

If your care needs increase  
**Family matters**



Ovacome is a national charity providing support and information to anyone affected by ovarian cancer.



We run a free telephone and email support line and work to raise awareness and give a voice to all those affected by ovarian cancer.

This information is part of our *If your care needs increase* series. It gives information about the decisions you may wish to make about your future care and treatments which could involve your family and other loved ones.



# Family matters

Being diagnosed with ovarian cancer may have meant years of treatment for you. Now you may be coming to a point where there are decisions to be made about your care in the future. These important decisions will probably involve your family and other loved ones and may mean difficult and emotive discussions with them.

Making these decisions at the right time for you can lead the way forward and help everyone to support you. They give you control, enable you to specify how you want to be treated and what you want to happen at the end of your life.

This is an area that is hard to talk about, but it is important as it happens to everyone.

## **Where would you like to be cared for?**

Conversations about the end of life are difficult to have, but they are very necessary. They may be about your family as much as yourself.

One of the first subjects to cover is where you would like to be cared for. Do you still want to be treated in hospital?

Have your choices been discussed with you? Where would you like to be cared for? People are often surprised to find out about the care at home provided by palliative care teams, and the outpatient and inpatient care given by hospices.

These services aim to manage symptoms you are experiencing and keep you as well as you can be for as long as possible.

You can find out more about accessing this care in the Ovacome booklet 'What services are there for me' now? Visit [ovacome.org.uk/if-your-care-needs-increase/what-services-are-there-for-me-now-](https://www.ovacome.org.uk/if-your-care-needs-increase/what-services-are-there-for-me-now-)

## **Advanced care plans and making an advanced statement**

When you have thought about and made decisions about how you would like your future care to be managed, there are several important steps you can take to make sure your wishes are carried out. First, it is sensible to discuss this with a health care practitioner, to create an advanced care plan (ACP) or an advanced statement. If you are referred to a palliative care team, this is something they will want to create with you. It is also something that GPs and hospital specialists can do.

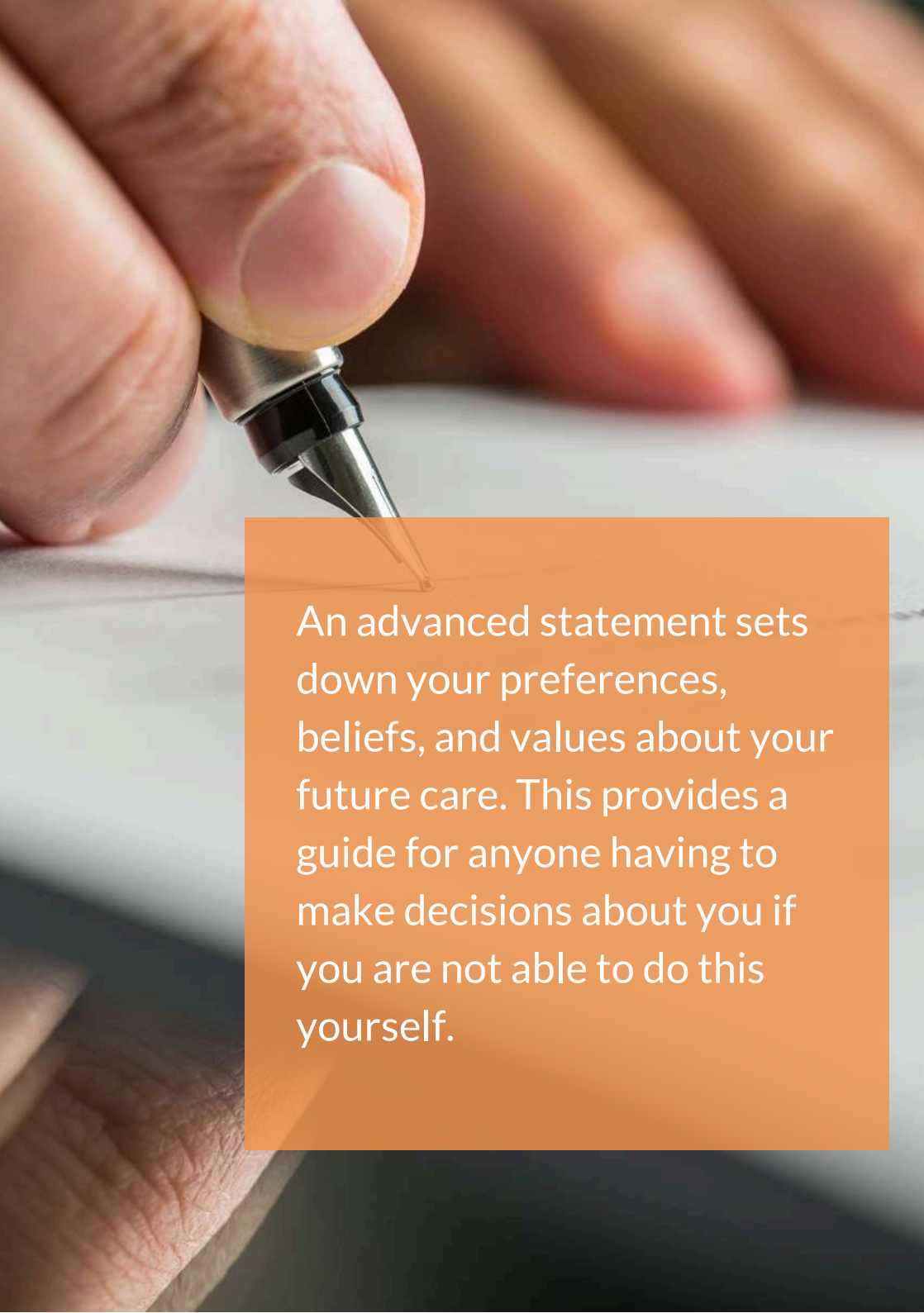
An advanced care plan is not legally binding, but it must be taken into account by anyone making decisions about your care.

An advanced care plan sets down your preferences, beliefs, and values about your future care. This provides a guide for anyone having to make decisions about you if you are not able to do this yourself.

It can cover where you would like to be cared for, whether your religious or spiritual beliefs should be part of that care, and practical matters such as wanting a bath or a shower and how your day might be structured.

You can write an advanced care plan with your family, friends, carers or health team. It does not need to be signed but some people choose to do so to make it clearer that your wishes have been recorded.

Advanced care plans in the NHS are recorded electronically. You can ask for a copy to keep yourself. You can also give copies to your friends and family, so they understand your wishes and the conversations you have had with your health care team.



An advanced statement sets down your preferences, beliefs, and values about your future care. This provides a guide for anyone having to make decisions about you if you are not able to do this yourself.

## **What is an advanced decision to refuse treatment?**

This is a record of your decisions about treatment you do not wish to have in the future. It is sometimes referred to as a living will. It is legally binding.

The treatments you wish to refuse must all be named. You may want to refuse a treatment in some situations but not others. In this case the circumstances in which you want to refuse the treatment must be very clearly explained.

You may decide to include a decision not to have cardiopulmonary resuscitation if your breathing stops or your heart stops beating. This is known as a DNAR, do not attempt resuscitation, and is discussed below.

You may choose not to have artificial ventilation or artificial feeding if these are suggested as an option for you in the future. Some people state that they do not wish to have intravenous antibiotics.

These are all personal choices and can be talked through with a healthcare professional. An advanced decision to refuse treatment allows you to refuse treatment, but you cannot request treatment.

## **Mental capacity**

You can make these decisions as long as you have mental capacity to do so. Otherwise, the advanced decision is not legally binding. This means you cannot make advanced decisions if you lack capacity.

The Mental Capacity Act 2005 describes the lack of mental capacity as; at the time of making a decision, being unable to make it for yourself because of an impairment of, or a disturbance in the functioning of, the mind or brain. This may be temporary or permanent.



People who lack mental capacity have protection under the Act's guidance and code of practice. These ensure people can still participate as much as possible in decisions made on their behalf, and that these decisions are made in their best interests. They include lasting powers of attorney for health (LPAs).

Your advanced decision will only be used if, at some time in the future, you are not able to make your own decisions about treatment.

### **Refusing future treatment**

If you decide to refuse treatment that could keep you alive in the future, your advance decision must be written down, signed by you and signed by a witness. If you wish to refuse treatments in situations where you might die as a result, then you must clearly state in your advanced decision that you understand this.

### **What is a DNAR?**

DNAR means do not attempt resuscitation. This is a decision, made by your doctor or healthcare team, normally after discussions with you, that cardiopulmonary resuscitation should not be attempted if your breathing stops or your heart stops.

It is also sometimes called a DNACPR, do not attempt cardiopulmonary resuscitation (CPR) or a DNR, do not resuscitate.

This decision is recorded on a special form and put in your medical notes. It can also be kept with you at home. You may already have made this decision yourself as part of an advanced decision to refuse treatment.

You can choose to refuse CPR at any time, as long as you have mental capacity. This may be when you recognise that you are approaching the end of your life. You can tell your doctor or healthcare team, and they will record it on a form.

If you have made this choice as part of your advanced decision to refuse treatment, you can change your mind at any time. If you change your mind, you must tell your healthcare team to check that they think resuscitation would be appropriate in the context of your health conditions. If they do think this, they will mark the form as no longer valid.

Completing a DNAR form is a medical decision which does not require your consent, but which should be discussed with you, so you understand the decision and why it has been made.

Your doctor may think that CPR will not help you to live longer, or that it could do you harm. Doctors do not have to give treatments that they think will not work.

Doctors can only not discuss the DNAR decision with you if doing so would cause you physical or psychological harm.

DNAR decisions must be made on an individual basis. They must be made about your individual health and needs.

If you do not agree with the decision, you can ask for a second opinion and a review.

### **What is a Lasting Power of Attorney?**

A lasting power of attorney (LPA) lets you appoint one or more people of your choice – often family members or trusted friends - to help you make decisions or to make decisions on your behalf.



There are two types of LPA: health and welfare where your attorney can make decisions on your daily care, medical care, residential care and life sustaining treatments. The other type is property and financial affairs where your attorney will make decisions for you about managing bank accounts, paying bills, benefits and pensions and, if you need to, selling your home.

Lasting powers of attorney are set up when you have mental capacity. There are strict safeguards in place to ensure you cannot be pressured into agreeing an LPA. An LPA must be registered with the Office of the Public Guardian.

A property and financial affairs attorney can make decisions with or for you when you have mental capacity. A health and welfare attorney can only make decisions for you if you no longer have capacity.

### **Have you made a will?**

You may have made a will ages ago, perhaps if you had children, got married – or divorced. As your circumstances change it is good to check and make sure your will reflects your current wishes and responsibilities.

If you haven't made a will this might be a good time to take that step. Otherwise, you could leave your family with a lot of sorting out to do. Making a will gives you control and the opportunity to give a tribute to the people who mean the most to you – or you can support your favourite causes.



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## Useful links

### Office of the Public Guardian

[patient.info/news-and-features/self-care-cancer-treatment-chemo](http://patient.info/news-and-features/self-care-cancer-treatment-chemo)

### Mental Capacity Act 2005 code of practice

[gov.uk/government/publications/mental-capacity-act-code-of-practice](http://gov.uk/government/publications/mental-capacity-act-code-of-practice)

### NHS information on advance decisions

[nhs.uk/conditions/end-of-life-care/planning-ahead/advance-decision-to-refuse-treatment](http://nhs.uk/conditions/end-of-life-care/planning-ahead/advance-decision-to-refuse-treatment)

### Do Not Resuscitate decisions

[nhs.uk/conditions/do-not-attempt-cardiopulmonary-resuscitation-dnacpr-decisions](http://nhs.uk/conditions/do-not-attempt-cardiopulmonary-resuscitation-dnacpr-decisions)

### Making a will

[gov.uk/make-will](http://gov.uk/make-will)

### Leaving Ovacome a gift in your will

[ovacome.org.uk/legacy](http://ovacome.org.uk/legacy)

This booklet is one of four in the series If your care needs increase.

We welcome your feedback on this booklet. Please email [ovacome@ovacome.org.uk](mailto:ovacome@ovacome.org.uk) or call 0800 008 7054. If you would like to discuss anything about ovarian cancer, please phone our support line on 0800 008 7054 Monday to Friday between 10am and 5pm. You can also visit our website at [www.ovacome.org.uk](http://www.ovacome.org.uk). This is one of a series of information booklets produced by Ovacome. You can see them here: [ovacome.org.uk/information](http://ovacome.org.uk/information)

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### Disclaimer

Ovacome booklets provide information and support. We make every effort to ensure the accuracy and reliability of the information at the time of publication. The information we give is not a substitute for professional medical care. If you suspect you have cancer, you should consult your doctor as quickly as possible. Ovacome cannot accept any liability for any inaccuracy in linked sources.

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ovarian cancer

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