

Compassion in Dying.

Your end of life. Your way.

Advance Decision Pack

Your document contains:

➔ **Advance Decision to Refuse Treatment**

This form sets out the situations in which you want to refuse medical treatment if you are unable to make or communicate that decision in the future.

➔ **Information for GPs**

A one page cover sheet for you to give to your GP along with your form.

➔ **Guidance Notes**

This gives information to help you complete your form. The notes explain when an Advance Decision would be used and offers support to consider your wishes.

You can contact us to order a wallet-sized '**Notice of Advance Decision**' card. This explains that you have made an Advance Decision and where a copy can be found.

To order a card contact us on:

 **0800 999 2434**

 **info@compassionindying.org.uk**

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Advance Decision to Refuse Treatment

This Advance Decision to Refuse Treatment sets out the situations in which I want to refuse medical treatment should I lack capacity to make or communicate that decision in the future. I have carefully considered these decisions and I confirm that I have capacity to make them. I understand that decisions about my diagnosis and prognosis will be made by the doctor in charge of my care.

Need help filling this in?

If you have any questions, you can contact Compassion in Dying's Information Line on:

 **0800 999 2434**

 info@compassionindying.org.uk

1. About me

Name:

Address:

Date of birth:

NHS number:

Distinguishing features:

2. GP details

Name:

Surgery:

Address:

Phone number:

3. I have discussed this Advance Decision with

4. My refusals of treatment

I confirm that the following refusal(s) of treatment are to apply even if my life is at risk or may be shortened as a result.

I refuse all life-sustaining treatment if:

- I have been diagnosed with any of the conditions I have included in (A) to (D) below, and
- I can no longer make or communicate decisions about my medical treatment, and
- I am unlikely to regain the ability to make these decisions.

I understand life-sustaining treatment includes but is not limited to CPR, clinically assisted nutrition and hydration, artificial or mechanical ventilation and antibiotics for life-threatening infections.

(A) Any type of dementia

Include

Do not include

(B) Brain injury

I understand that brain injury includes but is not limited to stroke, vegetative and minimally conscious states.

Include

Do not include

(C) Diseases of the central nervous system

I understand that a disease of the central nervous system includes but is not limited to motor neurone disease, Parkinson's Disease and Huntington's Disease.

Include

Do not include

(D) Terminal illness

Include

Do not include

(E) Refusing treatment in other situations

I have included additional pages for section 4.E and have attached them to this form

5. To avoid doubt (tick all that apply)

Pain relief

I wish to be given all medical treatment intended to alleviate pain or distress, or aimed at ensuring my comfort.

Yes

No

Pregnancy

If I am pregnant, I wish to receive medical treatment or procedures leading to the safe delivery of my child. Once my child is safely delivered I wish to reinstate my wishes as set out in this form.

Yes

No

Organ donation

I am on the Organ Donor Register

Yes

No

6. Advance Statement

This statement explains why I am making this Advance Decision and what is important to me in relation to my health, care, and quality of life.

I have included additional pages for section 6 and have attached them to this form

7. I would like the following people to be involved in my care

| | |
|---------------|---------------|
| Name: | Name: |
| Email: | Email: |
| Phone number: | Phone number: |
| Relationship: | Relationship: |

8. I have also made a Lasting Power of Attorney for Health and Welfare

The details of my attorney(s) are:

| | |
|---------------|---------------|
| Name: | Name: |
| Email: | Email: |
| Phone number: | Phone number: |

9. Signature

I confirm that I have carefully considered my wishes as set out in this form and that all the information and decisions within it are my own.

Signature: _____

Name: _____

Date: _____

10. Witness

I confirm that this Advance Decision was signed in my presence.

Signature: _____

Name: _____

Date: _____

Address: _____

Relationship: _____

11. Review dates

I have reviewed this Advance Decision and confirm that what is written reflects my current wishes.

| | |
|---------------|-------------|
| Signed: _____ | Date: _____ |
| Signed: _____ | Date: _____ |
| Signed: _____ | Date: _____ |

The information on this page is here to help you fill in your Advance Decision.

It includes instructions for each section. When you have finished you can tear this page off. This form comes with a booklet called 'guidance notes' where you can find more information about making your Advance Decision, refusing treatment and what to do when you have finished filling it in.

1. About me

Your personal details and any distinguishing features that would help people identify you in an emergency, like a birthmark or scar.

2. GP details

Who your GP is and how to contact them.

3. I have discussed this Advance Decision with

Here you can write details of anyone you have discussed your Advance Decision with, like your GP or a family member. This will help your healthcare team to understand who they should speak to if your wishes are not clear or if your capacity to make the Advance Decision is questioned.

4. My refusals of treatment

You can refuse life-sustaining treatment in any, all or none of the four scenarios described in this form. These are dementia, brain injury, diseases of the central nervous system and terminal illness.

These four scenarios are a refusal of all life-sustaining treatment.

To include any of these four scenarios in your form you should tick the 'include' box next to it. If you do not want to include the scenario tick 'do not include'.

If you do not want to refuse 'all life-sustaining treatment', or if you would like to refuse treatment in other situations, then you can write your own refusal in section (E).

5. To avoid doubt

Tick each box if you feel it is relevant to you. You do not have to tick anything here if you do not want to.

More information in guidance notes

 Page 6

 Page 6

 Page 6 and Page 18

 Page 7

 Page 14

6. Advance Statement

Here you can include anything that is important to your health and wellbeing. You could write about why you are making this Advance Decision, or the things that are important to your quality of life, values or beliefs. The things you write here are not legally binding, but are important because they must be considered if someone is making a decision for you.

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

Details of who you would like your healthcare team to talk to if you are unable to make a decision. The people you list here will not have any legal decision-making power, but their views should be taken into account when a decision is being made on your behalf.

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8. I have also made a Lasting Power of Attorney for Health and Welfare

Complete this section if you have already made and registered a Lasting Power of Attorney for Health and Welfare with the Office of the Public Guardian. If you have more than two attorneys you can write their details in the Advance Statement (section 6).

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9. Signature

If your Advance Decision contains a refusal of life-sustaining treatment then you must sign it in the presence of a witness for it to be valid. If you are unable to sign the form, you can ask someone else to sign it on your behalf in your presence.

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10. Witness

Your witness should watch you sign your Advance Decision. They should then add their own signature and write their name, address and relationship to you in the space provided.

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11. Review dates

It is a good idea to review your Advance Decision regularly. This will help a healthcare professional to be confident that what you have said in your Advance Decision is still what you want.

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There is a checklist on Page 22 of the guidance notes to help make sure your Advance Decision will be followed.

Compassion in Dying.

Your end of life. Your way.

Information for GPs

**This is an Advance Decision to refuse treatment.
You may know it as an Advance Directive or Living Will.**

An Advance Decision is a form people can use to refuse any medical treatment in advance. It only applies if a decision needs to be made about treatment and the person does not have mental capacity to decide.

➔ What to do next

1. Scan and upload a copy to the person's medical records.
2. Add the relevant SNOMED CT code.
3. Share with the local ambulance trust, hospital and out of hours team.

Important information

- It is legally binding in England and Wales under the Mental Capacity Act 2005. This means it must be followed by healthcare professionals if it meets certain requirements.
- A solicitor is **not required** to make an Advance Decision.
- Any adult with capacity can make one, they do not need to be unwell or over a certain age.
- As a GP you do not need to sign the form.
- This may be an opportunity to discuss a DNACPR if you think it is appropriate.

This form was made by Compassion in Dying. We are the leading provider of Advance Decisions in the UK. If you have any questions contact us by phone on **0800 999 2434** or email **info@compassionindying.org.uk**.

Making an Advance Decision to Refuse Treatment

Guidance notes



Need help?

If you have any questions, you can contact
Compassion in Dying's Information Line on:



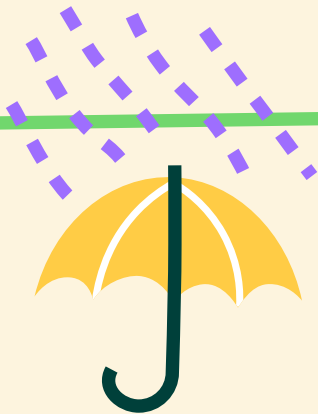
0800 999 2434



info@compassionindying.org.uk

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Why make an Advance Decision?

If you have wishes about how you would or would not want to be treated in the future, making an Advance Decision will help to ensure those wishes are respected if you cannot make decisions.

Here's what some people told us about why they made one:

"I made an Advance Decision to avoid a situation where treatment is given when I can't have a meaningful quality of life."

"I made an Advance Decision to make things easier for my family, my doctor, and to help my own confidence in the future."

"My Grandmother had an Advance Decision and her wishes were respected at the end of her life, it made every decision so much easier for our family regarding her care, and I want to do the same thing for my family."

Introduction

These guidance notes give information to help you complete **Compassion in Dying's Advance Decision to Refuse Treatment**. The notes describe how **Advance Decisions to Refuse Treatment** work in England and Wales. If you live in Scotland or Northern Ireland, see page 3 for more information.

What is an Advance Decision to Refuse Treatment?

An Advance Decision to Refuse Treatment allows you to record any medical treatments that you do not want to be given in the future, in case you later lack capacity to make or communicate a decision. It is commonly shortened to Advance Decision (the term that we use in these notes), and was previously known as a Living Will.

You can use an Advance Decision to refuse any treatment, including life-sustaining treatment. See page 8 for more information on this.

You cannot use an Advance Decision to:

- request or demand particular treatments
- ask for anything illegal, such as assistance to end your life
- refuse basic care that keeps you clean and comfortable
- appoint someone to make decisions on your behalf (see page 16 for more information on this)

What is capacity?

Capacity is the ability to make a decision for yourself. It is time and decision-specific. This means that whether or not you have capacity depends on when the decision needs to be made and what the decision is.

So, you might lack capacity to make a decision on one day but be able to make that decision at a later date. This might be, for example, because you have dementia and your ability to remember information differs from one day to the next.

Also, you might have capacity to make some decisions but not others. For example you might have capacity to decide what you want to eat every day, but not to decide whether to refuse life-sustaining treatment.

You lack capacity to make a decision if:

- you have an impairment or disturbance of the mind or brain, for example, because you are unconscious, have dementia, a brain injury or a stroke

and, because of that impairment, you cannot do one or more of these things:

- understand information relating to the decision
- retain that information for long enough to make the decision
- take that information into account when making the decision
- communicate the decision

The law says that people must be assumed to have capacity unless it is proven otherwise. However, if a decision needs to be made and a healthcare professional thinks that you might lack capacity, then they will assess whether or not you have capacity to make that decision.

Is my Advance Decision legally binding?

The laws on Advance Decisions vary depending on where you live in the UK.

England and Wales

An Advance Decision is legally binding in England and Wales under the Mental Capacity Act 2005, as long as it is 'valid' and 'applicable' (see page 4 for more information). This means that if a healthcare professional knows you have made a valid and applicable Advance Decision, they have to follow it. If they ignore a valid and applicable Advance Decision they could be taken to court.

Scotland

In Scotland, Advance Decisions are known as Advance Directives. Advance Directives are not recognised in legislation as they are in England and Wales, but are still widely recognised and used by healthcare professionals. If a decision ever had to be made in court, it is likely that the Scottish courts would take the same approach as England and Wales and say that a clear and specific Advance Directive should be followed.

An Advance Directive can be used as evidence of your wishes if you lack capacity. Under the Adults with Incapacity (Scotland) Act, a person's past and present wishes should be taken into account when decisions about medical treatment are being made on their behalf.



Northern Ireland

The Mental Capacity Act (Northern Ireland) was passed in 2016 but has not yet come into force. At the time these guidance notes were published, a Mental Capacity Act Code of Practice was being written which should explain what makes an Advance Decision 'effective' in Northern Ireland. Currently, Advance Decisions are given legal effect in Northern Ireland under common law which means a clear and specific Advance Decision to refuse treatment must be followed. Until the Code of Practice is published, we recommend that you follow the instructions for people in England and Wales to help ensure your Advance Decision is respected.

When is an Advance Decision used?

An Advance Decision will only be used if it is valid and applicable.

To be valid:

- You must be 18 or over and have capacity to make your Advance Decision.
- You must clearly state the treatments you wish to refuse and the circumstances that you wish to refuse them in. (The scenarios included in the form already do this. If you wish to write your own refusal these guidance notes will help you. See page 12 for more information).
- You must not have acted inconsistently with the decisions made in your Advance Decision. For example, since completing your form you have joined a religion that has certain values or beliefs about refusing medical treatment.
- You must not, after making your Advance Decision, have made a Lasting Power of Attorney for Health and Welfare, which gives your attorney power to make the same treatment decisions described in your Advance Decision (see page 16 for more information).
- If you want to refuse life-sustaining treatment, you need to clearly state that your Advance Decision applies even if your life is at risk. Section 4 of the form includes this wording.
- If you want to refuse life-sustaining treatment, you need to sign and date your Advance Decision in the presence of a witness. The witness also needs to sign the Advance Decision.

To be applicable:

- You must lack capacity to make the decision, and
- Your Advance Decision must include details of the specific circumstances you are in and refuse the treatments that your doctor has proposed for you, and
- There must be no reason to believe that something has happened since making your Advance Decision which would have affected the decisions you made. For example, if there have been developments in medical treatment that you did not expect.

You do not need a solicitor to make an Advance Decision.

Before I start: talking about my wishes



How you want to be treated and cared for in the future is personal to you. So, think about your wishes carefully before you fill in the form. It's a good idea to talk them through with those closest to you and your doctor. If you do not want to talk about it with your doctor, you do not have to. But they may be able to help you to understand your treatment options and how your decisions might affect you.

There's no right or wrong way to start talking about it. Everyone's different and we know some people find it more difficult than others. You might be worried about upsetting the people you care about. Or that your doctor might not support you. But talking openly and honestly about it can help with that. We asked people about their own experience of discussing their end-of-life wishes. Here's what they said:

"Think about what you want and get it clear in your mind. You could write down your thoughts so you have it straight before you speak to anyone else."

"I felt it was better not to talk about things in case it made them happen. But when I did, I felt relieved. It wasn't without challenges, but it's my life and I want my family to know what's important to me."

"When talking to your doctor - advise the GP surgery what the appointment is for beforehand, so that the GP is forewarned and it will then be easier to start the conversation."

"Drop a few little hints or ideas into normal conversation beforehand so they get used to you talking about the subject before you have a full conversation."

Filling in the form

Section 1: About me

This section records information about you. You can also include information about any distinguishing features you have like a birthmark or scar. This may help your healthcare team to identify you in an emergency. If you do not have any distinguishing features you can leave this blank.

If you do not know your NHS number you can get it from your GP surgery.

Section 2: GP details

This section records who your GP is and how to contact them. It is a good idea to discuss your wishes with your GP but you do not have to. Once you have made your Advance Decision, give a copy to your GP so they can include it with your medical notes.

Section 3: I have discussed this Advance Decision with

In this section you can write details of anyone you have discussed your Advance Decision with, like your doctor or a family member. This will help your healthcare team to understand who they should speak to if your wishes are not clear or if your capacity to make the Advance Decision is questioned. See page 18 for more information on this.

When you complete this part of the form, you should include the person's name, relationship to you and contact details.

Section 4: My refusals of treatment

This section is where you record your wish to refuse medical treatment if you lack capacity to make that decision in the future. Remember, your Advance Decision will only be used if you lack capacity to make a decision yourself.

There is a statement at the start of this section that says:
I confirm that the following refusal(s) of treatment are to apply even if my life is at risk or may be shortened as a result.

If an Advance Decision includes a refusal of life-sustaining treatment then it must contain a statement like this in order to be legally binding.

The form has four scenarios that refuse **all life-sustaining treatment**. You can include any, all or none of them.

To include a scenario in your form you must tick 'include'. If you do not want to include the scenario you must tick 'do not include'.

There is also space in Section 4 to write your own refusal of treatment. See page 12 for more information.

Usually, decisions about your diagnosis or prognosis (the likely course of your medical condition) will be made by the doctor in charge of your care.

Read more: life-sustaining treatment

What is life-sustaining treatment?

Life-sustaining treatment is any medical treatment that is intended to prolong or sustain your life. Here are some examples of life-sustaining treatment:

Cardiopulmonary resuscitation (CPR)

This is an emergency attempt to restart a person's heart and/or breathing if they stop (called a cardiopulmonary arrest). CPR includes chest compressions (repeatedly pushing very firmly on the chest in an attempt to pump blood round the body), artificially inflating the lungs (by inserting a tube into the windpipe, by placing a mask over the mouth and nose, or by mouth-to-mouth resuscitation) and defibrillation (using electric shocks to correct irregularities in the heart's rhythm). In many cases CPR is not successful at restarting a person's heart and breathing. If you have a long-term or chronic condition or a terminal illness then it is much less likely to be successful. For more information on refusing CPR see page 13.

Mechanical or artificial ventilation

Receiving mechanical or artificial ventilation means being put on a ventilator machine that helps you to breathe if you cannot do so on your own. Ventilators are also known as respirators or life-support machines.

Clinically assisted nutrition and hydration

If you cannot swallow, you may be given a liquid that contains the nutrition or hydration that you need. This can be given through an intravenous drip (directly into a vein), a tube through the nose or a tube directly into the stomach (sometimes known as a PEG feed).

Antibiotics

Antibiotics can be a life-sustaining treatment if they are given for a life-threatening infection such as pneumonia. These types of infections are more common when someone is very ill, for example if they have advanced cancer or have had a stroke. Antibiotics can be given through an intravenous drip (directly into a vein) or by mouth as a tablet or liquid.

(A) Refusing treatment if you have dementia

There are many conditions that cause dementia, but the most common ones are Alzheimer's disease and vascular dementia. Symptoms can include memory loss, difficulties with thinking and language, and behaviour or personality changes. Dementia is progressive, which means the symptoms get worse over time.

In the later stages of dementia you can lose capacity to make decisions about your care and treatment. In this situation you might want to refuse treatments aimed at sustaining your life.

In this scenario you will not be given any life-sustaining treatment if you have dementia **and** you are unable to make or communicate the decision about your medical treatment.

This will only take effect if you are unlikely to regain the ability to make that decision.

For more information about dementia, visit the Alzheimer's Society website at www.alzheimers.org.uk or call its helpline on 0333 150 3456.

(B) Refusing treatment if you have a brain injury

Brain injury occurs when the cells in the brain die or deteriorate. This can be caused by a range of things such as a head injury, a stroke, or an illness such as encephalitis (an inflammation in the brain). Brain injury can cause a wide range of short and long term effects, including difficulties with thinking, speaking or remembering things, changes in behaviour and emotion, or problems with movement or balance. Brain injury may also cause some people to lose consciousness or go into a coma, vegetative state or minimally conscious state.

Sometimes, brain injury can cause you to lose capacity to make decisions about your care and treatment. In this situation you might want to refuse treatments that are aimed at sustaining your life.

In this scenario you will not be given any life-sustaining treatment if you have a brain injury (including stroke, vegetative, and minimally conscious states) **and** you are unable to make or communicate the decision about your medical treatment.

This will only take effect if you are unlikely to regain the ability to make that decision.

For more information about brain injury, visit the Headway website at www.headway.org.uk or call its helpline on 0808 800 2244.

Read more: brain injury

Coma

Someone is considered to be in a coma if they are unconscious for more than six hours. Being unconscious means that they cannot be woken and they do not respond to light and sound. Sometimes people recover from their coma. But if a coma lasts for more than a few weeks, it usually means that the person will die, or that when they emerge from their coma they will be in a vegetative state or minimally conscious state.

Vegetative state

If someone is in a vegetative state, it means that they are awake but do not have a conscious awareness of themselves or their surroundings. If the symptoms of a vegetative state last for more than four weeks, this is referred to as a 'continuing vegetative state'. If the symptoms persist for one year after a traumatic brain injury (caused by a trauma to the head), or six months after any other acquired brain injury (such as a tumour or a stroke), the person may be diagnosed as being in a permanent vegetative state. If someone is in a permanent vegetative state, it is very unlikely that they will recover.

Minimally conscious state

If someone is in a minimally conscious state, it means they are awake but only have a small level of awareness and minimal response to things around them. For example, they may be able to respond to simple questions with words or movements. However, such awareness can come and go. If someone shows these symptoms for more than four weeks, it is diagnosed as a continuing 'minimally conscious state'. It is difficult to diagnose when a minimally conscious state becomes permanent, but evidence suggests that it would be very rare for someone to recover after five years.

(C) Refusing treatment if you have a disease of the central nervous system

Diseases of the central nervous system cause damage to the cells of the brain or spinal cord. This can have a significant impact on the way we think, move or react to things. Some common diseases of the central nervous system include Parkinson's Disease, motor neurone disease, multiple sclerosis and Huntington's Disease. Usually these conditions are progressive, which means they get worse over time. There is currently no cure for these conditions.

In the advanced stages, many diseases of the central nervous system can cause you to lose capacity to make decisions about your care and treatment. In this situation you might want to refuse treatments that are aimed at sustaining your life.

In this scenario you will not be given any life-sustaining treatment if you have a disease of the central nervous system **and** you are unable to make or communicate the decision about your medical treatment.

This will only take effect if you are unlikely to regain the ability to make that decision.

For more information about diseases of the central nervous system, visit the NHS Choices website at www.nhs.uk. You can also contact the following organisations for disease-specific information:

- Parkinson's UK - 0808 800 0303 www.parkinsons.org.uk
- MND Association - 0808 802 6262 www.mndassociation.org
- MS Society - 0808 800 8000 www.mssociety.org.uk
- Huntington's Disease Association - 0151 331 5444 www.hda.org.uk

(D) Refusing treatment if you have a terminal illness

A terminal illness is an illness that cannot be cured and is likely to cause a person to die. There are many illnesses that can become terminal, including cancer, heart failure, kidney failure and lung disease.

..... In this scenario you will not be given any life-sustaining treatment if you have a terminal illness **and** you are unable to make or communicate the decision about your medical treatment.

..... This will only take effect if you are unlikely to regain the ability to make that decision.

For more information about terminal illness, visit the Marie Curie website at www.mariecurie.org.uk or call its helpline on 0800 090 2309.

(E) Refusing treatment in other situations

If you do not want to refuse 'all life-sustaining treatment' in scenarios (A) to (D) or if you would like to refuse treatment in different scenarios, then you can write your own refusal here.

You can write your own refusal instead of, or as well as, scenarios (A) to (D). You can find more information on what to write in this section overleaf.

For your refusal to be legally binding, you must state the **treatments** that you want to refuse and the **situations** in which you want to refuse them.

..... If you wish to refuse all life-sustaining treatment in every situation, regardless of the cause or your prognosis, you can write it here.

If you would like to write your own refusal but are unsure how to explain it in writing, you can contact Compassion in Dying for support on 0800 999 2434 or info@compassionindying.org.uk.

If you need more space, you can include additional pages. You should then attach them securely to your Advance Decision and tick the box next to the statement that says: 'I have included additional pages'.

Read more: writing my own refusal of treatment

What can I write here?

Any refusal of treatment you include in section E should reflect your personal wishes. Here are some examples from people who have made their Advance Decision:

CPR

Some people we speak to want to refuse cardiopulmonary resuscitation (CPR) if their heart or breathing stop in every situation. If you want to do this, you can write “I refuse CPR in every situation”.

You should also ask your GP for a DNACPR (Do Not Attempt Cardiopulmonary Resuscitation) form to be added to your records. For more information about this speak to your GP or contact Compassion in Dying.

Situations that you would find intolerable

You might wish to refuse life-sustaining treatment if you lack capacity but only if you also show certain symptoms or behaviours.

We asked people when they wanted their refusal of treatment to take effect and this is what they told us:

I want to refuse life-sustaining treatment if I am:

- persistently unaware of my surroundings
- persistently unable to recognise friends or family members
- persistently anxious or agitated
- unable to attend to my personal hygiene
- unable to swallow
- unable to interact with others

Section 5: To avoid doubt

Tick each box if you feel it is relevant to you. You do not have to tick any if you do not want to.

Pain relief

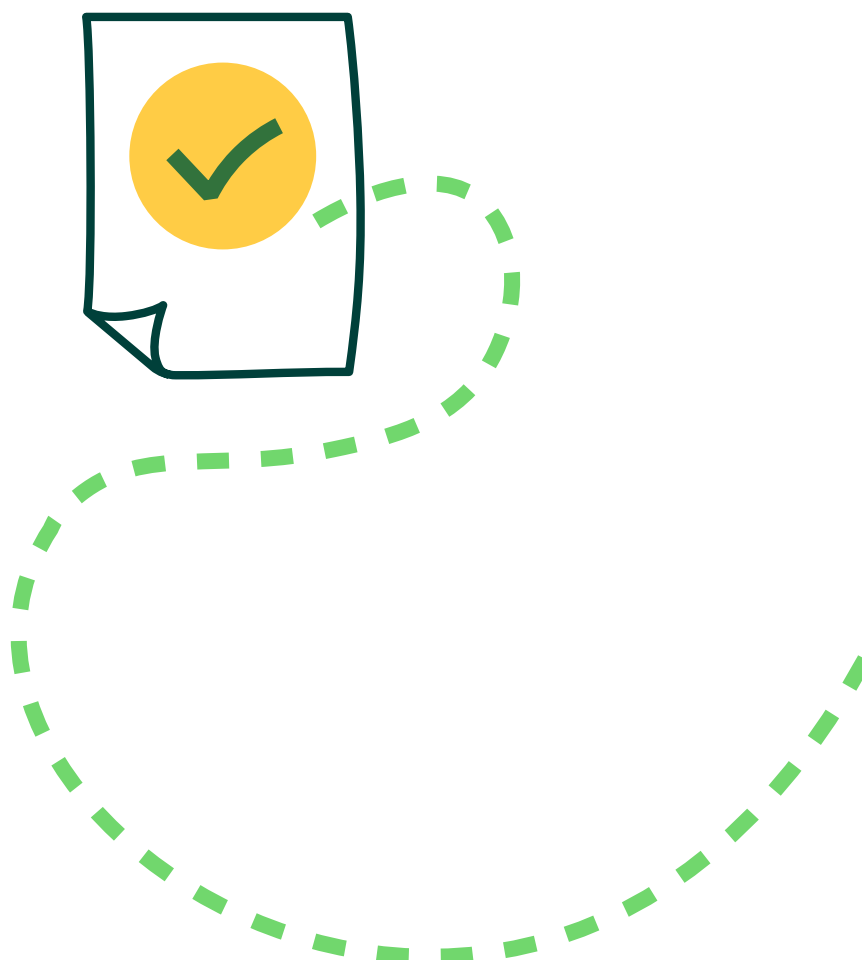
Whatever treatment you refuse in your Advance Decision, your healthcare team will still do everything they can to keep you comfortable and free from pain. However, ticking the box next to this statement gives you the opportunity to clearly state that you would like all available treatment intended to lessen or relieve pain and discomfort.

Pregnancy

You should tick the box next to this statement if you do not want your refusals of treatment to apply during pregnancy. By ticking this box, you are consenting to all treatments necessary to ensure your child is safe during the course of your pregnancy and delivery. As soon as your child is delivered, your refusals of treatment will come into effect again.

Organ donation

You should tick the box next to this statement if you are a registered organ donor. To join the NHS Organ Donor Register call 0300 123 23 23 or visit www.organdonation.nhs.uk



Section 6: Advance Statement

An Advance Statement allows you to record your wishes, feelings, beliefs and values. It also provides space to record why you are making an Advance Decision.

You can write down anything that is important to you in relation to your health and wellbeing, for example your food preferences, religious or spiritual views, your daily routine, where you would like to be cared for (at home, in a hospice, in hospital or in a residential home). It is also helpful to include information about the things that are important to your quality of life, for example hobbies, pastimes or spending time with your family.

Everyone is different, and therefore the things that are important to you and your quality of life are individual to you. By writing something here you will give those around you (your family, carers, and healthcare team) a clear idea of what you want if you cannot tell them. It will also help your healthcare team decide how to treat you if you lack capacity and are in a situation that is not specified in your refusals of treatment.

An Advance Statement is not legally binding. This means that a healthcare professional does not have to follow the instructions that are in it. However, what you write in your Advance Statement is still very important because it must be taken into account when someone is making a decision for you.

If you need more space, you can include additional pages. You should then attach them securely to your Advance Decision and tick the box next to the statement that says: 'I have included additional pages'.

Section 7: I would like the following people to be involved in decisions about my care

In this section you can write details of the people you would like your healthcare team to talk to if you lack capacity to make a decision about your treatment or care.

If a decision needs to be made for you, the views of the people you list here should be taken into account. But they will not have any legal power to make decisions for you. If you want to give someone the legal power to make decisions for you, you should make a Lasting Power of Attorney for Health and Welfare (see page 16 for more information).

Section 8: I have also made a Lasting Power of Attorney for Health and Welfare

You should only fill out this section if you have made and registered a Lasting Power of Attorney (LPA) for Health and Welfare with the Office of the Public Guardian.

Read more: LPAs

An LPA allows you to give someone you trust the legal power to make decisions for you in case you later lose capacity and are unable to make decisions for yourself. There are two different types of LPA:

- An LPA for Property and Financial Affairs covers decisions about money and property
- An LPA for Health and Welfare covers decisions about health and care

An LPA for Health and Welfare allows you to appoint one or more attorneys to make decisions for you. They can make decisions about anything to do with your health and personal welfare, including medical treatment and the type of care you receive. You must choose whether or not you want your attorney to be able to make decisions about life-sustaining treatment.

You do not need to have an LPA for Health and Welfare to make an Advance Decision. However, you can have both. If you are considering making both an LPA and an Advance Decision, it is important to know that **the more recent document takes precedence**. This means that if you appoint an attorney after you make your Advance Decision, your attorney can override your Advance Decision (as long as you have given them that power). If you do not want this to happen you can include an instruction in the LPA form that says your attorney must follow your Advance Decision. For more information about this contact Compassion in Dying.

Enduring Power of Attorney

If you made an Enduring Power of Attorney (EPA) before October 2007, you do not need to include this on your Advance Decision form. This is because an EPA only covers finance and property and does not give an attorney power to make decisions about health and personal care.

Section 9: Signature

If your Advance Decision contains a refusal of life-sustaining treatment then you must sign it in the presence of a witness for it to be valid.

If you are unable to sign the form, you can ask someone else to sign it on your behalf in your presence. If you do this:

- the person signing should write a statement next to the signature explaining that you have directed them to sign on your behalf
- your witness cannot be the same person who signed the form on your behalf

Section 10: Witness

Your witness can be anyone over the age of 18. If possible, it is a good idea to make sure your witness is not a close relative, partner, anyone who will inherit your money or property after your death, or your attorney (the person appointed to make decisions on your behalf through a Lasting Power of Attorney). This is to avoid someone later questioning if you were put under pressure to make your Advance Decision.

Your witness should watch you sign your Advance Decision. They should then sign and write their name, address and relationship to you in the space provided. They are witnessing you signing your Advance Decision, and that your signature confirms the wishes you have written in it. The witness is not confirming that you have capacity to make the decisions in the form.

Section 11: Review dates

It is a good idea to review and re-sign your Advance Decision every two years. The more recent the signature, the more confident your healthcare team will be that what you have said in your Advance Decision is still what you want.

It is also a good idea to review and re-sign your Advance Decision if your health changes, or if you are going into hospital for treatment or surgery.

To review your Advance Decision you should read it and check you are happy with your decisions and the information it contains. If you are happy that it still reflects your wishes then you should sign and date it in the space provided. If you would like to make changes see page 21 of these guidance notes. Once you have reviewed it you should give a copy of the updated version to anyone who you shared your original Advance Decision with.

What if people doubt my capacity to make an Advance Decision?

If your Advance Decision is valid and applicable, healthcare professionals must follow it. The only situation where someone does not have to follow it is if you are detained under the Mental Health Act (known as being 'sectioned') and your Advance Decision refuses treatment for your mental illness.

There are several conditions that need to be met for your Advance Decision to be valid - one of them is that you had capacity at the time you made it. If you lack capacity to make your Advance Decision, it is not valid and will not be followed.

A healthcare professional must presume that you had capacity when you made your Advance Decision unless there is evidence that shows you did not. This might be, for example, because you have had a diagnosis of dementia or have a history of mental illness.

These things do not necessarily mean you lack capacity to make an Advance Decision. But if you are concerned that your Advance Decision might be challenged in the future, it would be helpful to get evidence that you have capacity to make it. One way of doing this is by getting a capacity assessment from your doctor. If you are concerned about this, you can talk to your GP or Compassion in Dying.

You could also ask your GP to sign section 3 of the form. They should include their name and surgery and a statement that says that they have discussed the form with you and are satisfied that you have capacity to make the decisions it contains.



What to do next

Making sure people know about my Advance Decision

It is important that you tell people that you have made an Advance Decision. If your healthcare team does not know that you have one, they will not know how you wish to be treated and will not be able to follow the instructions in your Advance Decision.

➔ Read more: sharing my Advance Decision

There are several things that you can do to make sure people are aware of your Advance Decision:

- Ask your GP to keep a copy of your Advance Decision with your medical records.
- If you live in England, ask your GP to add the fact that you have an Advance Decision to your Summary Care Record. A Summary Care Record is an electronic record of important information about your health that is accessible to any healthcare professional 24 hours a day.
- Give a copy of your Advance Decision to anyone who is regularly involved in your care. This could be, for example, a consultant, health visitor or your local hospital.
- Give a copy of your Advance Decision to your friends and family members.
- Your Advance Decision comes with a wallet-sized Notice of Advance Decision card, which you can keep on your person in case of emergency. If you do not have a card you can order one from Compassion in Dying.
- Speak to your GP about what local arrangements are available to record your wishes. For example, some ambulance Trusts will hold copies of people's Advance Decisions if they are near the end of life.
- Order a free 'bottle' from Lions Clubs International to keep a copy of your Advance Decision in the fridge. Paramedics should know to look for the Lions symbol when entering someone's house and to check the fridge for the container. To order call 0121 441 4544.

Registering with MedicAlert

MedicAlert provides jewellery for people who need to convey important information in an emergency. If you join MedicAlert, you can get 'Advance Decision' engraved on your jewellery so that the healthcare professionals treating you will know you have made one. MedicAlert will also create a secure, detailed medical record that can include your Advance Decision. This information will be accessible by healthcare professionals in an emergency. There is an annual fee and a charge for jewellery.

You can register with MedicAlert and select your jewellery by calling 01908 951045 or visiting their website at www.medicalert.org.uk

What if I change my mind or my situation changes?

While you have capacity to make decisions about medical treatment and care you can change your mind at any time.

If you would like to change the decisions in your form then you should make a new one. If you make changes to an existing form, it could make it hard for others to read. Filling out a new form will ensure that your wishes are clear and easy to follow. You will need to share copies of your new form as explained on page 19. You will also need to make sure that all copies of your old Advance Decision have been destroyed (for example those held by your GP or family and friends).

You can cancel your Advance Decision completely by destroying it and telling anyone who has a copy to do the same.

Remember that your Advance Decision will only come into effect if you lack capacity. So, if you are still able to make decisions about medical treatment, your Advance Decision will not apply.

Updating your contact details in your Advance Decision

If your contact details change or you have a new GP, you can simply cross out the old information and write in any new details. You should sign and date the change but it does not have to be witnessed.

Checklist

This checklist will help make sure your Advance Decision is valid and applicable and will be followed by your healthcare team if you lack capacity.

Section 4 (A) - (D)

- I have ticked 'Include' next to the scenarios that I want to refuse life-sustaining treatment in.
- I have ticked 'Do not include' next to the scenarios that I want to leave out.

Section 4 (E)

- In addition to, or instead of, section 4 (A) to (D), I have clearly stated any treatments that I wish to refuse and the situations that I wish to refuse them in. If you do not want to include anything here you can leave it blank.

Section 4 and 6

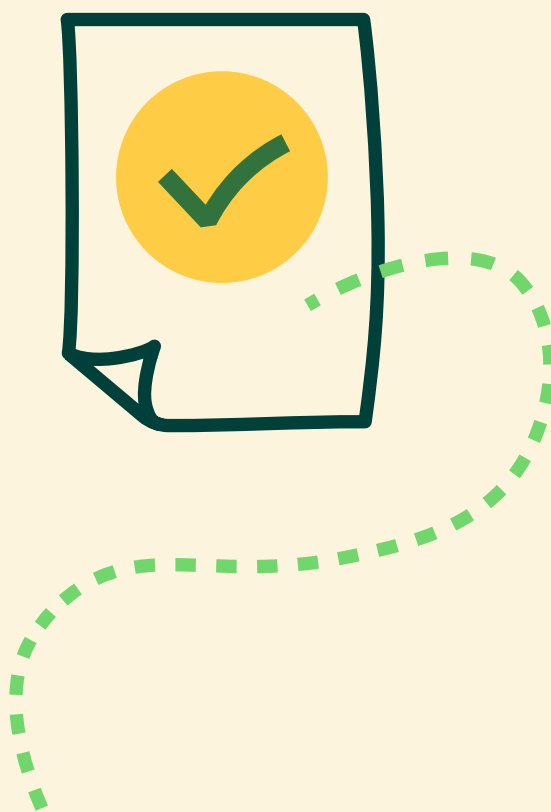
- If relevant, I have securely attached any additional pages to each copy of my Advance Decision and ticked the box(es) stating that there are additional pages for each section.

Section 9

- If my Advance Decision refuses life-sustaining treatment, I have signed and dated my Advance Decision in the presence of a witness.

Section 10

- If my Advance Decision refuses life-sustaining treatment, my witness has signed my Advance Decision.
- I have given my family, friends and GP a copy of my Advance Decision.



Compassion in Dying.

Your end of life. Your way.

**At Compassion in Dying,
we want people to be in
control of their end-of-life
decisions because there is
no-one better to make them.**

**We champion everyone's
right to make informed
decisions. Free of cost and
free of judgement.**

Contact us

181 Oxford Street, London, W1D 2JT

T 0800 999 2434

E info@compassionindying.org.uk

W www.compassionindying.org.uk

 www.facebook.com/compassionindying

 [@agooddeath](https://twitter.com/agooddeath)

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