

Planning ahead for your treatment and care: Advance Statements, Advance Decisions and DNAR



What is this toolkit for?

Most people have an opinion about the treatment and care they want to receive. This guide will support you to record your preferences to help ensure they are respected if you cannot make a decision for yourself or tell people what you want. It provides an introduction to the ways you can plan for your treatment and care. It is best to make plans for your future while you are well and able to do so. Any adult can plan for their treatment and care - you do not need to be unwell or over a certain age. This toolkit will help you lay out your wishes for particular treatment options via documents called Advance Directives, Advance Statements and Do Not Attempt Resuscitation (DNAR).

This toolkit is one in a series of toolkits about planning for the future and end of life. Other toolkits are available, covering how to talk about your wishes with your family and friends, Power of Attorneys (giving decision making power to others), planning and paying for funerals and writing wills.

This booklet explains your rights under the Mental Capacity Act 2005, which is a law in England and Wales. If you live in Scotland or Northern Ireland, please contact Compassion in Dying or

Leukaemia Care for information on how to make your wishes known.

Why should I plan for my treatment and care?

There may come a time when you are unwell and cannot tell the people around you what you do and do not want. By making plans now, you can record your preferences for treatment and care so that if you are ever in this situation, your wishes are known and can be followed.

Recording your wishes allows you to express who you are and what is important to you. This gives you control over your treatment and care, and reassurance that the right decisions will be made. It can also be a good way to start conversations with your friends and family about what you want in the future.

Everyone has different reasons for wanting to plan future treatment and care. These could include:

- Avoiding your family having to make difficult decisions for you or disputing decisions
- Preventing pain or not prolonging your life when you have a poor quality of life
- Preserving your dignity
- Being able to continue treatment for as long as

possible

- Allowing you to be cared for in a way you want

Who can make decisions about my treatment and care?

While you have capacity, you have the right to make decisions about your treatment and care. You can decide if you want to consent to or refuse treatment, even if doing so may shorten your life. If you lack capacity to make a decision for yourself, and you have not recorded your wishes, the healthcare professional in charge of your care will decide how to treat you. They must make decisions based on what they think would be in your best interests, but there is no guarantee that this would be what you would choose for yourself. Many people think that their family or next of kin can make decisions about their treatment or care if they are unwell, but this is not always the case. Even though these people should be consulted when a decision is made, they will not have the final say. By making plans now you can ensure the important people in your life, and your healthcare team, know your wishes.

If you choose to plan ahead by making an Advance Statement, Advance Decision or DNAR document, they will only be used if you can no longer make decisions

for yourself. You can cancel or make changes to them at any time.

What is capacity?

Capacity is the ability to make a decision for yourself. Your capacity to make a decision depends on when the decision needs to be made, and what the decision is. You might lack capacity to make a decision on one day but be able to make that decision at a later date. For instance, this might be because you have dementia and your ability to remember information differs from one day to the next. You might also have capacity to make some decisions but not others. For example, you might have capacity to decide what you want to eat each day, but not to make a decision about 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 mental health condition, 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
- Remember 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.

How does someone decide what is in my best interests?

If you lack capacity to make a decision, someone may have to make that decision for you. If this happens, they have to act in your best interests. A best interest decision is based on your values, beliefs and preferences. It should be the decision you would make for yourself if you could.

The Mental Capacity Act 2005 says the decision-maker must consider:

- All the relevant information, including the potential benefits or risks of a particular treatment, or any long-term consequences of giving or withholding the treatment such as the impact on your quality of life.

- Your past and present wishes and feelings, any wishes you have previously expressed, written down, or what you say you want now.
- Any values and beliefs you have that would be relevant to the decision.
- The views of your family members, carers and other

Talking about your wishes to your friends, family and healthcare professionals

Talking about your health and your priorities for the future is important for you and the people around you. It can help you to make informed decisions and give you peace of mind knowing that others understand what is important to you. Having these conversations can also help to make the important people in your life feel involved, and ensure they are not left guessing if your healthcare team asks them for information about your wishes when making a decision in your best interests.

Talking about your wishes and feelings with your family, friends or a healthcare professional can be emotionally demanding, especially if they do not agree with you, or have values which challenge your own. But these conversations can also bring you

closer together, and many people find them rewarding. To prepare for these conversations, you may want to take some time to think about what is important to you and your quality of life. Some people find writing their thoughts down helpful.

If you need more help talking to others about your decisions, please see the toolkit "Talking about your wishes".

How to record your wishes for future treatment options

Once you have thought about and discussed your preferences for your treatment and care, you can put these in writing. This is an important step because it will help to ensure that your wishes are clear, and that they can be followed by a healthcare professional. There are three main ways that you can record your wishes. You can make an:

- Advance Statement
Information about you, your lifestyle, and the care you would prefer to receive (free)
- Advance Decision Details of any treatments you do not want to receive (free)
- Lasting Power of Attorney for Health and Welfare Choosing someone you trust to make decisions for you (registration

fee only) – This is covered in our toolkit entitled Power of Attorney

- You can also set up a Do Not Attempt Resuscitation (DNAR) form with your doctor, to cover CPR only.

1. Advance Statement

An Advance Statement is a general statement of anything that is important to you in relation to your health or wellbeing. It can contain information about your lifestyle, the care you would prefer to receive, and information about what is important to your quality of life. Your Advance Statement will only be used if you are unable to tell people how you wish to be cared for.

It will give the people caring for you an idea of who you are and how best to care for you, if you cannot tell them. It will also help to make sure health and care professionals take your preferences into account.

An Advance Statement is not legally binding. This means that a health or care professional does not have to follow the exact instructions in it, but they should consider it when caring for you, and making a decision in your best interests. It does not cost

anything to make an Advance Statement and you do not need a solicitor.

There is no set form for making an Advance Statement. Compassion in Dying provides free forms or you can make one online using their free website: www.mydecisions.org.uk. You should then share it with important people to you, including healthcare professionals involved in your care.

You might like to include:

- The things that are important in your life: activities you enjoy, people you like spending time with, things you like to talk about and places you like to visit.
- The things that are important to your identity: what independence, privacy and dignity mean to you. The clothes you like to wear, what you like to be called, and how you like to present yourself.
- Your values and religious or spiritual beliefs: what your religious or spiritual beliefs mean to you. How your values and beliefs affect the decisions you make about your treatment and care.
- Information about your lifestyle: what time you like to get up and go to bed. What your

preferred mealtimes are, or if there is a time of day when you feel particularly good or bad.

- Your food preferences: anything you like or dislike, anything you are allergic to or intolerant of.
- Living arrangements: where you would like to live and be cared for, and by who.
- The important people in your life: when you like to see them and at what time of day.
- Information about your health: your current conditions or illnesses, any medication you are taking, anything that helps you to feel better, or anything you would prefer not to happen to you.

2. Advance Decision (Living Will)

An Advance Decision allows you to record any medical treatments that you do not want to be given in the future, in case you later lack capacity and cannot make or communicate a decision for yourself. The legal name is an Advance Decision to Refuse Treatment, and it is sometimes called a Living Will or an Advance Directive.

If an Advance Decision meets certain requirements it is legally binding and healthcare professionals must follow it. Your

Advance Decision will only be used if you lack capacity to make a decision.

An Advance Decision can only be used to refuse medical treatment. You cannot use it to demand a particular treatment. Your Advance Decision will only apply to the treatments and circumstances that you include. It will not apply if you are in a situation that is not covered in your Advance Decision. You cannot use your Advance Decision to refuse basic care, such as food and drink by mouth. If you are making one in relation to an illness you already have, it is a good idea to talk to your current doctors about treatment you may be given in different scenarios, so you can include as many eventualities as possible.

If you are refusing life-sustaining treatment, your Advance Decision must be in writing and include the words 'my refusal applies even if my life is at risk or shortened as a result'. If you are refusing life-sustaining treatment, you must sign and date your form in the presence of a witness. Your witness must also sign and date the form.

It does not cost anything to make an Advance Decision and you do not need a solicitor. Compassion

in Dying provides free forms that take you through different scenarios in which you could lose capacity such as dementia, brain injury, diseases of the central nervous system, or terminal illness. There is also space for you to record a refusal of treatment in other situations. The form allows you to record what treatment(s) you want to refuse in each scenario. You can also make one online at www.mydecisions.org.uk. You should then share it with important people to you, including healthcare professionals involved in your care.

You should review your Advance Decision every two years, or sooner if your health changes. If you are satisfied that your Advance Decision still reflects your wishes, then you can resign and date your form - there is a review date section on the Compassion in Dying form.

If you have made an Advance Decision before registering an Lasting Power of Attorney for Health and Welfare, your attorneys can override your Advance Decision. However, your attorneys must always make decisions that are in your best interests. This includes taking into account anything that you have said or written down. If you have made an Advance Decision after registering an LPA for Health and Welfare,

3. Do Not Attempt Resuscitation (DNAR)

A DNAR form is a document issued and signed by a doctor, which tells your medical team not to attempt cardiopulmonary resuscitation (CPR) – a treatment used to try to restart a person’s heart and/or breathing. There are many names used for a DNAR form including a DNAR order, a DNACPR order, and a ReSPECT form.

DNAR forms are designed to be easily recognised, allowing healthcare professionals to make decisions quickly about how to treat you. A DNAR form only refuses CPR, so if you have a DNAR form you will still be given all other types of treatment for your condition as well as treatment to ensure you are comfortable and pain-free. You can request a DNAR form from your doctor, or they can choose to discuss this with you. A DNAR form is not a legally binding document. Instead, it is a tool used by healthcare professionals to communicate to other healthcare professionals that CPR should not be attempted. If you would like to record your wish to refuse CPR in a legally binding way, then you can make an Advance Decision.

CPR stands for cardiopulmonary resuscitation (CPR). It is an

emergency attempt to restart a person’s heart and/or breathing if they have a cardiac arrest. CPR is used to keep the person alive while the cause of the cardiac arrest is found and treated if possible. CPR can include:

- Chest compressions (repeatedly pushing very firmly on the chest in an attempt to pump blood around the body).
- Defibrillation (using electric shocks to correct irregularities in the heart’s rhythm).
- Artificially inflating the lungs (by inserting a tube into the windpipe or by placing an oxygen mask over the mouth and nose, to push air into the lungs).
- Intravenous medication (administering medications such as adrenaline into a vein to improve heart muscle contraction and blood pressure).

The type of CPR used will depend on where the person is when their heart and/or breathing stop, and who is treating them. CPR success rates vary depending on how well you are in the moments before your heart and/or breathing stop, and how quickly you receive medical treatment. Following CPR a few people make a full recovery, some will still be very unwell

and need more treatment, some will never get back to the level of health they had before, and most will not survive.

No one has the right to demand a treatment, including CPR. You can record your preference to be resuscitated, but like all medical treatments, you cannot demand that it is offered to you. If someone is in cardiac arrest, only their healthcare team can decide if resuscitation is a suitable option. This means that they will take into account the person's wishes and values, and those of their family, but CPR cannot be insisted on. You can choose to refuse CPR by asking for a DNAR form and also recording this in your Advance Decision.

How do I make sure people know my wishes?

If you make an Advance Statement, Advance Decision or DNAR, it is important that the people involved in your care know about it. There are things that you can do to make people aware of your wishes:

- Ask your GP to keep photocopies with your medical records.
- Give photocopies to anyone who is regularly involved in your care. This could be a consultant, social worker,

your local hospital, and local ambulance service.

- Give photocopies to people you know and trust. It is important that anyone who might be contacted if you are admitted to hospital knows how your wishes are recorded.
- Keep a copy with you, preferably the original so that you can review it regularly.
- If you make an Advance Decision, you can contact Compassion in Dying to request a Notice of Advance Decision card to keep in your bag or wallet.
- MedicAlert provides jewellery for people who need to convey important information in an emergency. There is an annual fee and an additional charge for jewellery. For more information visit: www.medicalert.org.uk.
- Order a free 'bottle' from Lions Club International to keep a copy of your Advance Statement or Advance Decision in the fridge. Paramedics should know to look for the Lions symbol when entering someone's house. To order call 0845 833 9502.

Further information:

Compassion in Dying are a charity that can help you prepare for end of life, regardless of your stage of life or current health. They have a free information line: 0800 999 2434 or you can email them at info@compassionindying.org.uk.

You can also contact our Patient Advocacy team. They are available Monday to Friday from 9:00am - 5:00pm. If you would like to speak to them, you can:

- Call our helpline free of charge on 08088 010 444
- Send them an email at advocacy@leukaemiacare.org.uk

Please note that our Patient Advocacy team are unable to provide:

- Detailed medical advice or recommendations
- Legal advice
- Advocacy for a course of action which is contrary to the aims and objectives of Leukaemia Care.

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