

Information Line: 0800 999 2434

Website: compassionindying.org.uk

Advance Decisions (Living Wills): How will people know about my wishes?

What is an Advance Decision?

An Advance Decision allows you to record any medical treatments that you do not want to have in the future, in case you later become unable to make or communicate decisions for yourself. It will be used only if you cannot make or communicate a decision. The legal name is an Advance Decision to Refuse Treatment, and it used to be called a Living Will.

For more information, see our factsheet *Advance Decisions (Living Wills): An Introduction*

Why do I need to tell people about my Advance Decision?

Advance Decisions are legally binding in England and Wales, as long as they meet certain requirements. This means that if a healthcare professional knows you have made an Advance Decision they have to follow it.

The healthcare professional treating you must take 'practical and appropriate' steps to find out if you have made an Advance Decision.

But it is also your responsibility to take steps to make sure that your Advance Decision can be found by healthcare professionals when it is needed. There is currently no national register of Advance Decisions. So it is very important that those close to you, your GP, and anyone else involved in your care, know that you have made one.

For more information on the requirements Advance Decisions need to meet, see Compassion in Dying's factsheet *Advance Decisions (Living Wills): Is my form legally binding?*

What can I do to make sure people know about my Advance Decision?

There are a few things you can do to help make sure people are aware of your Advance Decision:

- **Speak to your GP**

Once you have made an Advance Decision, you can ask your GP to keep a copy with your medical records. It is very important to do this because it reflects your wishes for medical treatment and this information should be available to anyone involved in your care.

- **Give a copy of your Advance Decision to your friends and family members**

You can give a copy of your Advance Decision to your friends and family members. It is important that anyone who would be contacted in an emergency knows both that you have an Advance Decision, and where a copy is kept.

- **Give a copy to anyone else involved in your care**

You can give a copy of your Advance Decision to anyone who is involved in your care, such as a specialist doctor or nurse, health visitor or your local hospital.

- **Keep a copy of your Advance Decision with you**

You can keep a copy of your Advance Decision on your person, for example in your bag. This will make it more likely that it will be found if something happens to you.

- **Complete a Notice of Advance Decision card**

You can complete a 'Notice of Advance Decision' card, available from Compassion in Dying, and carry it with you in your purse or wallet. This card states that you have made an Advance Decision and where a copy is kept.

- **Lions Clubs International**

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 0845 833 9502.

- **Join 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, which can include your Advance Decision. This information can be provided to healthcare professionals. There is an annual fee and additional 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

Summary care records

You can ask your GP to record on your Summary Care Record that you have made an Advance Decision. A Summary Care Record is an electronic record of important information about your health that is accessible to healthcare professionals at any time.

It contains key information such as what medication you are taking, if you have any allergies and if you have had bad reactions to any medicines in the past. It also includes your name, address, date of birth and your unique NHS number. This makes it easier for doctors to know how to treat you if you are taken to hospital while you are away from home, in an emergency or when your GP's surgery is closed.

A Summary Care Record can record the fact that you have made an Advance Decision, any relevant supporting information contained in the Advance Decision, or where a copy can be found. Your Doctor will not automatically add details of your Advance Decision to your Summary Care Record so you must ask them to do so.

Electronic Palliative Care Co-ordination Systems (EPaCCS)

Electronic Palliative Care Systems (EPaCCS) are electronic systems used in some areas of England. They are for people believed to be in, or near, the last year of life. They allow important information about you and your care plan to be accessed by healthcare professionals.

There are different systems in use in different parts of the country. Some systems will automatically flag details of your care plan to emergency services, NHS 111, 999 and out-of-hours doctors.

Your EPaCCS record should include whether you have made an Advance Decision, the decisions within it, when it was made, and where a copy can be found. Some local healthcare providers are also able to upload and record a copy of the original document on their EPaCCS system.

In an emergency how will my wishes be known about?

Contact your local Ambulance Trust

If you have made an Advance Decision, you can speak to your local ambulance Trust to find out if they can record it on their system.

Ambulance services are provided by one of ten NHS Ambulance Trusts in England, and by one in Scotland, one in Wales and one in Northern Ireland. They each have different policies on whether or not they will record your Advance Decision.

In an emergency, for example if you have an accident such as a fall, it is likely that you will be treated by your local ambulance service. The nature of the service they provide means that their staff are often required to make difficult decisions very quickly about how to treat you.

In practice this can mean that, if you are treated by a paramedic in an emergency and are not able to communicate your treatment wishes to them, they may not have time to check to see if you have an Advance Decision. Even so, recording your Advance Decision on their system will make it more likely to be followed.

If you do not know who your local ambulance trust is, you can contact Compassion in Dying, or view a list of all NHS authorities and trusts here: www.nhs.uk/ServiceDirectories/Pages/CareTrustListing.aspx

London and the South East: Register your Advance Decision with Coordinate my Care

If you are based in London and the South East, you can register with Coordinate My Care, which is an electronic record available to those who care for you. Coordinate My Care is a type of EPaCCS. A doctor or a nurse can talk to you about your health, illnesses and wishes, and create a personalised urgent care plan. Details of your Advance Decision will be entered into the Coordinate My Care system.

The record can be accessed by your GP, community nurses, hospital team, out-of-hours doctors, specialist nurses, London Ambulance Service and NHS 111 (NHS 111 is the NHS non-emergency telephone number that operates at any time).

You can find out more about Coordinate My Care by calling them on 020 7811 8513, or by visiting their website: www.coordinatemycare.co.uk

How can we help?

We can send you a free Advance Decision or Advance Statement form along with guidance notes that explain how to complete them. Alternatively, you can complete these documents online for free at www.MyDecisions.org.uk

We can also support you to complete your forms over the phone.

If you have any questions about Advance Decisions, Lasting Power of Attorney for Health and Welfare, planning ahead or medical decision-making more generally then please contact our Information Line.

The following free publications may also be helpful:

- *Advance Decisions (Living Wills) – An Introduction*
- *Advance Decisions (Living Wills) - Is my form legally binding?*

Every effort has been made to ensure that the information provided in this factsheet is accurate and up-to-date, but information can change over time. Compassion in Dying does not accept any liability arising from its use, and it should not be used as an alternative to legal or medical advice. You can find the latest version of this publication on our website.

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Compassion in Dying supports people to plan ahead to ensure their wishes for treatment and care are respected.

**COMPASSION
IN DYING.**
SUPPORTING YOUR CHOICES

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