital, treatment for infection, oxygen treatment, and ventilation).

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**If they do not have an Advance Care Plan, you can consider their wishes and preferences for future care on the next page.**

## Cardiopulmonary resuscitation (CPR)

Cardiopulmonary resuscitation (CPR) is a way to help restart a person's heart and breathing if they stop. Some people would like to have this treatment. Others would prefer not to. It is possible to make a decision about this in advance with the health care team and consider if this is suitable for them. If a decision has been made to not to give CPR, this will be recorded in a Do Not Attempt Cardio-pulmonary Resuscitation (DNACPR) form.

**Does your relative have a DNACPR form or order?**

Yes  No

**If your relative does not have a DNACPR, you can consider their wishes and preferences on the next page.**

**For more information:** The Marie Curie website has information explaining resuscitation and DNACPR during coronavirus: <https://www.mariecurie.org.uk/cpr-during-coronavirus>

**Speak to their health care team and ask:**

- **When is it suitable?**
- **Will it work?**
- **What does it involve?**
- **What are the risks and benefits?**

# Wishes and preferences

This section is to help you consider your own wishes and preferences and the person with dementia's wishes and preferences about their care and treatment if they have suspected or confirmed to have coronavirus. This is important if they do not already have an advance care plan.

## What is important to the person living with dementia?

For example, staying in their own home or a particular care home, being pain free and comfortable, having family and loved ones around, having their cultural/religious needs met, seeing and talking to their pet

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## How might coronavirus affect their wishes and preferences?

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## What is important to you?

*For example:*

My friend/relative is able to stay where they feel familiar/comfortable

Being able to be with them if they are seriously unwell or at the end of life

Knowing they are getting the care they need

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# Legal aspects of decision making

This section is to help you consider some of the legal aspects of making decisions on behalf of the person you are caring for when they lack capacity.

## Mental Capacity Act

Under the Mental Capacity Act 2005 (England and Wales)<sup>1</sup>, when a person is unable to make decisions for themselves, decisions may need to be made about their care and treatment in **their best interests**.

## Lasting Power of Attorney (LPA) for health and welfare<sup>2</sup>

The person (or people) appointed under an LPA for health and welfare can make decisions about the person's health and personal welfare. An LPA is made while the person living with dementia has the mental capacity to do so. The person appointed under the LPA can make decisions about medical treatment, where the person is cared for, and the type of care they receive.

**Is there a Lasting Power of Attorney in place for your family member or friend?**

Yes	No
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If you have not been given LPA for health and welfare you can still be involved in making decisions with the health and care team. Professionals will work with you to ensure decisions are made in line with the wishes and best interests of the person living with dementia but **the decision is the health and care team's responsibility**.

Decisions may include deciding on the appropriate level of medical care for the individual, while ensuring that the person is comfortable and pain free. It may involve stopping tests or certain treatments (for example, ventilation) and whether they go to hospital. It may also involve putting 'do not attempt cardiopulmonary resuscitation orders' (DNACPR/DNAR) in place. If a DNACPR order is in place, other treatments like oxygen and antibiotics can still be given. While it is the duty of the professionals involved in the person's care to make these decisions, they will work with you to make these decisions. You should not feel responsible for making these types of decisions.

<sup>1</sup> these differ for Scotland and Northern Ireland, check local legislation

<sup>2</sup> this is different to Lasting Power of Attorney for property and financial affairs and processes differ in Scotland and Northern Ireland



# Managing care at home

If the person you are caring for lives with you and begins to show symptoms of coronavirus, you may need to make decisions about their care. These may include which services to access for support during this time. But, if their symptoms become worse, you may need to consider if they need to be admitted to hospital (see pages 12-13). Below are some decisions or challenges you may face:

**TIP:**  
Speak to other carers or contact the listed organisations on page 17 for support

**Tick the decisions you need to make or challenges you face at the moment. You can add more as needed.**

Is it safe to allow people from NHS and care services (and other visitors) to come into our home?	
What do I do if my relative becomes more unwell?	
Should I call 111 or 999 if I am concerned?	
Their breathing is becoming worse, what can I do at home?	
Other:	

## What support and services are available for me at home?

- Speak with your GP or community nursing team about what support and services may be available to your relative or friend at home
- Community nurses may help with a range of services, such as administering medication or provide advice about this
- Palliative or end of life care is available in the community – ask your GP
- Arrange for medication and other supplies (such as incontinence pads) to be delivered to you at home (most delivery companies offer no-contact delivery) and arrange repeat prescriptions with your GP
- Volunteer services can help deliver medication – contact your GP, pharmacist, or NHS Volunteers
- Food deliveries are available – you may be able to find out about these through your local authority or council or arrange directly with supermarkets or local shops

## Learning points for care at home

- Care at home is possible even if a person living with dementia has coronavirus
- Do not be afraid to ask for help, it's ok to call 111 or 999
- Speak with your GP and community nursing team to get more help and support
- GPs or community nurses may not visit, but you can arrange a virtual or phone consultation
- If your GP feels you need a home visit, they may be able to arrange this through a local dedicated coronavirus service (if available in your area). If a doctor or other professional visits you, they will wear full Personal Protective Equipment (PPE)
- Consider which services are important and which are not essential at the moment
- If you have care workers coming to help, speak with the home care agency about their guidelines and what they can offer
- Consider if you or anyone in your household can provide support at home
- Make sure you have the benefits you are entitled to – see page 17 for details of groups that can help or contact your local Citizens Advice

# Supporting someone in a care home

If you are supporting/caring for someone who lives in a care home, and is suspected to have coronavirus, you may need to make decisions about their care.

**Tick the decisions you need to make or challenges you face at the moment.**

**You can add more as needed.**

Who do I contact if I am worried about their wellbeing (for example, if you think their symptoms are becoming worse)?	
Not knowing whether to visit or not – even outside their window or in a room that has a screen separating residents from visitors	
Being able to stay in touch by other means e.g. video call	
Communicating with care home staff	
How do I support/care for my relative if they are isolated in their room?	
Other:	

## Learning points

Below are some ideas that might help you in your decision. Use the additional space to record other tips and advice you have picked up either from speaking to family, friends and other carers, professionals, leaflets, online forums, or when speaking with support organisations (see page 17).

- Contact the care home by telephone during quiet periods (check the best time with the care home)
- Contact the GP in charge of your relative's/friend's care if you are worried about their wellbeing or symptoms
- Use video technology to talk to your relative/friend (such as a smart phone or a computer), ask a family member or neighbour to show you how to do this if unsure
- You may be able to visit your relative/friend by remaining outside and seeing them through a window
- You may be able to visit your relative/friend inside if you have a negative test result
- Send your relative/friend photographs (write on the back who is in the photo) and ask care home staff to show these and talk about what's in the photo
- Send your relative/friend parcels or other items that might be meaningful or pleasant for them, for example, hand cream, sweets

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# Should they go to hospital if they are very unwell?

Consider what support can be made available at home or in the care home. But if your relative/ friend develops severe symptoms they may need to go into hospital.

Remember to **speak with the GP, care home or district nursing team** about what additional support could be provided at home or in the care home. Use the information in the boxes below when talking to these professionals and making decisions about hospital.

## Why might your relative/friend need to go to hospital

- They may have severe symptoms of suspected coronavirus
- They are very breathless and might need oxygen\*
- They become unwell suddenly and unexpectedly without a clear cause

**TIP**  
Think  
back to the  
advance care  
plan on  
page 6

## Benefits and disadvantages of a hospital admission

It is important to consider the benefits and disadvantages of going into hospital

### Disadvantages of a hospital admission for suspected coronavirus

- You may not be able to visit them
- They may be anxious and confused in an unfamiliar environment
- They may struggle communicating with unfamiliar people who are wearing Personal Protective Equipment (PPE), such as face masks
- They may lose some of their abilities, for example, finding the toilet and may struggle to walk as their movements may be restricted in hospital
- They may become much sicker
- They may develop other infections while in hospital
- The staff will be unfamiliar to your relative/friend, and will not know them (or their preferences for care) well
- They may get less dedicated attention from hospital staff
- Hospital treatments can be invasive and distressing. For example, repeated blood tests and regular monitoring through the day and night

\* Breathlessness may be managed at home with appropriate medication, check with the GP or district nursing team.

## Benefits of a hospital admission for suspected coronavirus

- Treatments such as oxygen, drips and antibiotic treatments are more easily available should your relative/friend need these
- Tests such as xrays and scans can help diagnose what is wrong (although these can also be provided at an outpatient appointment)
- Some tests and treatments may be available that are not available at home
- There will be nurses and other staff on-hand round the clock
- There will be doctors on-hand on site should your relative's/friend's condition change or if they become very unwell

Do you think you have enough information about these options to help decide on your preference?

Yes

No

If yes, what is your preference about hospital admission?

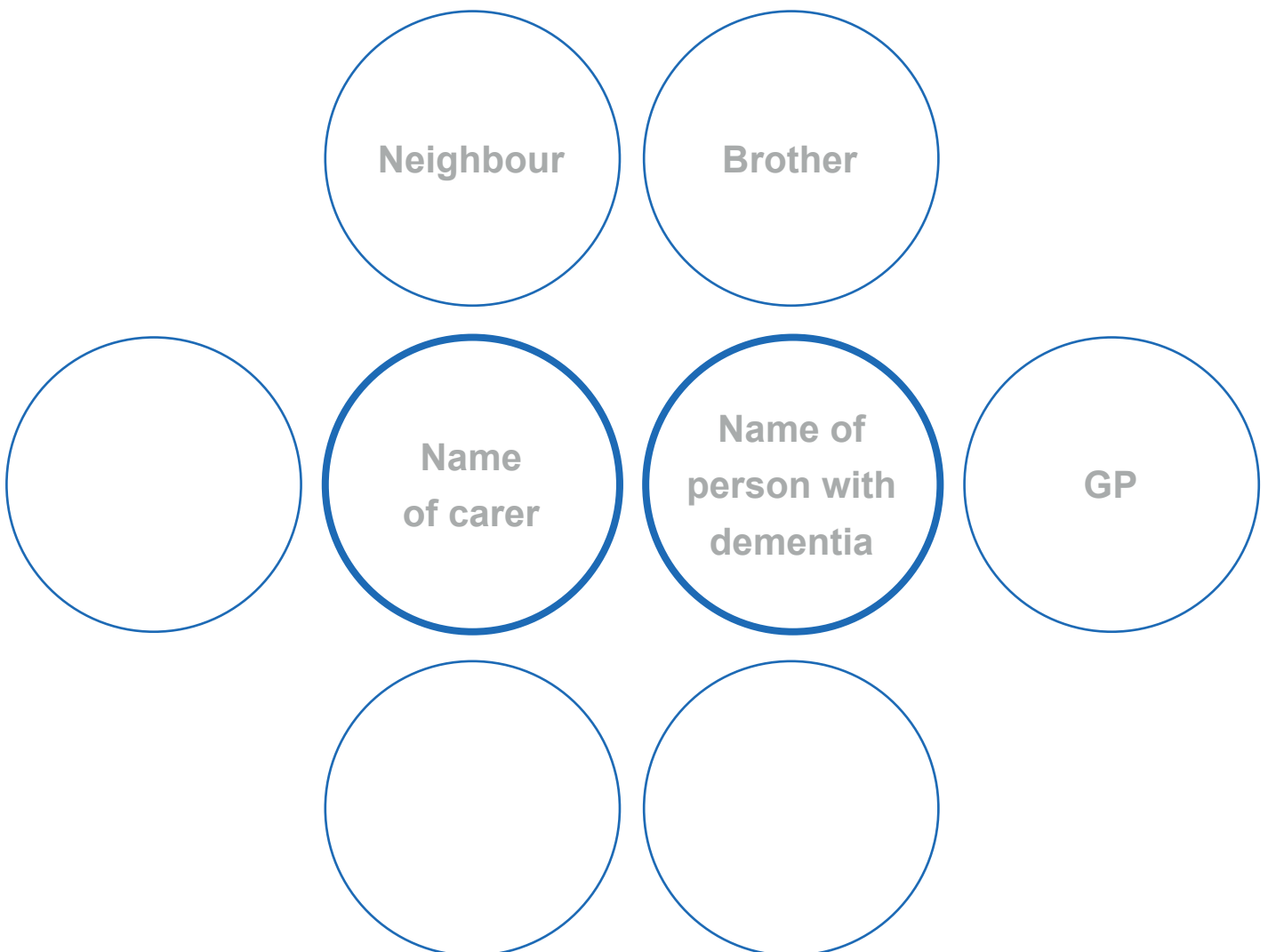
**TIP**  
Refer to the advance care plan on page 6

If no, further services are listed on page 17 for more information.

# Who is supporting you?

You may feel this is your responsibility alone to do this but we all need support from people to maintain our physical and mental wellbeing. If you are caring for someone you may benefit from extra practical, emotional and moral support from others. Draw your support network below by writing the names of people who support you in the circles. For example, spouse or partner, daughter, son, sister, GP, home care worker, neighbour, friend, social worker, religious leader or volunteers.

Place yourself and the person with dementia in the centre two circles. Not everyone in your network will provide direct care, but they may support you in other ways. Add and delete circles as needed.



***If you can fill no or few circles, speak with your GP about how to access more support. Contact details for services are on page 17.***

# Looking after yourself during coronavirus and beyond

Most people caring for someone with dementia experience feelings of grief and loss as well as positive feelings of love and tenderness. You may sometimes feel that your relative or friend is no longer the same person, or no longer someone you can discuss problems or share memories with.

Dementia may have impacted on your work, other care commitments, or your ability to get a break. Activities that have previously brought enjoyment may no longer be possible but there may be alternatives. During lockdown you may have faced new obstacles such as not being able to see friends and family or visit your friend or relative with dementia. You may struggle to get them to shield and follow social distancing rules. Making decisions on behalf of the person you care for can also be very difficult and feel like a big responsibility; this is normal.

## Taking care of yourself

- Remember that it is normal and common to grieve and feel sad while caring for someone with dementia.
- Find someone you feel comfortable talking with about how you are feeling. It may be family, friends, health and care professionals, or other carers. Look for a local support group, dementia café (may open soon) or 'Talking Point' on the Alzheimer's Society website. Some telephone support services and support groups run via video conferencing. See page 17 for contact details.
- Zoom worship services may be available. In place of this some may find personal prayer has heightened importance for you at this time.
- If you struggle to find the right person to talk to, it may be helpful to keep a diary. It can be a way of letting out frustration and anger and reflecting on positives.
- Try to make some time for exercise like walking, dancing or yoga.
- Try relaxation strategies or listen to your favourite music.
- Try to maintain a regular sleep pattern if you can.
- Be kind to yourself. The pandemic is not an ordinary situation and many people are feeling stressed, overwhelmed, and uncertain about the future.
- Allow yourself the time to grieve your losses.

# Your questions and support

**What do you need to know more about? What will you do next?**

- Make a list of questions and speak with someone you trust
- Speak with other people caring for someone with dementia (for example, carer support groups, telephone support, online communities)
- Contact the support services available to you listed on page 17

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## Further support and contact details

You may have found it difficult to complete some or all of the sections of this decision aid. Here are contact details for further information and support for yourself and the person you provide care for. Some of these organisations may have local branches. Check their websites for more information.

### **Alzheimer's Society**

0333 150 3456

[www.alzheimers.org.uk](http://www.alzheimers.org.uk)

### **Admiral Nurse Dementia Helpline (Dementia UK)**

0800 888 6678

[www.dementiauk.org](http://www.dementiauk.org)

### **Wales Dementia Helpline**

0808 808 22 35

[www.dementiahelpline.org.uk](http://www.dementiahelpline.org.uk)

### **Carers Trust**

0300 772 9600

[www.carers.org](http://www.carers.org)

### **Alzheimer Scotland**

0808 808 3000

[www.alzscot.org](http://www.alzscot.org)

### **Carers UK**

0808 808 7777

[www.carersuk.org](http://www.carersuk.org)

### **Marie Curie**

0800 090 2309

[www.mariecurie.org.uk](http://www.mariecurie.org.uk)

### **Independent Age**

020 7605 4200

[www.independentage.org](http://www.independentage.org)

### **Young Dementia UK**

[www.youngdementiauk.org](http://www.youngdementiauk.org)

### **Age UK**

0800 055 6112

[www.ageuk.org.uk](http://www.ageuk.org.uk)

### **Rare Dementia Support**

07388 220355 or 07341 776317

[www.raredementiasupport.org](http://www.raredementiasupport.org)

### **The Silver Line**

0800 470 8090

[www.thesilverline.org.uk](http://www.thesilverline.org.uk)

# Who has developed this decision aid?

We are an experienced team of researchers and health and social care professionals including GPs and Psychiatrists from University College London and King's College London, and a group of people living with dementia and family carers. We have used the latest evidence from research and clinical practice, together with the views and experiences of people with dementia and family carers. We have received expert input and this document has been reviewed by GPs, palliative medicine doctors, nurses, geriatricians, psychiatrists, and social care professionals. This project has been supported by Marie Curie, Alzheimer's Society, Dementia UK, and Royal College of Nursing who have all contributed to the development and reviewed this document.

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