

# 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 mental capacity to make or communicate that decision in the future. I have carefully considered these decisions and I confirm that I have mental capacity to make them. I understand that decisions about potential 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](mailto:info@compassionindying.org.uk)

**There are guidance notes to help complete this form. For a copy, contact Compassion in Dying.**

## 1. About me

Name:

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Address:

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---

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Date of birth:

---

NHS number:

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## 2. GP details

Name:

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Surgery:

---

Address:

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---

Phone number:

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### 3. 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

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

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#### (A) Any type of dementia

Tick to include

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#### (B) Brain injury

I understand that brain injury includes but is not limited to stroke and prolonged disorders of consciousness.

Tick to include

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#### (C) Progressive neurological conditions

I understand that a progressive neurological condition is a disease affecting the brain, spinal cord or nervous system that causes neurological function to deteriorate over time. Examples include but are not limited to motor neurone disease, Parkinson's disease, Huntington's disease and multiple sclerosis.

Tick to include

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#### (D) Terminal illness

Tick to include

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#### (E) Refusing treatment in other situations

I refuse the following specific treatments:

In these circumstances:


I have included additional pages for section 3.E and have attached them to this form

## 4. Symptom management

I understand that I will be given all appropriate treatment, medication and care aimed at relieving pain, managing symptoms, reducing distress and ensuring my comfort, as long this respects any valid and applicable refusals of treatment in section 3.E.

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## 5. 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 decisions as set out in this form.

Tick to include

---

## 6. My reasons for making this advance decision

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 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:
LPA reference number:	

## 8. People to contact if I have lost mental capacity to make decisions about treatment

Name:	Name:
Email:	Email:
Phone number:	Phone number:
Relationship:	Relationship:

## 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

It is a good idea to review the decisions within your advance decision form every two years or sooner if your health or situation changes.

I have reviewed this advance decision and confirm that what is written reflects my current wishes.

Signed:	Date:
Signed:	Date:
Signed:	Date:

## 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 mental 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**.

# Compassion in Dying.

Your end of life. Your way.

## 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:



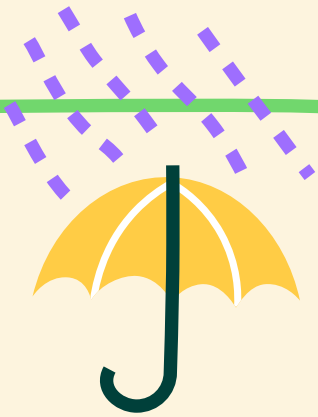
**0800 999 2434**



**[info@compassionindying.org.uk](mailto:info@compassionindying.org.uk)**

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# Why make an advance decision?

If you would like to make a decision now to refuse treatment in the future, in case the time comes when you no longer have the mental capacity to make that decision for yourself, this can be documented in an advance decision to refuse treatment form.

# Introduction

These guidance notes give information to help you complete **Compassion in Dying's advance decision to refuse treatment form**. 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 mental capacity to make or communicate a decision about treatment. It is commonly shortened to advance decision (the term that we use in these notes), and is also known as a living will or advance directive.

You can use an advance decision to refuse any treatment, including life-sustaining treatment. See page 7 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 14 for more information on this)

## What is mental capacity?

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

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

**You lack mental capacity to make a decision if 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

**And:**

- the reason you cannot is because of an impairment or disturbance of the mind or brain, for example, because you are unconscious, have dementia, a brain injury or a stroke.

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

For most people, there will be no doubt about their capacity to make an advance decision. Even those who lack capacity to make some decisions may have the capacity to make an advance decision. In some cases, it may be helpful to get evidence of a person's capacity to make the advance decision (for example, if there is a possibility that the advance decision may be challenged in the future). See page 16 for more information on getting an assessment of your mental capacity.

## Is my advance decision legally binding?

The laws on advance decisions vary depending on where you live in the UK.

### England and Wales

The Mental Capacity Act 2005 makes clear that an advance decision is legally binding if it meets certain requirements. If an advance decision meets these requirements and applies to the situation, then a doctor must follow it.

### Northern Ireland

An advance decision is legally binding in Northern Ireland if it meets certain requirements and applies to the situation. This means healthcare professionals must follow a valid and applicable advance decision. Unlike in England and Wales, where the legal status of advance decisions is set out in legislation, in Northern Ireland their status is currently established through case law.

### Scotland

In Scotland the form is called an advance directive. At present, there is no legislation in Scotland covering advance decisions. However, they should be followed by doctors under common law if they meet certain requirements.

Regardless of where you live, it can be helpful to have your wishes clearly written down so your doctor knows about any treatments you do not want to be given.

## When is an advance decision used?

**In England and Wales, an advance decision should only be used if it is valid and applicable to the treatment in question.**

### **To be valid:**

- You must be 18 or over and have mental 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.
- The Mental Capacity Act states that 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.
- 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 3 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 mental 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.

Legally, you do not have to involve a solicitor to make an advance decision.

You do not have to get proof that you have capacity to make the decisions within your form. However, in some situations it may be helpful to do so (see page 16 for more information).

# Talking about my decisions

Your decisions about treatment in the future are personal to you. It can be helpful to talk it 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.



# Filling in the form

## Section 1: About me

This section records information about you.

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

## Section 2: GP details

This section records who your GP is and how to contact them. It is a good idea to discuss your decisions with your GP but you do not have to. They do not have to sign your advance decision for it to be valid. Once you have made your advance decision, give a copy to your GP so they can include it with your medical notes.

## Section 3: My refusals of treatment

This section is where you record your wish to refuse medical treatment if you lack mental capacity to make that decision in the future. Remember, your advance decision will only be used if you lack mental 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 the box next to it. If you do not want to include the scenario, leave the box blank.

There is also space in Section 3.E to write your own refusal of treatment. See page 12 for more information.

Usually, decisions about your diagnosis or prognosis 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)

Cardiopulmonary resuscitation (CPR) is an emergency treatment that may be used if your heart and breathing stop working. It involves a combination of treatments that aim to restart your heart and breathing and restore the circulation of blood and oxygen around your body. CPR may include pressing firmly on the chest (chest compressions), helping you breathe using a mask or ventilator, medicines, and sometimes electrical shocks to the heart.

### Mechanical or artificial ventilation

Mechanical ventilation is a treatment that helps a person breathe when they are unable to breathe adequately on their own. A machine called a ventilator moves air in and out of the lungs to provide oxygen and remove carbon dioxide. Mechanical ventilation may be provided for a short period of time during an acute illness or injury, or for longer periods in people with some long-term health conditions. Mechanical ventilation does not treat the underlying illness or condition itself.

Mechanical ventilation can be provided in different ways, including:

- Non-invasive ventilation (NIV) – breathing support delivered through a mask worn over the nose, mouth, or both. Examples include CPAP (Continuous Positive Airway Pressure) and BiPAP (Bilevel Positive Airway Pressure).
- Invasive ventilation – breathing support delivered through a tube placed into the windpipe (trachea) through the mouth or nose (intubation).
- Tracheostomy ventilation – breathing support delivered through a tube inserted directly into the windpipe through an opening in the neck (tracheostomy). This may be used for longer-term ventilation.

### Clinically assisted nutrition and hydration

Clinically assisted nutrition and hydration (CANH) refers to nutrition and fluids that are provided when a person is unable to eat or drink enough themselves. CANH is considered medical treatment rather than basic care, so it is lawful for a person to refuse CANH in an advance decision.

CANH may be provided in a number of ways, including:

- Nasogastric (NG) tube feeding: a tube passed through the nose into the stomach to provide nutrition, fluids and, in some cases, medication.

- Percutaneous endoscopic gastrostomy (PEG) feeding: a feeding tube inserted directly into the stomach through the abdominal wall to provide nutrition, fluids and medication over a longer period.
- Radiologically inserted gastrostomy (RIG) feeding: a feeding tube inserted directly into the stomach using radiological imaging guidance to provide nutrition, fluids and medication.
- Intravenous nutrition (parenteral nutrition): nutrients delivered directly into the bloodstream through a vein when the digestive system cannot be used.
- Intravenous or subcutaneous fluids: fluids given through a vein or under the skin to maintain hydration.

CANH does not include assistance with eating and drinking by mouth, such as offering food and fluids, helping someone to eat or drink, or spoon-feeding. These forms of personal care will continue to be offered where appropriate.

CANH supports nutrition and hydration when a person cannot meet their needs by eating and drinking normally, but it does not treat the underlying illness or condition.

### **Haemodialysis**

Haemodialysis is a treatment used when the kidneys are no longer able to remove waste products and excess fluid from the body effectively. During haemodialysis, blood is removed from the body through a tube or needle, passed through a machine containing a special filter (dialyser) to remove waste products and excess fluid, and then returned to the body. Haemodialysis is usually carried out several times a week and may take several hours for each treatment session.

### **Haemofiltration**

Haemofiltration is a treatment that removes waste products and excess fluid from the blood when the kidneys are unable to function adequately. Blood is passed through a machine containing a special filter, which removes excess fluid and waste products before the blood is returned to the body. Haemofiltration is most commonly used in hospital, particularly in intensive care settings, for people who are critically ill and have acute kidney injury.

### **Antibiotics**

Antibiotics are medicines used to treat bacterial infections. Depending on the circumstances, antibiotics may be used to relieve symptoms, treat an infection or prolong life by treating an infection that could otherwise be life-threatening. Antibiotics can be given by mouth, through a feeding tube, by injection or directly into a vein (intravenously). The benefits of antibiotic treatment will depend on the type of infection, the person's overall health and whether treatment is likely to achieve the person's goals of care. In some situations, intravenous antibiotics might need admission to hospital.

## (A) Refusing treatment if you have dementia

Dementia is a term used to describe a group of symptoms caused by diseases that affect the brain. It can affect memory, thinking, communication, understanding, decision making and behaviour. Symptoms usually worsen over time. Examples include Alzheimer's disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia.

In the later stages of dementia you can lose mental capacity to make decisions about treatment. You might want to think about what you would want to happen at that point, and in particular, whether you would want treatment 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.

For more information about dementia, visit the Alzheimer's Society website at [www.alzheimers.org.uk](http://www.alzheimers.org.uk) or call its helpline on 0333 150 3456.

## (B) Refusing treatment if you have a brain injury

A brain injury is damage to the brain that affects how it functions. Depending on how serious the injury is, it may affect a person's ability to communicate, make decisions, understand information or carry out everyday activities. Examples include traumatic brain injury caused by an accident, stroke, a brain haemorrhage, brain infection, brain tumour or injury caused by a lack of oxygen to the brain. Severe brain injuries can sometimes lead to a prolonged disorder of consciousness (PDOC), such as unresponsive wakefulness syndrome or a minimally conscious state.

Sometimes, brain injury can cause you to lose mental capacity to make decisions about your care and treatment. You might want to think about what you would want to happen at that point, and in particular, whether you would want treatment 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, unresponsive wakefulness syndrome, and minimally conscious states) **and** you are unable to make or communicate the decision about your medical treatment.

For more information about brain injury, visit the Headway website at [www.headway.org.uk](http://www.headway.org.uk) or call its helpline on 0808 800 2244.

## ➔ Read more: brain injury

If a brain injury is severe, many people will go through stages of coma, unresponsive wakefulness syndrome and minimally conscious state as they emerge into a state of full awareness and start to get back some of their independence. Other people will stay in a prolonged disorder of consciousness for the rest of their lives.

### **Coma**

A coma is a deep state of unconsciousness. People in a coma are alive but unable to move or respond to their surroundings. Coma is usually short term. Sometimes people transition from a coma into a prolonged disorder of consciousness.

### **Prolonged disorders of consciousness**

If someone is unconscious for more than 4 weeks, they are in a prolonged disorder of consciousness. Doctors will then carry out assessments and tests to diagnose if you are in a state of unresponsive wakefulness syndrome or a minimally conscious state.

Unresponsive wakefulness syndrome (previously called vegetative state) is wakefulness without awareness. People have a sleep-wake cycle and may respond to stimulation with reflexes like grasping with the hand or spontaneous actions like grimacing. However, there is no awareness of surroundings and no purposeful movement.

Minimally conscious state is wakefulness with minimal awareness. Sometimes people who are minimally conscious might respond to people they know by smiling or crying, or purposely reach for things that are near them. Their ability to do these things will change day to day.

## (C) Refusing treatment if you have a progressive neurological condition

A progressive neurological condition is a disease that affects the brain, spinal cord or nerves and can cause increasing loss of function over time. Symptoms may gradually worsen and can affect movement, mobility, communication, swallowing, thinking, breathing and a person's ability to carry out everyday activities. Examples include motor neurone disease (MND), Parkinson's disease, Huntington's disease, multiple sclerosis (MS) and progressive supranuclear palsy (PSP).

Many progressive neurological conditions can cause you to lose mental capacity to make decisions about your care and treatment. You might want to think about what you would want to happen at that point, and in particular, whether you would want treatment aimed at sustaining your life.

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

You can visit the following organisations for disease-specific information:

- Parkinson's UK - 0808 800 0303 [www.parkinsons.org.uk](http://www.parkinsons.org.uk)
- MND Association - 0808 802 6262 [www.mndassociation.org](http://www.mndassociation.org)
- MS Society - 0808 800 8000 [www.mssociety.org.uk](http://www.mssociety.org.uk)
- Huntington's Disease Association - 0151 331 5444 [www.hda.org.uk](http://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 expected to shorten a person's life. People with a terminal illness may continue to live for months or years, but their condition is expected to get worse over time and eventually lead to their death. Examples include advanced cancer, advanced heart failure, advanced lung disease, advanced kidney disease, motor neurone disease (MND) and other progressive neurological conditions.

With a terminal illness, you might lack capacity to make decisions about treatment. There are many reasons why this might be the case, for example because of an acute illness like sepsis or being unconscious because of medication. You might want to think about what you would want to happen at that point, and in particular, whether you would want treatment aimed at sustaining your life.

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.

## (E) Refusing treatment in other situations

You do not have to put anything in this section. However, 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).

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 in the relevant boxes. Any refusals need to be clear and specific, for example:

I refuse the following specific treatments:

In these circumstances:

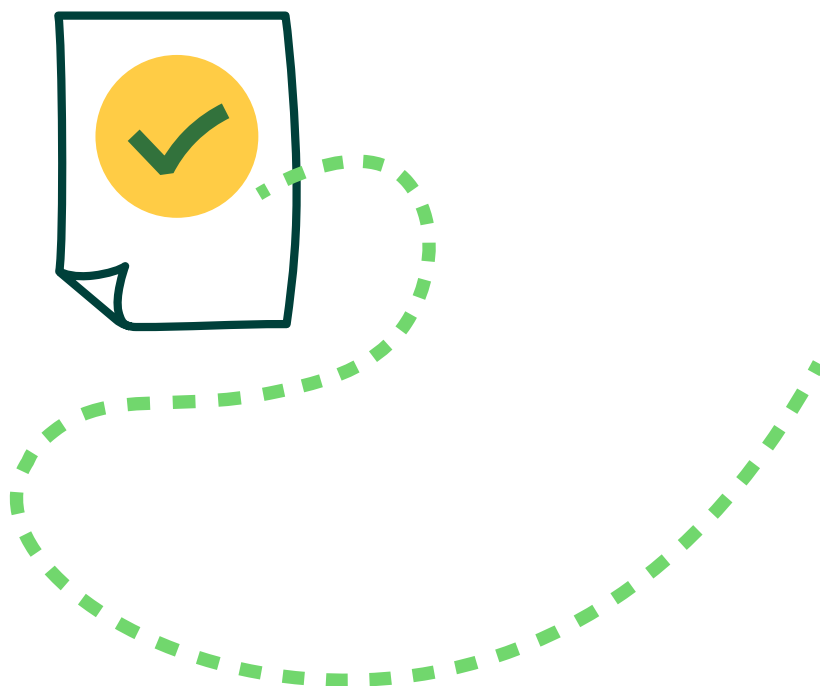
CPR

in all situations regardless of cause or prognosis

If you are writing your own refusal, it can be helpful to explain in section 6 of the form why you are doing this. Writing something in that section can help doctors to feel confident you have carefully considered and understand the consequences of your decision. See page 13 for more information.

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](mailto: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'.



## Section 4: Symptom management

Whatever treatment you refuse in your advance decision, your healthcare team should continue to provide treatment aimed at managing your symptoms, relieving distress and maintaining your comfort. This may include treatment for pain, breathlessness, anxiety, nausea, agitation and any other symptoms that may arise.

## Section 5: 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.

## Section 6: My reasons for making this advance decision

You can record here why you have made your advance decision. Explaining this can help your doctor to feel confident that you understand and have considered the decisions within it.

Some healthcare and legal professionals have suggested that completing this section can help reduce doubt over if your advance decision form is valid and applicable to the treatment in question. Also, if your advance decision cannot be followed for some reason, the information you include in this section can help doctors to make decisions about your medical treatment that most closely align with your wishes.

You might want to include information about the things that are important to your quality of life, or things that are essential for your life to feel meaningful, for example hobbies, pastimes or spending time with the people you love. You can also explain what things might cause your quality of life to feel unacceptable, or list any situations that you want to avoid being in.

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 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 for health and welfare with the Office of the Public Guardian.

Add the names of your attorneys and the LPA reference number. This can usually be found on the first page of your paper LPA form.

### Read more: Lasting power of attorney

There are two different types of lasting power of attorney:

- A lasting power of attorney for property and financial affairs covers decisions about money and property.
- A lasting power of attorney for health and welfare covers decisions about health and care.

A lasting power of attorney 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.

## Section 8: People to contact if I lose mental capacity

In this section you can write details of the people you would like your healthcare team to contact if you lose mental capacity, to update them about the situation.

Including people's names here will not give them 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.

## 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.

The role of the witness is to watch you sign the advance decision form and then sign the form themselves. They should 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 mental 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 at least 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, 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 sign and date it in the space provided. If you would like to make changes see page 18 of these guidance notes. Once you have reviewed it, give a copy of the updated version to anyone who you shared your original advance decision with.

# What if people doubt my mental 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 mental capacity at the time you made it. If you lack mental capacity to make your advance decision, it is not valid and will not be followed.

A healthcare professional must presume that you had mental 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 mental 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 mental capacity to make it. One way of doing this is by getting a mental capacity assessment from your doctor. If you are concerned about this, you can talk to your GP or Compassion in Dying.



# What to do next

## Sharing my advance decision

It is important that you tell people that you have made an advance decision. If you lose mental capacity and the team caring for you do not know that you have one, they will not know what your decisions to refuse treatment are and will not be able to follow the instructions in your advance decision form.

### 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 decisions. For example, some ambulance Trusts will hold copies of people's advance decisions if they are near the end of life.
- Order a '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.

- Register 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 by calling 01908 951045 or visiting their website at [www.medicalert.org.uk](http://www.medicalert.org.uk)

## What if I change my mind or my situation changes?

While you have mental 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 can 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 help to ensure that your decisions are clear and easy to follow. You can share copies of your new form as explained on page 17. 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 revoke 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 mental 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, but the decisions within the form remain the same, you can simply cross out the old information and write in any new details. Sign and date the change but it does not have to be witnessed.

# 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](mailto:info@compassionindying.org.uk)

**W** [www.compassionindying.org.uk](http://www.compassionindying.org.uk)

**f** [www.facebook.com/compassionindying](https://www.facebook.com/compassionindying)

**🦋** [@compassionindying.bsky.social](https://bsky.app/profile/compassionindying.bsky.social)

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