

Planning your Care in Advance

Using this booklet

This booklet is about making an Advance Care Plan (ACP). You may be reading it because you have been diagnosed with a serious condition, as part of planning for retirement, or for any other reason that prompts you to think about the possibility of illness or frailty in the future.

What is an Advance Care Plan (ACP)?

ACP is a process in which you can think, talk and write about what is important to you, and describe the kind of care you would want if you became unable to make decisions for yourself. It broaches the subject of dying, and how you would like to be looked after at that time. It may seem difficult to think ahead in this way, but writing an advance care plan makes a clear record of your wishes so that these can be respected and, where possible, carried out by people caring for you in the future.

How do I start planning?

Advance Care Planning is entirely flexible. Most people will talk things through with a relative, friend or healthcare professional who knows them well. They may have a series of conversations which may or may not result in a written plan.

This booklet suggests various ways in which an Advance Care Plan can record your wishes, and you can focus on the areas that seem relevant to you. You might make your ACP all at once or gradually over time. The plan is not set in stone – you are encouraged to update it as your situation and priorities change. The booklet is intended only to guide you – each Advance Care Plan is completely individual.

Documents which may be included in an Advance Care Plan

Advance Statement of Wishes (pages 4-12)

This is an informal statement of what you would like to happen. It is not legally binding, but must be taken into account when decisions are made on your behalf.

Making a will (page 9)

Lasting Power of Attorney (page 6)

This is a legally binding document by which you appoint a person to make decisions on your behalf.

Advance Decision to Refuse Treatment (pages 13-17)

This is a legal document recording treatments you do not wish to receive. In specified circumstances, it can be legally binding. If you do not wish to be resuscitated in the event of cardiopulmonary arrest (when the heart and breathing stop), you can state this here.

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Personal details

This Advance Care Plan is for:

Name:	Date of birth:
NHS number:	
Address and postcode:	
Phone:	

The following people have copies of this Advance Care Plan:

Consider giving copies of this plan to as many people as possible who may be involved in your care, e.g. family members, GP, nurse, consultant, key worker or carer.

Name:	Relationship to me:
Contact details:	

Name:	Relationship to me:
Contact details:	

Name:	Relationship to me:
Contact details:	

Name:	Relationship to me:
Contact details:	

Name:	Relationship to me:
Contact details:	

This Plan was first written on:

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I reviewed this Plan on the following date(s):

Advance Statement of My Wishes

In this statement you can record things that would be important to you if you became too unwell to discuss your care or treatment and unable to make decisions for yourself. Writing your priorities down in advance will ensure that family, carers and professionals looking after you try to provide care and make arrangements in keeping with your wishes.

This statement is not legally binding. It is not always possible to do exactly as you have asked, but your wishes must be taken into account by anyone making decisions on your behalf.

To help you start writing, the statement is divided into sections, as below. These are just suggestions – you can write the statement in whatever way suits you best.

1. Important people and conversations

Whom do you consider your next of kin? (This is the relative or friend you would wish to be contacted first in an emergency).

Whom would you like to be told about your care or treatment?

Is there anyone to whom information about your care should not be given?

Any discussions you want to have with family or friends.

Have you appointed anyone as an Attorney under a Lasting or Enduring Power of Attorney?

2. My care

Where would you like to be looked after if you could no longer care for yourself?

Where would you like to be looked after when you are dying?

Who would you like to support or visit you?

Important things about your religion or culture.

3. Putting affairs in order

Organising important paperwork.

Have you made a will?

Do you want to plan your funeral?

Do you want to donate your organs after death if this is possible? (Your family may have to give consent, so you will need to tell them about this).

Have you made plans for those who depend on you (e.g. children, elderly relatives, or pets)?

1. Important people and conversations

My next of kin is:

Relationship to me:

Contact details:

I would like my care or treatment to be discussed first with:

Name and contact details:

My care or treatment should **not** be discussed with the following people:

I have appointed the following people as Attorneys under a Lasting Power of Attorney:
(You do not have to do this. See page 7 for further information. If you have appointed attorney(s), give their details below)

Lasting or Enduring Power of Attorney (LPA) for Property and Affairs

Name and contact details:

Lasting Power of Attorney (LPA) for Health and Personal Welfare

Name and contact details:

Things I want to discuss with my family or friends:

I may want this person to help me with conversations:

Name and contact details:

Lasting Power of Attorney (LPA)

LPA is a legal document that lets you appoint a person (known as an ‘attorney’) to make decisions on your behalf. Your attorney can be a relative, friend or professional (such as a solicitor) and you can appoint more than one. At the time when you make your LPA, you must be 18 or over and have mental capacity – the ability to make your own decisions. LPA could be used if you lose mental capacity. You can read more about how mental capacity is assessed at www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act.

There are 2 types of lasting power of attorney (LPA): health and welfare, and property and financial affairs. You can choose to make one type or both. They are registered separately because they work slightly differently, as described below.

1 Health and welfare lasting power of attorney (LPA)

This allows you to choose a person or persons to be involved in decisions about things like:

- your daily routine (e.g. eating and what to wear)
- medical care
- moving into a care home
- life-sustaining treatment

This type of LPA can only be used when it has been registered and healthcare or legal professionals are confident you have become unable to make decisions for yourself.

2. Property and financial affairs enduring or lasting power of attorney (LPA or EPA)

This lets you choose a person or persons to make decisions about money and property for you, such as:

- paying bills and collecting benefits or selling your home.
- selling your home

If you give your permission, this type of LPA can be used as soon as it is registered. This means your attorney can begin to help you as soon as you wish, and continue to do so if you become unable to make decisions.

How to make a lasting power of attorney

1. Choose your attorney (you can have more than one).
2. Fill in the forms to appoint them as an attorney (available to download at www.gov.uk/power-of-attorney).
3. Register your Lasting Power of Attorney with the Office of the Public Guardian (this can take up to 10 weeks).

Further information: www.gov.uk/power-of-attorney
Office of the Public Guardian: www.publicguardian.gov.uk

2. My Care

If I could not care for myself independently, I would most like to be looked after at:

(Professionals call this **Preferred Place of Care (PPOC)**)

When I am dying, I would most like to be cared for at:

(Professionals call this **Preferred Place of Death (PPOD)**)

I would like the following people to visit or support me:

Name(s) and contact details:

My faith, beliefs or important customs, including things that I would or would not want to happen to me (continue on a separate sheet if necessary):

My other wishes and things that are important to me. You could write here about plans for those who depend on you (continue on a separate sheet if necessary).

3. Putting affairs in order

Important paperwork

You may wish to put some of the following documents in a safe place. If you want to, you can nominate someone you trust to help with your paperwork in the future if needed. Make sure they know where your documents are and record their contact details below.

Bank account and credit card details	☐
Insurance policies	☐
Pension documents	☐
Passport	☐
Birth certificate	☐
Marriage or civil partnership certificate	☐
Mortgage details	☐
Hire-purchase agreements	☐
Will	☐
Important contact details (e.g. executor, solicitor, GP)	☐
Funeral plan	☐
Contact details for family, friends and colleagues	☐
Tax office address	☐
National Insurance Number	☐

Person nominated to deal with paperwork

Name:	Relationship to me:
Address:	
Phone:	

4. Sorting out your digital assets and legacy

A digital legacy is the digital information that is available about someone following their death, often formed by the information that they leave on line. This may include any website or blog listings about the person, their social media profiles, photos, videos, gaming profiles and interactions they have had online.

Digital assets are possessions that are purchased, stored or available on digital devices or online services. These may include photos, videos, music, websites, blogs and eBooks.

Information about how to preserve your digital legacy, and how to pass down your digital assets can be found at <https://digitallegacyassociation.org/for-the-public/>

5. Making a Will

Your will is a document stating what you want to happen to your money and property after your death. It can include arrangements for dependents or pets. Any adult can write a will. It is a good idea to do this because if a person dies without a will, the law decides what happens to their property. This can take a long time and be distressing and expensive for the surviving family.

You can write your will yourself, but you should get legal advice to make sure your will is interpreted in the way you want, for example from a solicitor or Citizens Advice (see below),. Before you do this, decide what you would like to include in your will and whom you would like to appoint as executor (to deal with distributing your property after you die). You need to get your will formally witnessed and signed to make it legally valid.

If you want to update your will, you need to make an official alteration (called a codicil) or make a new will.

Further information:

Advice on making a will:

<https://www.gov.uk/make-will/overview>

Citizens Advice:

http://www.adviceguide.org.uk/england/relationships_e/relationships_death_and_wills_e/wills.htm

I have ☐ have not ☐ made a will.
A copy of my will is held at:

Organ or tissue donation

Depending on your medical history, it may be possible to donate your organs and/or tissue for transplantation after death. You can find out more about this at <https://www.organdonation.nhs.uk> or by ringing 0800 432 0559.

If you decide to join the organ donor register, tell your family because if your wishes are not known or cannot be established, they will be asked to give their consent at the time of donation.

I have registered for organ and/or tissue donation after my death Yes ☐ No ☐

I want to donate the following for transplantation after my death:

Any of my organs and tissues ☐

Or

Skin	☐	Liver	☐	Heart	☐	Small bowel	☐	Kidneys	☐
Eyes	☐	Lungs	☐	Pancreas	☐	Heart valves	☐	Bone/cartilage	☐

Donating my body to medical science or Donating my brain and spinal cord for research

These are separate procedures for which forms must be completed before death.

Further information about body donation is available from:

<http://www.hta.gov.uk/bodyorganandtissuedonation/howtodonateyourbody.cfm>

Information about brain and spinal cord donation is available from:

<http://www.hta.gov.uk/bodyorganandtissuedonation/howtodonateyourbody/donatingyourbrain.cfm>

Make sure you keep a copy of the paperwork relating to this. Tell your family and healthcare professionals about your decision and where the paperwork can be found.

I wish my body to be donated to medical science after my death Yes ☐ No ☐

I wish my brain and spinal cord to be donated for research after my death
Yes ☐ No ☐

My copy of the paperwork about this is held at:

Additional cop(ies) of the paperwork are held at:

7. Funeral Planning

I would like this person to be responsible for arranging my funeral:

Name and address:

I would like the following funeral director:

I have a pre-paid funeral plan as detailed below:

I would like to be

Buried ☐ Cremated ☐ Other, as described below ☐

I would like the funeral to be in line with my faith as specified below:

I would like the funeral held at:

I would like the following person to conduct the service:

Name:

Contact details:

Music, songs or readings I would like:

My other wishes are recorded below (for example, donations to charity, flowers, funeral invitations)

Advance Decision to Refuse Treatment (ADRT)

This is a formal, legally binding document (previously known as a Living Will).

It allows you to state in advance that you would refuse certain treatments in particular circumstances. Before you make an ADRT you should get advice from someone who understands the process, such as your GP or a solicitor.

Key facts about an ADRT:

- You must be at least 18 years old and able to make decisions for yourself at the time you make the ADRT. This is known as mental capacity.
- An ADRT will only apply at a time when you have lost the mental capacity to consent to or refuse treatment. Professionals involved in your care must assume that you have mental capacity until proven otherwise and must give you help and time to communicate your decisions (Mental Capacity Act 2005).
- An ADRT must specify precisely what treatment is to be refused and the circumstances in which the refusal will apply. It is only legally valid if both these conditions apply. For example, you might state “If I have a stroke which results in swallowing problems, I would not wish to be fed artificially by tube or drip”. This refusal would not be legally binding if swallowing problems were due to another cause.
- ADRT does not allow you to have your life ended and cannot be used to ask for particular medical treatments. If you want to refuse treatment that could potentially save your life (such as artificial breathing on a ventilator) you must state that your wishes apply “even if my life is at risk as a result of my decision”.
- An ADRT should be in writing, signed and witnessed. An ADRT must be in writing, signed and witnessed if applying to life sustaining treatments.

- You can change your mind and cancel your ADRT at any time, as long as you still have mental capacity. There is no formal process to follow and you can cancel your decision verbally or in writing. Where possible, you should tell anybody who knew about your ADRT that it has been cancelled.
- You can make changes to your ADRT verbally or in writing, unless the change includes a refusal of life-sustaining treatment, in which case you must follow the procedure above and ensure the change is in writing and is witnessed.
- You should tell professionals (such as your GP, nurse, hospital or hospice doctor or keyworker) about your ADRT form and consider giving them a copy.
- If you do not wish to be resuscitated in the event of cardiopulmonary arrest (when the heart and breathing stop), discuss your decision with your doctor and record it on page 16. If you decide against resuscitation, ask your doctor to complete a form telling healthcare professionals not to attempt resuscitation. (This is known as a DNACPR form).

Further information about resuscitation is available at:

<https://www.resus.org.uk/pages/DecisionsRelatingToCPR.pdf>

If you want to make an Advance Decision to Refuse Treatment (ADRT), fill in the form on page 15.

Further information:

ADRT: www.nhs.uk/Planners/end-of-life-care/Pages/advance-decisions-to-refuse-treatment.aspx

Mental Capacity Act: www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act).

My Advance Decision to Refuse Treatment

Name:	Date of birth:
NHS number:	
Address:	

Important note for health and social care professionals

You should assume that the patient can make their own decisions (has capacity) until proven otherwise. You must offer them help and time to communicate.

Before implementing this decision to refuse treatment, you must check that it is valid and applies in the patient's circumstances at the time.

You should share this information with everyone involved in the patient's treatment and care.

Basic care, comfort and support are not treatments and should be offered to every patient, whatever their advance decisions.

I do not want to receive the specific treatments shown below in the circumstances specified. ***If you are refusing a treatment that is or may be life-sustaining, you must also state in the box: "I am refusing this treatment even if my life is at risk as a result".***

Specific treatment I want to refuse:	Circumstances in which I refuse this treatment:

I have discussed cardiopulmonary resuscitation with my doctor. In the event of cardiopulmonary arrest (when the heart and breathing stop):

☐
☐

I do not wish to be resuscitated in the following circumstances, or
I do not wish to be resuscitated in any circumstances

Signature:

Date:

A completed DNACPR form can be found at:

Declaration to everyone involved in my care:

I make this decision to refuse treatment voluntarily and am mentally capable to do.
I am fully aware of the possible consequences of my refusal as documented above.

I understand that I can cancel this decision to refuse treatment at any time.

Name:

Date of birth:

NHS number:

Address:

Signature:

Date:

Witness declaration:

An Advance Decision refusing life-sustaining treatment must be signed by you (or by another nominated person in your presence and by your direction) and witnessed by someone else.

The person making this Advance Decision to Refuse Treatment signed it voluntarily in front of me.

Witness's signature:

Date:

Address and postcode:

Phone:

Relationship to person making the decision:

I give permission for my Advance Decision to Refuse Treatment to be discussed with:

I do **not** give permission for my Advance Decision to Refuse Treatment to be discussed with:

Changes to my Advance Decision to Refuse Treatment

Name:

Date of birth:

NHS number:

Address:

You should regularly review your ADRT to make sure it still represents your wishes.

- Write changes in the box below. Continue on a separate sheet if needed.
- Each change must be signed, dated and witnessed
- Tell the people who know about your ADRT of the changes and provide updated copies.

Details of change:

Signature:

Date:

Witness's signature:

Date:

Address and postcode:

Phone:

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