

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?

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 Ovacom booklet *What services are there for me now?* Visit ovacom.org.uk/what-services-booklet

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.

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

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.

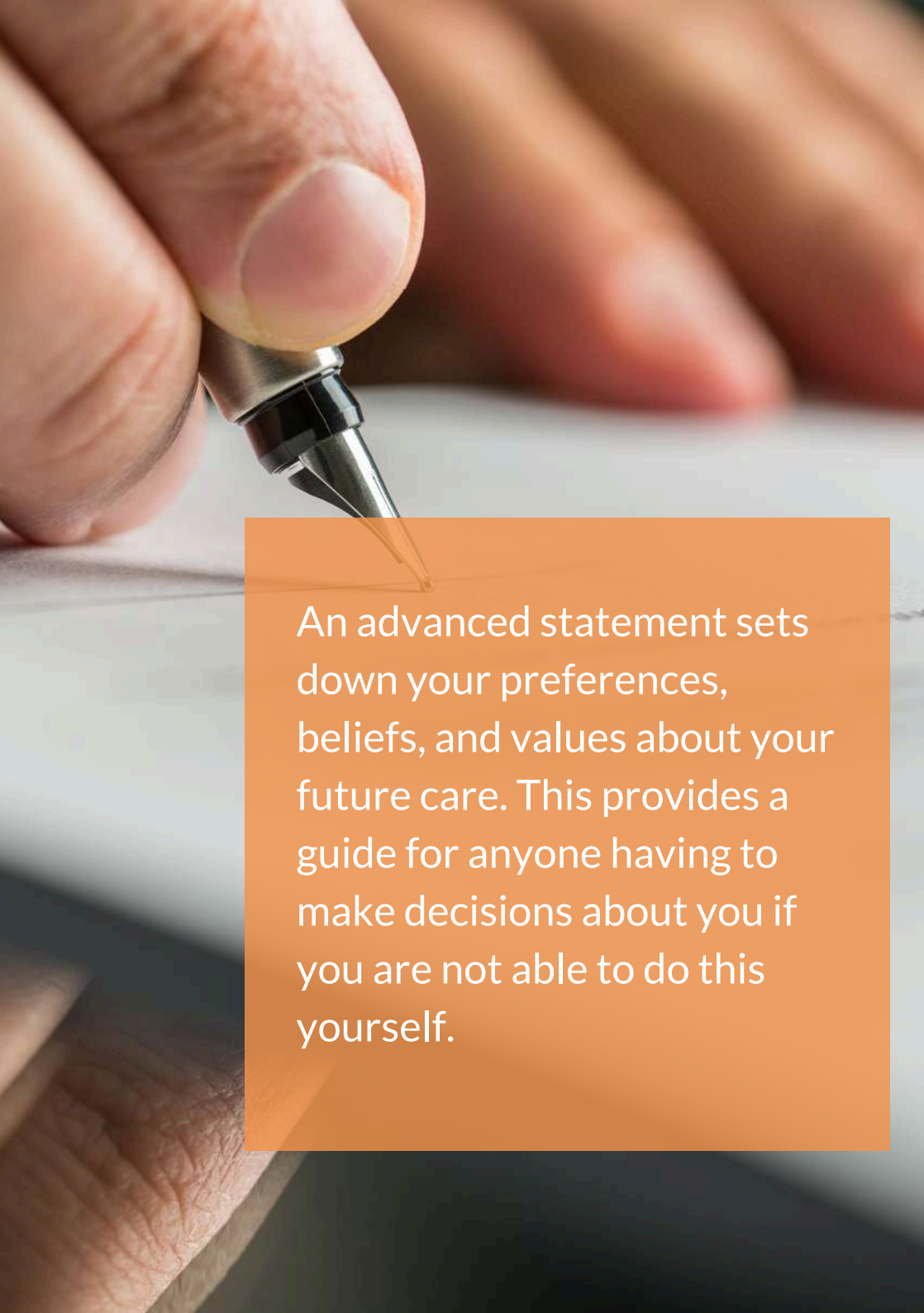
It can cover where you would like to be cared for, whether your religious or spiritual beliefs should be part of that care, and practical matters such as wanting a bath or a shower and how your day might be structured.

You can write your statement with your family, friends, carers or health team. You don't have to sign it but if you do it makes it clearer that your wishes have been recorded.

Keep your advanced statement in a safe place and on your medical notes and make sure people know where to find it if they need to.

What is an advanced decision?

This is a record of your decisions about how you would like to be treated and cared for in the future as your needs change. It is sometimes referred to as a living will. It is legally binding.



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.

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 DNR and is discussed below.

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 (LPAs).

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.

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.

What is a DNR?

DNR means Do Not Resuscitate. 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 DNAR, do not attempt resuscitation. 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 are approaching the end of your life. You can tell your doctor or healthcare team and they will record it on the form.

If you have made this choice as part of your advanced decision, 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 DNACPR 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 DNACPR decision with you if doing so would cause you physical or psychological harm.

DNACPR 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.

Lasting powers 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 take decisions for you about managing bank accounts, paying bills, benefits and pensions and 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 has to 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.



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.

Useful links

Office of the Public Guardian

gov.uk/government/organisations/office-of-the-public-guardian

Mental Capacity Act 2005 code of practice

gov.uk/government/collections/mental-capacity-act-making-decisions

Information on advanced decisions

ageuk.org.uk/information-advice/money-legal/legal-issues/advance-decisions

Information on Do Not Resuscitate decisions

nhs.uk/conditions/do-not-attempt-cardiopulmonary-resuscitation-dnacpr-decisions

Macmillan information

macmillan.org.uk/cancer-information-and-support/treatment/if-you-have-an-advanced-cancer/advance-care-planning/advance-decision-to-refuse-treatment

Making a will

gov.uk/make-will

Leaving Ovacome a gift in your will

ovacome.org.uk/legacy

This booklet is one in four in the series If your care needs increase, funded by the James Tudor Foundation.

We welcome your feedback on this booklet. Please email 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. This is one of a series of information booklets produced by Ovacome. You can see them here: ovacome.org.uk/information.

Reviewed by:

Dr Sarah Batty, Speciality Doctor in Palliative Medicine and GP

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.

Version 1 | Date published January 2022 | Date for review January 2025

ovacome..
ovarian cancer

Support line: 0800 008 7054

Office phone: 0207 299 6654

Website: www.ovacome.org.uk

Email: ovacome@ovacome.org.uk

Ovacome is a charity. We receive no government funding and most of our funding is provided by our community of supporters. We want to continue providing free support and information to people when they need it most. If you can, then please help us by making a donation. You can scan the QR code to the right or visit www.ovacome.org.uk/donate.



Registered with



Charity number **1159682**