



Planning ahead

Living with
dementia series





Contents

1	Planning ahead	3
2	Powers of attorney	4
3	Trusts	8
4	Advance decision to refuse treatment	10
5	Advance statement	12
6	Future and end-of-life care planning	14
7	Wills	16
8	Funeral planning	18
9	Organ donation	19
	Checklist	21
	Other useful organisations	24
	Appendix – Template advance statement	27

1



2

Planning ahead

1

If you have been diagnosed with dementia this booklet is for you. It will help you plan ahead and think about what may happen in the future.

It's important to plan ahead because dementia is a progressive condition. This means there may come a time when you find it hard to make decisions for yourself. Planning ahead can also help your family and friends, especially if you become ill or less able to communicate. If they know what you want to happen in the future, they can support your wishes.

This booklet explains some ways you can plan ahead. It can help to think about these as soon as you feel able to. However there may be some things you find difficult to think and talk about. If so you can wait to read some sections of this booklet later on, when you are ready.

The booklet explains some legal documents you can make. You need to have the ability (the 'mental capacity') to decide for yourself to make a legal document. You can make changes to the documents in the future as long as you have the mental capacity to do that at the time. You could also organise any paperwork you have about your finances and personal affairs. This will help you access it and will be helpful for anyone who looks after your affairs in the future.

There is also a template advance statement at the back of this booklet. You can use it to record your wishes for your care in the future. You can also download it at alzheimers.org.uk/publications-list



For more help and advice call our Dementia
Connect support line on **0333 150 3456**

Powers of attorney

2

There may come a time when you need someone to make decisions for you. If you live in England or Wales a Lasting power of attorney (LPA) is a legal document that allows you to appoint someone to do this. You can choose who you appoint to act for you (the 'attorney') and you can decide what decisions they can make for you. You can choose to appoint more than one attorney. Creating an LPA can help you and those close to you in the future. The attorney has to do what is best for you and they must always think about your wishes and needs.

There are two types of LPA, depending on the decisions you want the attorney to make. The first covers decisions about property and financial affairs – for example paying bills, managing bank accounts and selling property. The second covers decisions about health and welfare – for example day-to-day care and medical treatment, including life-sustaining treatment if you specify that.

A property and affairs LPA can work in two different ways, depending on which option you choose. One option is to allow the attorney to only make decisions when you can't make them yourself. The other option is to allow the attorney to make decisions (with your consent) as soon as the LPA is registered. This can be a way to give yourself extra support. You can choose which option you want on the LPA form.



A health and welfare LPA will only allow the attorney to make decisions when you can't make those decisions for yourself.



For more information on LPAs see factsheet 472, Lasting power of attorney.

If you don't have access to the internet or you don't feel able to complete the LPA forms on a computer, Alzheimer's Society offers a digital assistance service. Our trained volunteers can complete the forms on your behalf using the Office of the Public Guardian's (OPG) online tool. For more information on this service call our support line on **0333 150 3456**. The service doesn't provide legal advice.

If you live in Northern Ireland you can create an Enduring power of attorney (EPA). It is not possible to make an EPA online. An EPA only gives the attorney the power to make decisions about your finances and property. It does not cover decisions about your health and welfare.



For more information see factsheet NI472, Enduring power of attorney and controllership.

'I think it's entirely sensible to forward plan... I would start with making a will and granting LPA.'

Person living with dementia

2

You may come across something called a General or Ordinary power of attorney. However unlike an LPA or EPA, these will not be effective if you become unable to make decisions about your finances in the future.

If you don't make a property and affairs LPA or an EPA and you later become unable to manage your property and finances, there may come a time when no one can legally do that for you. This can make it difficult to do things like pay your bills or care costs. If this happens, someone such as a partner or family member may need to apply to the Court of Protection to become your deputy.

If you're in Northern Ireland they will need to apply to become your controller with the Office of Care and Protection. The processes to set up a controller or deputy take longer and are more expensive than making an LPA or EPA. Also the court will choose who is appointed as the controller or deputy, not you.



For more information see factsheet 530, Deputyship, and for Northern Ireland see factsheet NI472, Enduring power of attorney and controllership.

Also see 'Future and end-of-life care planning' on page 14. for information about what happens if you don't or can't make an LPA for health and welfare.





Trusts

3

If you have assets such as property or savings, you may be able to set up a trust. This is done by making a legal document that allows someone else to manage these assets for you, in line with your wishes. It will make sure your money is used how you want it to be. The trust could also include money used to pay for your care or where you live in the future.

There are several types of trust and different ways to arrange them. Setting up a trust can be complicated and expensive because there are specific rules attached to them. It isn't something everyone can do, so if you're thinking of setting one up you should talk to a solicitor.





Advance decision to refuse treatment

4

Another way to plan for your future medical care is to make an advance decision – this is sometimes called a ‘living will’. This is a legal document that sets out in advance your decision about medical treatments you don’t want to receive in certain situations. For example you may decide not to have a blood transfusion or that you don’t want to be resuscitated in certain circumstances.

In England and Wales if you have made an advance decision to refuse a certain treatment, health professionals must follow it if you’re unable to make the decision about the treatment for yourself. For this to happen the advance decision must apply to the specific situation. If the advance decision relates to refusing life-sustaining treatment it must be made in a certain way.



For more information see factsheet 463, Advance decisions and advance statements.

‘I’ve made an advance decision and placed it in a sealed envelope.’

Person living with dementia

In Northern Ireland the law is different but it is possible to make an advance decision – it may also be called an ‘advance directive’ or a ‘living will’. You do not need to use a particular form to make an advance decision in Northern Ireland.



**For more information see factsheet NI467,
Financial and legal tips.**

You may want to speak to your GP about making an advance decision. If you make one, keep it in a safe place and make sure the people close to you know that you’ve made it and where it is. You may also want to give a copy of your advance decision to your GP, any other medical professionals involved in your care and your attorney for health and welfare (if you have one).

4



Advance statement

An advance statement is different from an advance decision to refuse treatment (see [page 10](#)). An advance statement is not a legal document – it is a record of your wishes and preferences for your care in the future. This could include your favourite foods, hobbies and interests, music you like, or your preferences about where you'd like to live in the future.

An advance statement also gives you somewhere to cover more difficult topics. For example this could include whether you'd prefer to die at home or in a hospital. The document can be really helpful for those close to you and anyone caring for you because it tells them about your wishes, likes and dislikes.

5

Advance statements are not legally binding. However if someone makes a decision for you in the future, they should consider any advance statement you have made. There has to be a good reason for them to make a decision that goes against your advance statement. You can make an advance statement at any time – however any written statement you make while you have mental capacity to make it will be given particular importance.

If you decide to complete an advance statement, discuss it with family members and friends who you trust. You should also tell all the people involved in your care where the statement is kept.



It is possible to make an advance statement in England, Wales and Northern Ireland.

Template advance statement

There is an advance statement template at the end of this booklet. It shows how you can record your likes, dislikes and preferences on a number of topics. You don't have to fill in all the sections if you don't want to. Fill in the sections you want to and cross out the ones you don't. You can also add other preferences or wishes you have on extra pages if you need. You can always make changes to your advance statement if you change your mind in the future. However remember that there may come a time in the future when you find it difficult to express your wishes – and a statement that you make while you have the mental capacity to make it will be stronger.

5

‘Talking enables you to tell loved ones how you’re feeling and they in turn should also feel able to talk. If you don’t talk, how do people know how to help you?’

Person living with dementia

Future and end-of-life care planning

Because dementia gets worse over time it can be helpful to think about what sort of care and treatment you'd like to receive in the future, including at the end of your life. Planning for your future care and treatment is known as 'advance care planning'.

You might not want to think or talk about how you want to be cared for in the future, particularly at the end of your life. Many people find it difficult to talk about this – including health and social care professionals. But having these conversations now and planning ahead can help to make sure your wishes are followed. It will also help your family, friends and the professionals involved in your care to know what you want.

6

There are different ways to plan ahead for your care and treatment, such as:

- making an LPA for health and welfare (in England and Wales) – see **page 4**
- making an advance decision – see **page 10**
- making an advance statement – see **page 12**.



How you choose to record your wishes is up to you. Some people do one of these things, some people do all of them and some people choose a combination of them. Even if you decide not to make any of these things, having a conversation with your family or close friends about them can be a good way to talk about what you want for the future. You may also want to discuss your wishes with health and social care professionals so that they can be recorded in your medical records and/or your care plan.

There may come a time in the future when you don't have the mental capacity to decide about your care or treatment. If you have not appointed a health and welfare LPA attorney to decide for you or if you haven't made an advance decision that applies, health or social care professionals will normally decide what happens based on what is in your 'best interests'. They would still need to take account of your wishes and feelings (including any you have expressed in an advance statement) but the decision would be theirs.



For more information about making a decision in a person's best interests see factsheet 460, Mental Capacity Act 2005.

6

'If you are in a place that you want to tell someone your wishes when you come to the end of your life, do so, or at least write it down while you can.'

Person living with dementia

Wills

If you make a Lasting or Enduring power of attorney it will automatically come to an end when you die. If you want to plan what will happen to the things you own after you die you need to make a will.

A will is a legal document that says who should receive the things you own when you die – such as your property, savings or valuables. You don't have to ask a solicitor to help you make a will but it can be a good idea.

If you already have a will, you may want to update it.

If you don't make a will then some legal rules – the 'intestacy rules' – will decide what will happen to the things you own after you die. This may not be what you want, so it's a good idea to make a will if you want to make sure your wishes are followed. (Alzheimer's Society can put people in touch with a solicitor through our Will to Remember scheme – for details go to alzheimers.org.uk/willtoremember.)

If you own anything jointly with someone else (for example a property or a bank account) the other person will often automatically become the owner of the whole thing when you die. This will happen whatever your will or the intestacy rules say. You should get advice from a solicitor about what to do if you don't want that to happen.





7

Funeral planning

Many people plan for their funeral in advance. You may choose to do this so you can plan the funeral you want – for example a particular religious ceremony or special requests such as a favourite song, reading or flowers. It can also make it easier for your family and friends to understand and carry out your wishes. Funeral directors can give you more information about planning a funeral.

‘My will is done and my funeral arranged and paid for so I don’t have to worry about those things... long ago I decided I would not look back at what I can’t do, but forward to what I can!’

Person living with dementia

Organ donation

You can think about whether you want to donate one or more of your organs when you die. There are different systems for organ donation depending on whether you live in England, Wales or Northern Ireland. In England if you want to donate an organ you have to 'opt in' by registering on the NHS Organ Donor Register – see **'Other useful organisations' on page 24**. However the law in England will change in Spring 2020 so that unless people 'opt out' in most cases it will be assumed that they agree to organ donation. Wales already uses this 'opt out' system. However Northern Ireland has an 'opt in' system and at the moment there are no plans to change this. For more information contact the NHS Organ Donor Register.

You can also consider donating your brain to help with dementia research. To find out if brain donors are needed you will need to contact your local brain bank. For details see the Medical Research Council (MRC) UK Brain Banks Network in **'Other useful organisations' on page 24**.







Checklist

Below is a list of things you may want to do after you've read this booklet.



Organise any paperwork you have about your finances and personal affairs. This will help you access it easily. It will also help anyone who is looking after your affairs in the future.








Make a Lasting power of attorney (or an Enduring power of attorney in Northern Ireland) so that someone you trust can make decisions on your behalf if you're not able to. See factsheet 472, **Lasting power of attorney** or factsheet NI472, **Enduring power of attorney and controllership** for more information. If you are in England or Wales and you want to use the LPA Digital Assistance Service, call **Alzheimer's Society** on **0333 150 3456**.



Consider creating an advance decision to refuse treatment. You may find it helpful to speak to your GP about creating one. For more information see factsheet 463, **Advance decisions and advance statements**. If you are in Northern Ireland see factsheet NI467, **Financial and legal tips**.



For more help and advice call our Dementia Connect support line on **0333 150 3456**

-  Read the advance statement template at the end of this booklet and fill in the parts you want to. You can also download the template at alzheimers.org.uk/publications-list. Let your family and friends know where your advance statement is kept so that they are aware of your wishes.
-  Add any further wishes, thoughts and preferences that you would like people to know about you to the advance statement. You can attach as many extra pages as you want.
-  Make or update your will.
-  Consider planning for your funeral, or tell the people closest to you about your wishes.
-  Think about whether you want to be an organ donor and what (if anything) you need to do to make sure your wishes are followed – for example depending on where you live there may be an ‘opt in’ or an ‘opt out’ system (see [page 19](#)).

‘Let loved ones and friends know your desires and wishes for when you progress, how you want to be cared for, and generally tending to those final important matters. That proved to be highly beneficial to my loved ones. It also gave me peace of mind. Less worry meant less stress.’

Person living with dementia



Other useful organisations

Medical Research Council (MRC)

UK Brain Banks Network

www.brainbanknetwork.ac.uk/public/donating/

The MRC UK Brain Banks Network aims to give people the contact details for their local brain bank so they can find out whether it is accepting brain donation.

NHS Organ Donor Register

0300 123 23 23

enquiries@nhsbt.nhs.uk

www.organdonation.nhs.uk

The NHS Organ Donor Register is a list of people who want to donate their organs and/or tissue. It is a confidential list held by NHS Blood and Transplant. It now includes a record of people who do not want to donate their organs, for the new 'opt out' law in England and Wales.



Office of Care and Protection (OCP) in Northern Ireland

0300 200 7812

OCP@courtsni.gov.uk (for general enquires)

epa@courtsni.gov.uk (for enquiries about Enduring power of attorney)

www.justice-ni.gov.uk/topics/courts-and-tribunals/
office-care-and-protection-patients-section

The OCP is part of the High Court of Justice in Northern Ireland. It deals with the registration of Enduring powers of attorney and the appointment of controllers.

Office of the Public Guardian (OPG)

0300 456 0300

customerservices@publicguardian.gov.uk

www.gov.uk/opg

The OPG supports and promotes decision making for people who lack capacity or who would like to plan for their future within the framework of the Mental Capacity Act 2005.

Solicitors for the Elderly

0844 567 6173

admin@sfe.legal

www.sfe.legal

Solicitors for the Elderly is a national association of solicitors, barristers and legal executives who are committed to providing legal advice for older people, their families and carers.



For more help and advice call our Dementia
Connect support line on **0333 150 3456**



Appendix

Template advance statement

My wishes and preferences for the future

Fill in the sections that are relevant for you. You can also download this template at alzheimers.org.uk/publications-list



Contact details

Name

Address

Telephone

Email

Date of birth



For more help and advice call our Dementia
Connect support line on **0333 150 3456**



Lasting powers of attorney (LPAs)

Fill in this section if you have made an LPA for property and affairs.

My attorneys are

1. Name

Contact details

2. Name

Contact details

3. Name

Contact details

4. Name

Contact details



Fill in this section if you have made an LPA for health and welfare.

My attorneys are

1. Name

Contact details

2. Name

Contact details

3. Name

Contact details

4. Name

Contact details





Enduring power of attorney (EPA)

Fill in this section if you have made an EPA.

My attorneys are

1. Name

Contact details

2. Name

Contact details

3. Name

Contact details

4. Name

Contact details





Other people to be involved in decisions about my care

Fill in this section if you have no attorneys.

I would like the following people to be involved in decisions about my care

1. Name

Relationship to me

Contact details

2. Name

Relationship to me

Contact details

3. Name

Relationship to me

Contact details

(add extra pages if you need)





Advance decision to refuse treatment

**I have made an advance decision to refuse treatment.
It is kept**

(for example – the original document is kept on the shelf in my living room, and a copy is kept with my GP)



Future choices about my care

If I need more care and support in the future I would like to live

(for example – in my own home, with a family member, in a care home that is near my family)

If I need to move to a new home in the future I would like it to have the following

(for example – a garden, my own bedroom/bathroom, no pets in the residence, somewhere I can keep my pet)



My views and wishes about who will deliver my care are

(for example – care to be given only by someone who is the same gender as me, not by my children or another relative)

When I am at the very end of my life I would prefer to be

(for example – in my own home, in a care home if I have moved to one, in a hospice, in a hospital)

I would like the following people to be with me at the very end of my life

I have the following religious/spiritual beliefs

I have the following political/ethical beliefs





My appearance and personal care

I like to wear the following clothing

I do not like to wear

My preferences for washing are

(for example I prefer a bath to a shower, I only like to wash my hair twice a week)

My other preferences for my personal care are

(for example I like to wear makeup every day, I like to shave every day)

(add extra pages if you need)





Hobbies and activities

Likes

The hobbies and activities that I'd like to continue with in the future are

Dislikes

The activities that I do not enjoy are

My favourite...

TV programmes are

Types of music are

Radio programmes are





Daily routine

I usually get up at

I usually have breakfast at

I usually have lunch at

I usually have dinner/tea at

My preferences for eating times are

(for example – I like to eat three main meals a day, I eat my main meal at lunchtime, I like to snack throughout the day)

I usually go to bed at

My usual bedtime routine is

(for example – I have a cup of tea and a biscuit before bed, I watch the news in bed, I have a bath/shower before bed)





Food and drink

Allergies

I am allergic to

Beliefs about food

I have the following preferences and beliefs about the food I eat

(for example – I am a vegetarian/vegan, I don't eat red meat, I only eat fish or white meat, I don't eat beef/pork)

Likes

I like the following food and drink

Dislikes

I dislike the following food and drink

My favourite

Drink is

Meal is

Treat is





My surroundings and possessions

My possessions

If I move to a new home I want the following items with me

(for example – photographs, furniture, jewellery)

My bedroom

I would like my bedroom to be laid out in a certain way

(for example – I like my bed to face the window, I like to have a table with a lamp on it next to the bed)





Other information about me

I would like you to know

(include anything about yourself you would like other people to know)

[illegible]

For more help and advice call our Dementia
Connect support line on **0333 150 3456**

Our information is based on evidence and need, and is regularly updated using quality-controlled processes. It is reviewed by experts in health and social care and people affected by dementia.

Reviewed by: Linda Johnston, Partner at Francis Hanna & Co Solicitors, and Irene Chenery, Consultant at Harrison Drury Solicitors, who are both members of Solicitors for the Elderly

To give feedback on this publication, or for a list of sources, please email **publications@alzheimers.org.uk**

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We are Alzheimer's Society. We are a vital source of support and a powerful force for change for everyone affected by dementia. We provide help and hope.

If you have any concerns about Alzheimer's disease or any other form of dementia, visit **alzheimers.org.uk** or call our **Dementia Connect support line** on **0333 150 3456**. (Interpreters are available in any language. Calls may be recorded or monitored for training and evaluation purposes.)



People affected by dementia need our support more than ever. With your help we can continue to provide the vital services, information and advice they need. To make a single or monthly donation, please call us on **0330 333 0804** or go to **alzheimers.org.uk/donate**



Alzheimer's Society
43–44 Crutched Friars
London EC3N 2AE

0330 333 0804
enquiries@alzheimers.org.uk
alzheimers.org.uk

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