Target Ovarian Cancer

My care, my future

A guide for anyone living with incurable ovarian cancer

targetovariancancer.org.uk

Welcome to our guide for anyone living with incurable ovarian cancer.

This guide is for you if you are told that the cancer is no longer able to be cured (incurable ovarian cancer). This may not be easy to hear, think or talk about. This guide aims to help you and your loved ones. It focuses on your practical and emotional needs as you deal with this news. It has been written with experts in ovarian cancer – so you can trust that it's reliable, accurate and up to date.

There's a lot of information in this guide. We have broken it down into sections so you can read as much as you want to and come back to it when you feel ready.

Throughout this guide we have included **Notes from Alison**. These are written by Dr Alison Farmer. She is a psycho-oncology nurse specialist. She was diagnosed with ovarian cancer in 2001.

Notes from Alison

"I originally trained as a nurse and later switched to research. In 1996 I was awarded a PhD for my work on the psychological aspects of breast cancer. After working as a teaching fellow at the University of Southampton for a number of years, teaching psycho-oncology, I decided to return to nursing. I now work as a Psycho-oncology Nurse Specialist, offering psychological support to people with cancer. I was diagnosed with ovarian cancer in 2001 and my experience of surgery and chemotherapy has given me valuable insight into the impact of the disease."

Dr Alison Farmer

1 Understanding what's being said and who's looking after you

In this section

- The health professionals looking after you may tell you that the cancer is incurable when you are first diagnosed with ovarian cancer. Or when the cancer comes back or spreads.
- Health professionals may use the terms palliative care, end of life care and hospice care. The aim with all these types of care is to keep and improve your quality of life while living with an incurable illness.
- Depending on your situation, you may be looked after by your clinical team, a palliative care team or by both teams. If you are looked after by both teams, the health professionals in these teams will work closely together to care for you.

Understanding the terms used

You might hear a variety of terms and words being used. These might mean different things to different people. Many of the words used in this guide aren't ones we hear in everyday conversation. They may feel unfamiliar or uncomfortable to you when you read them. We hope that by explaining some of these words we will make it easier for you to deal with conversations with the health professionals looking after you and with your loved ones.

It's also important to understand exactly what the health professionals looking after you are saying. If you aren't sure, or don't understand the words they use, ask them to explain.

In this guide we use the word **incurable** to mean that the cancer is no longer curable. There may still be treatments that can help to:

- reduce the cancer's impact on you by relieving pain and other symptoms
- slow down the cancer's **progression** (when it grows or spreads in the body)
- live as well as possible with cancer.

The health professionals looking after you may tell you that the cancer is incurable when you are first diagnosed with ovarian cancer. Or when the cancer comes back or spreads. You may also hear incurable cancer called **treatable but not curable** or **advanced cancer**.

You may hear other words to describe this phase of your treatment and care. They're words that can help all of us talk about living with an incurable illness.

Health professionals may use the terms **palliative care**, **end of life care** and **hospice care**. It can be worrying to hear these words. The aim with all these types of care is to keep and improve your quality of life while living with an incurable illness. These types of care can also offer support to you, your family and friends during your illness.

- Palliative care can be given from your diagnosis onwards. It can be given for months or years. It is sometimes called **supportive care** and you can have active cancer treatments at the same time as palliative care. The focus of palliative care is to help you live well with cancer. It also supports you to think ahead about what is important to you and plan the care and support you might need.
- End of life care is a term used when someone is entering the last phase of life. This could be a year, months or weeks but it's not easy to predict the exact time. It's helpful to find out what your healthcare team mean if they use this term. Health professionals use this term so they can talk to you about planning the help and support you might need.
- Hospice care is where you are given palliative and end of life care in a hospice building. There is more information about hospice care in the **Support for you** section of this guide.

The term **terminal care** may be used to describe the last weeks or days. But it's important to remember that people may live with an incurable illness for weeks, months or even years.

All these types of care focus on you and your concerns. These could be:

- physical – how to manage symptoms or side effects, such as pain, breathlessness or sickness
- emotional – how you feel and manage your feelings
- spiritual – how you find meaning and make sense of the world
- social – how you see yourself within your family or workplace.

Give yourself time to ask questions about these terms, now or in the future. While the cancer may not be curable, there are still many things that can help you live as well as possible.

How do I access palliative care?

Each area of the UK has a local hospice or specialist palliative care service. Palliative care can be given at any time in your illness. It's run in the community, in hospitals and in care homes.

Palliative care teams see people based on their needs and symptoms, it's not always because someone has a short life expectancy. A referral to a palliative care team or hospice is to give you extra support so that you can live as well as possible with the cancer. Several studies show that early referral to a hospice or palliative care team can help people feel well for longer.

You can ask for a referral to a specialist palliative care team or a hospice at any stage of your illness.

You may already have met a **palliative care clinical nurse specialist (CNS)**. If you haven't, you can ask to be referred to your local team by your gynae-oncology CNS or GP. Some palliative care teams accept referrals from patients so you may be able to refer yourself.

Depending on where you live in the UK, your access to palliative care teams and the support they can give you might be different. Some hospices and palliative care teams only accept referrals when you need extra support to help control your symptoms. It is likely that you will see a district or community nurse who will then refer you to a palliative care CNS if you have complex symptoms.

Once you have met with the palliative care team they will agree your plan of care with you.

For more information about accessing palliative care services watch our recorded event *Living with incurable ovarian cancer and accessing palliative care services*: **targetovariancancer.org.uk/living-with-incurable-ovarian-cancer**

Who is looking after me?

Depending on your situation, you may be looked after by your **clinical team**, a **palliative care team** or by both teams. If you are looked after by both teams, the health professionals in these teams will work closely together to care for you. In this guide we use the term **healthcare team** to describe all the health professionals looking after you.

Your clinical team

You may continue to be looked after by your clinical team. This is a **multi-disciplinary team (MDT)** made up of specialists who treat ovarian cancer. You may also hear your clinical team called a **medical team**, **treatment team**, an **oncology team** or **cancer team**. The main hospital staff you may come across are:

Oncologists

An oncologist is a doctor who treats cancer. Depending on your treatment plan you will meet a **clinical or medical oncologist** who organises chemotherapy, radiotherapy and treatments such as PARP inhibitors and hormone therapies. In this guide we call this person an **oncologist**.

Gynae-oncology clinical nurse specialist (CNS)

This is a nurse who has had extra training to look after anyone with gynaecological cancers, including ovarian cancer. In some places CNSs are called **specialist gynaecology nurses**. In other places they are called **Macmillan nurses**. You may also hear them called your **key worker**. In this guide we call them a **gynae-oncology CNS**.

Your gynae-oncology CNS should be the person who is involved in every step of your clinical care and treatment from when you are first diagnosed. You may have access to one CNS or a team of CNSs depending on where you live in the UK.

Chemotherapy nurse

If you are treated with chemotherapy, a team of **chemotherapy nurses** will help you through your treatment. They will also help with any side effects that you have.

Your palliative care team

When you are referred to palliative care you will be looked after by a **palliative care MDT**. The main people you may come across are:

Palliative care consultant

A **palliative care consultant** is a senior doctor that leads the palliative care MDT. They recommend medications and treatments within the MDT and also to hospital doctors and GPs.

Palliative care clinical nurse specialist (CNS)

This is a nurse who has had extra training in palliative and end of life care. In some places they are called **supportive and palliative care nurses**. In this guide we call them a **palliative care CNS**.

Palliative care CNSs can work in the hospital, community, hospice or in a care home. They work with your gynae-oncology CNS, oncologist, GP, hospice and community nurses to give you the care that you need.

You may have access to one CNS or a team of CNSs depending on where you live in the UK. You may see them face-to-face or speak to them on the phone.

Some clinical teams and palliative care MDTs will also have a very senior nurse working with them called a **nurse consultant**.

In this guide we call both gynae-oncology CNSs and palliative care CNSs your **CNS**. Speak to the CNS who is currently looking after you.

GP

Your **GP** is your main contact for your medical care if you are living at home or in a care home. Your GP isn't part of the palliative care MDT, but they will work closely with the health professionals in it.

Your GP will:

- prescribe medications and help you to manage any symptoms
- work with your district or community nurse, and your palliative care team to make sure you are getting the right care for you
- refer you to community specialist palliative care or hospice services
- they may also talk to you about advance care planning and record your wishes and decisions.

District or community nurse

A **district or community nurse** gives you care at home if you can't leave your house for treatment. They will support you at home and refer you to any other health or care professionals that can help with your care. This type of nurse may also do a **holistic needs assessment** and put together a care plan with you.

There is more information about a holistic needs assessment in the **Looking after your wellbeing** section of this guide.

End of life care nurses

This is a nurse with extra training in end of life care who looks after you at home in the last weeks of life. Nurses can be from the hospice, community team or the Marie Curie charity. In some places this type of care is called **hospice care at home**. You may hear end of life care nurses called **Marie Curie nurses**. In this guide we call them **end of life care nurses**.

Some people choose to hire an **end of life doula**, also called a **death doula**. This is someone who focuses on the emotional, psychological and spiritual side of dying as well as more practical aspects. They work with your palliative care team to make your death as comfortable as possible. Some end of life doulas charge a fee and some offer their support for free.

Visit End of Life Doula UK for more information: **eol-doula.uk**

Other health professionals

Other people who may be involved in the clinical or palliative care MDT are:

- **advanced clinical practitioners (ACPs)** – who diagnose conditions, make treatment plans, prescribe medications and refer you for more care or tests and work closely with your palliative care CNS
- **occupational therapists** – who help you cope with daily tasks that are difficult because of illness. They may also assess you for specialist equipment at home

- **physiotherapists** - who help you with movement and exercise
- **dietitians** – who give you advice about what to eat and drink
- **psychologists** or **counsellors** – who help your mental health when you are living with incurable cancer
- **social workers** – who assess your care needs, arrange personal care support and support you to adapt your home or have meals delivered
- **care workers** or **healthcare assistants** – who help you with your personal care such as washing, dressing and taking your medication
- **chaplaincy** or **spirituality teams** – who support your religious or spiritual needs
- **pharmacists** – who give out medication and can deliver it to your home if needed.

The clinical and palliative care MDTs meet up often to talk about the care and treatment of their patients. They review test results and talk about plans for treatment and care. Remember that you should also be fully involved in decisions about your treatment and care.

Who should I speak to if I have questions or problems?

You should be told who the main person looking after your care and treatment is. This is usually a CNS or GP. You should be given contact details for them so that you can get in touch with them with any questions or problems.

It is important that you understand what is happening to you and why. You may have different key contacts for different parts of your care. If you are not sure who they are, or how to contact them, ask someone in your clinical team or palliative care team to write down the details for you. There is space at the end of this guide to keep note of useful contacts.

Sharing key contacts with your loved ones means they can contact them for you if you would like them to. You may want to share key people in your clinical team, palliative care team, hospice team and your GP's details.

Good to know

If you would like to get a **second opinion** about your treatment and care, just ask. A second opinion is when you speak to another health professional about your diagnosis, treatment and care options. Your CNS, hospital doctor or GP should be able to tell you how to do this.

Notes from Alison

"This guide aims to help you get the most from every day, while living with incurable ovarian cancer. The things you have always enjoyed don't suddenly stop being important when you're ill. The following chapters offer insights into looking after yourself, understanding symptoms you may have, and your relationships with others.

Family and friends can be a tremendous comfort and support. But you may feel torn between leaning on your loved ones and feeling that you are a burden to them. Most likely they will be desperate to help but may not know what to do. Sharing your thoughts and feelings with your family and friends can be helpful to both you and them. Enjoying a social life is therapeutic and having a sense of humour and a good laugh is one of the things valued most by people with cancer. Laughing releases all sorts of feel-good hormones and can happen during even the darkest moments.

People often want to know what symptoms to expect as their cancer progresses and are particularly concerned about being in pain or short of breath. We have included ways to help you manage these symptoms.

Some people ask about their prognosis and how their quality of life can be kept, while others do not feel ready for this information. For many, knowing what to expect can help them to make the most of each day. Others may feel overwhelmed by thoughts of the future. Everyone is different, there's no right or wrong way and we hope this guide offers some help to each of you.

We have also included information about hospice and palliative care teams. These teams can be involved at all stages of an illness, working with your treatment team and GP. They're often a valuable source of information and support for you and your loved ones. Having a serious illness can make you feel that you're losing your identity and are just seen in the context of your illness. Hospice and palliative care teams try to reconnect you with what matters to you and can help bring perspective back to your life.

Finally, and most importantly, make sure you do things for you. Perhaps there are things you have always wanted to do, places you would like to visit and people you would like to see? You may be feeling tired and unwell at times but setting small goals and letting others know your wishes can help you achieve what you want and give you a sense of control. We are often not good at putting ourselves first, so we hope this guide gives you some hints on how to do just that!"

2 Dealing with the news

In this section

- When you find out that the cancer isn't curable you may want to be alone to absorb the news. Or you may want to be with the people you are closest to and talk about what's happening.
- Telling people that the cancer is no longer curable can be difficult. How you tell them and when you tell them is your choice.
- Talking to your CNS or a counsellor can help you to prepare for telling your family and friends. There is support available for you and for them.

Finding out that the cancer isn't curable

When you find out that the cancer isn't curable, it's common to have a variety of feelings such as fear, anger, shock or disbelief. Many people have a lot of strong emotions when they hear this news. You might have found out that the cancer is incurable when you were first diagnosed. Or the cancer might have come back after treatment, or it might have spread.

Some people know that the cancer is incurable for a long time. This might mean they have lots of different treatments to slow down the cancer's growth. During this time, they carry on with their day-to-day life, spending time doing things that they love.

Other people might decide that they don't want to continue chemotherapy, radiotherapy or hormone treatment. This could be because of side effects or uncertainty about its benefits. Some people might become too unwell to continue treatment. If this is the case, your healthcare team will focus on making you as comfortable as possible. This will involve treating any painful or upsetting symptoms.

One of the questions that you might have is, "how long will I live for?" It is tricky for health professionals to give an exact answer to this question. Some of those with incurable ovarian cancer live for months to years, others live for a shorter time. Your healthcare team may not be able to give you an exact timescale. But you will still have choices. This may mean spending time with people you love, going on trips when your energy levels are good, and taking the time to do the things you want to.

Some people find that taking control of practical things helps them to make sense of their news. This could be decisions about treatment and planning for the future. You can find more details about these in the **Thinking about the future – advance care planning** section of this guide.

Taking time for yourself

Although the future seems uncertain, it's often helpful to think about what helps you make the most of your days. You might choose to spend time with family and friends or enjoy simple pleasures such as going for a walk. You might also want to focus on your work.

You may have days when your energy and mood is lower. It's not uncommon to feel like you're experiencing a rollercoaster of emotions such as anger, sadness and fear about what's happening.

Spending time with people who care about you and doing things that you enjoy can help you to manage these feelings. They can also help you cope when you're feeling overwhelmed. Many of us keep our feelings to ourselves because we worry about upsetting others. But talking about what you're feeling or thinking can be useful to help you process your thoughts and feelings.

Give yourself permission to do the things that are meaningful to you or give you joy. You're still you, the same person you've always been. Someone who loves some things and hates others. A person with a life to live.

Although it can be difficult, try to take a break from thinking about the cancer. Try not to let it take over every waking moment. Consider making a pact with yourself, "Today, I'm not going to think about ovarian cancer, I'm sending it away in my mind. I'm putting it to one side to enjoy my day. Ovarian cancer, you're not controlling me today." If a day feels unachievable then start smaller. Try just an hour and gradually build up the time.

Make a plan of things you want to do and things you'd like to think about. Write it all down and try to stick to it. If it works for you, try to have a day when you think about or do these things once a week. Then perhaps try a whole weekend.

You may find it helpful to watch our recorded events about mindfulness and self-compassion to manage uncertainty:

- ▶ Mindfulness: **targetovariancancer.org.uk/mindfulness**
- ▶ Self-compassion and how to be kinder to yourself: **targetovariancancer.org.uk/self-compassion**

How it felt for me

"I was diagnosed with a rare ovarian tumour. I hoped that my treatment could be curative as it didn't follow the usual ovarian cancer treatment for more common tumour types. My tumour type was known to be aggressive. But after surgery, chemotherapy and radiotherapy I had a clear scan.

Then I had a follow-up scan which showed that there were nodules (small tumours) on my lung. They had spread from the ovarian tumour. This is when I did most of the processing that the cancer wasn't able to be cured.

I'm now having immunotherapy. The rare tumour type means that I'm on a rare treatment pathway. Most people with ovarian cancer won't have any immunotherapy.

It helps me to remember that most people go through the same thoughts and feelings on a human level when they have an incurable illness. Going to my local Maggie's cancer support centre was really good because I met other people with other kinds of cancers. I realised that there's lots of people who have been living with incurable cancers for a long, long time."
Sarah

Sharing the news

Hearing that cancer is incurable can be difficult. You may find it hard to think clearly. You may be in shock, even if you were aware that the cancer was growing or spreading. It's not unusual to feel both shocked yet not surprised by the news. You may want to be alone at this time to absorb and process the news. Or you may wish to spend more time with the people who are closest to you to talk about what's happening.

How you tell others and when you tell them is your choice. You might want to wait a few days or weeks before you tell them. You might only want to tell close family and friends. You also might choose to ask someone close to you to tell others for you.

Top tips from our community for sharing the news

"It helped me to grade people who I needed to tell. There's my family who need to know. Then there's people who are genuinely interested in understanding and I can have more detailed conversations with them. My best friend has had breast cancer, so she's been through something similar, which gives us a great bond."

Sarah

"Throughout my treatment whenever I had a medical phone call or a hospital appointment, I'd write an email to update everyone in my family. It worked very well as everyone knew the same information at once. It also helped me to process the news. I did the same thing after I was told that the cancer was incurable and had an appointment to discuss advance care planning."

Helen

Talking to children

Telling children that someone they're close to isn't going to get better is very hard. Children are likely to feel frightened, angry, guilty and helpless when a parent or grandparent is ill. The best way to tell children is to:

- use simple language
- be open and honest
- use clear language that's appropriate for their age
- allow them to share their worries with you
- welcome all their questions
- give regular, small updates.

Try not to assume that children know what's happening. Share the truth with them, as difficult as this is. Showing your sadness will help children to share their own feelings. Children of all ages have great imaginations. They may think the worst if they don't understand what's happening.

When it's possible, try to give children choices. This could be around when they visit the hospital or hospice. Talk to them before they go to prepare them for what they might see when they visit.

It's also important to reassure children that they will be looked after when their parent dies. To help support you and your children as you come to terms with the news, your CNS or GP may be able to put you in touch with professionals such as:

- a therapist or counsellor
- a hospice social worker
- a local children and young person's bereavement support group.

Many hospices also have child and adolescent support teams to support children and teenagers before and after bereavement.

Speak to your child's school so that they are aware that they may be going through a sad and uncertain time. The school may also have access to counsellors who can offer support as well.

Find more information about supporting children in the **Families, children and creating precious memories** section of this guide.

There is also more information about organisations that can offer practical support for looking after children when an adult has incurable cancer in the **Help for you** section at the end of this guide.

The reactions of others

You might find that talking openly and honestly to others about your diagnosis can help you to come to terms with it and accept what's happening. But you might be worried about the reactions of your friends and relatives. People who love and care about you might feel shocked and upset when they hear that the cancer is no longer curable. You might feel as though you need to look after other people's emotions as they deal with your news.

You may find that talking to your CNS or a counsellor helps you to prepare for conversations with family and friends. You may also want to encourage those close to you to speak to your CNS or a support line to help understand your diagnosis and some of their own worries. Target Ovarian Cancer's support line and your CNS can share information about where family and friends can find extra support.

If you're not sure how to share the news, or just want to talk, Target Ovarian Cancer's specialist nurses are here for you.

Call **0808 802 6000** or email **support@targetovariancancer.org.uk**

If you're unsure about using the support line, try our online tool to find out how our nurses can help you on **targetovariancancer.org.uk/support-line-tool**

3 Relationships

In this section

- Living with incurable ovarian cancer can affect your relationships. Talk to your loved ones and healthcare team about what's important to you and what you want from your care.
- You may find it hard to accept that you need extra help from your loved ones. If you don't feel comfortable asking for their support, speak to your CNS, your local hospice, a counsellor or your GP.
- It's OK if what you want from an intimate relationship has changed. Your sexual feelings may also change. If you are finding sex uncomfortable there are things that can help.

Living with incurable cancer can have an impact on your relationships. You may feel that your loved ones are trying to protect you and make decisions for you. Tell them if this isn't what you want.

You may want to protect your family and friends from the reality of your diagnosis. This can happen if you have been the centre of your family, or if you're used to putting the needs of others before your own. It may feel difficult to accept that you now need their support. If you don't feel comfortable asking for your family and friends' support, speak to the health professionals looking after you. This could be one of the following people or a mix of health professionals:

- your gynae-oncology CNS
- your palliative care CNS
- your local hospice team
- a counsellor
- your GP.

Often your partner, family members or friends will take on the role of caring for you when you need extra help. It's important to talk to them and your healthcare team about what's important to you and what you want from your care.

Health professionals like your CNS will be able to support you to have this conversation with your partner, family or friends. They can help you to prepare what you will say. Or they may be able to join a meeting with your loved ones to talk about your future care.

Sex and intimacy

Having ovarian cancer can cause emotional and physical difficulties. Changes to your body can affect your confidence. This can all impact your sexuality, sex life and relationships. Your sexual feelings may or may not have changed. But it's normal for your wants and needs for sex and intimacy to vary.

If you have a partner, it's OK to want, or not want, to hold hands, kiss, or have sex with them. It's important to find the right balance for you. Try to talk to your partner to explain how you're feeling. You may also find that talking to your friends or your CNS is helpful.

If you're finding sex difficult, sometimes simple changes can help. This could be trying a different position or being intimate when you're not tired or in pain. Lubricants can help with vaginal dryness and make having sex more comfortable. There are many different types of lubricants, which you can buy in most supermarkets, chemists or online.

We can also make ourselves feel good by touching ourselves. This is called **masturbation**. It may help you to feel a greater ownership of your body. Touching yourself may be comforting after having had doctors examining you. It can also help you to reconnect with your body.

How do I find out more?

- Target Ovarian Cancer has an information sheet called *Ovarian cancer sex and intimacy* that you can download at **targetovariancancer.org.uk/guides** or you can read our online information at **targetovariancancer.org.uk/sex-and-intimacy**
- For more information about body image, sex and intimacy search **body image** or **sex** at **macmillan.org.uk**
- For information about sexuality, intimacy and relationships search **intimacy** at **mariecurie.org.uk**
- Look Good Feel Better offer free confidence-boosting workshops for anyone living with cancer: **lookgoodfeelbetter.co.uk**

④ Support for you

In this section

- Talking to a trained professional such as a counsellor about your worries and fears can help you to feel more in control.
- Your local cancer support centre will offer complementary therapies, exercise sessions and other specialist services.
- Hospices aren’t just for people at the end of their life. They can be a great source of comfort and offer a range of specialist services for all stages of cancer treatment and care.

Recognising and seeking support for difficult feelings

Having incurable cancer can affect your mental health and emotional wellbeing. It's understandable if you have the odd day of feeling upset and overwhelmed. But if how you feel stops you living your life, or if your emotions are feeling out of control, you may need some extra support.

When we feel upset, frightened and hopeless it can seem impossible to explain these feelings to others or to ask for help. You might think that you shouldn't bother your CNS or GP about your feelings. But it's important to look after yourself emotionally as well as physically. There is help available. Take a look at the **Help for you** section in this guide.

Talk to the team looking after you, they will be able to help. This may be your GP, CNS or another health professional looking after you. They may recommend medication or a referral for counselling or cognitive behavioural therapy (CBT). These therapies can give you skills and empower you to take back control at a time when there seems to be very little control to take.

How it felt for me

"I'm not worried about my illness and treatment as I can't be in control of it. But I am 'bossy' about the bits of my life I can have control over like arranging transportation to and from hospital.

I don't try and think too far ahead. I'm a great planner but I try not to plan too much. My advice is to tackle what you can control and live day-to-day or week-to-week without making big long-term plans or wondering what will happen. Although it is hard to, I try to concentrate on the now."

Helen

"I've never been one for counselling or mindfulness. I've never been an anxious person. But I now have counselling every three weeks. When I first started seeing my counsellor my anxiety levels were high but they've come down since seeing her.

I do have my moments where I think 'I might not be here in six months.' But then none of us know that do we? It's only because I've got this illness that I think about it."

Claire

"I went through the stages of loss and grief when I found out I had an incurable diagnosis. I zip backwards and forwards through these stages at different times and I find it helpful to identify what stage I might be in.

One way that my family and I cope is to talk about the disease as if it's a third person. The disease is separate to me and my relationships with my children. In this way I am no different to anyone else because what we've all got in common is that we have a limited time on this earth."

Sarah

Cancer support centres

Most hospitals will have a cancer support centre. This may either be their own or a charity-run cancer support centre, such as a Macmillan or a Maggie's centre.

There may be a local cancer support centre closer to your home. These centres can be a great source of comfort and offer a range of specialist services. Some centres allow you to meet people in a similar situation. They are a safe environment where others will support you and understand what you're going through.

Cancer support centres will have:

- nurses who can help with cancer treatment and side effects
- psychologists you can speak to for emotional support
- support groups for you and for your family and friends
- complementary therapy sessions, such as acupuncture, massage and reflexology
- exercise sessions, such as yoga, tai-chi, walking and gardening
- practical and financial help.

Cancer support centres are run by qualified health professionals and trained volunteers. All cancer centre support is given free of charge.

> "I go to my local Maggie's cancer support centre regularly for different things. I attended their fatigue workshops as I was struggling with my tiredness. I'm now going to a cognitive and memory clinic each week. Their services are brilliant."
>
> **Claire**

How do I find out more?

- Your GP, CNS or another health professional that's looking after you can give you details of your nearest cancer support centre. Or ask our specialist nurses by calling **0808 802 6000**
- Use Target Ovarian Cancer's directory to find cancer support centres near you: **targetovariancancer.org.uk/support-groups**
- Find your local Macmillan support centre: **macmillan.org.uk/in-your-area**
- Find your local Maggie's support centre: **maggies.org/our-centres**

Hospice care

You might be worried about the idea of a hospice and think that they are only for people at the end of life. But hospices can be a great source of comfort and they offer a range of specialist services for all stages of cancer. Many people spend one or two weeks at a hospice to get extra **symptom control** before going home again. Symptom control is where any physical symptoms you have are assessed and eased or managed.

What is hospice care?

Hospice care values the whole experience of a person, as well as their family and friends. They don't just treat physical symptoms, they will support your emotional and spiritual needs as well. Many hospices around the UK are independent charities that work closely with local health services.

You may connect staying in a hospice with dying. Some people do choose to go to a hospice when they're near death. But many people come in and out of the hospice. Hospices are often beautiful buildings, with light airy rooms and lovely gardens. Many people are frightened of the idea of hospice care. But once they visit, they often wish they had met the hospice team earlier.

Types of hospice care

Hospices offer **inpatient care** where you can stay overnight at the hospice for a short period of time if you need to. This could be for a few days to have treatments to help you manage your symptoms. Referrals are usually made by a health professional who knows you and the hospice will offer you a bed when it's available.

Most hospices also offer **outpatient care** to people living with an incurable illness. For instance, you can visit for specific support once a week for a few hours.

Some hospices allow people to stay for **respite care**. This is a type of care that gives your family and friends who are caring for you a short break.

What services do hospices offer?

All hospice teams will offer:

- **symptom management** - by an experienced multi-professional team for symptoms such as pain, breathlessness and fatigue
- **advance care planning** – support making decisions about the treatment or care you would or wouldn't like in future
- **psychological support** - to help support your emotional and mental health
- **physiotherapy and occupational therapy** - to help you stay active and independent
- **complementary therapies** – therapies to complement your medical treatment and care such as massage, acupuncture or reflexology
- **spiritual care** – supporting you with your spiritual or religious customs and reflecting on your life
- **practical and financial advice** – support for things like adapting your home, claiming benefits and accessing your pension.

Hospice care is given free of charge by health professionals and experienced volunteers who have had extra training in palliative and end of life care.

> “My local hospice helped me to sort out my Blue Badge. They are arranging for physiotherapists and occupational therapists to visit me at home to help with arthritis in my hip. They also have Thursday afternoon socials which are nice to attend.”
>
> **Helen**

Can I have palliative or hospice care at home?

Most areas of the UK have palliative care and hospice teams who work in the community. Your GP, gynae-oncology CNS or hospital team can refer you to this team. The palliative care team will often have a palliative care consultant, a palliative care CNS and other health professionals to support you.

Your palliative care CNS will visit you at home to support you and help you to manage your illness. They can also support your loved ones. They may see you in an outpatient clinic if you're well enough to attend. They will agree a plan of care with you. This will include how often they will visit you at home.

There are also schemes such as **hospice care at home** where nurses give you care at home in the last weeks of life. Nurses can be from the hospice, community team or the Marie Curie charity. You can find out more about this type of care at **mariecurie.org.uk** and the National Association for Hospice at Home's website: **nahh.org.uk**

Your GP or CNS may ask you where you want to spend your final days. This is an emotional and difficult conversation, but it is important to talk about. To make the best choices for you, it's important to know what help is available in your area to support your wishes.

If the hospice or specialist palliative care team are seeing me, will my consultant and GP still stay in touch?

All the teams looking after you keep in close contact with each other. The hospice and palliative care teams then work with them to support you.

Your main contact depends on where you are being treated:

- if you are having care in the community, it's a GP
- if you are being cared for in hospital, it's a hospital consultant.

If you are only being cared for by the hospice team or by the specialist palliative care team, your hospital consultant and gynae-oncology CNS may hand over your care completely. But they will often stay in contact.

Your GP will also be able to tell you about any extra practical support that may be available locally. Other local services and charities may offer extra support. For instance, your local carers charity may be able to give advice to those caring for you at home.

Your GP, CNS or another health professional that's looking after you can give you details of your nearest hospice. Or ask our specialist nurses by calling **0808 802 6000**

Find your local hospice: **hospiceuk.org/hospice-care-finder**

Complementary therapies at cancer support centres and hospices

Cancer support centres and hospices may offer **complementary therapies**. These 'complement' the treatments you have in hospital. They are not alternative treatments for cancer. They can give someone a sense of wellbeing and relaxation. One-to-one or group therapies you may be able to have include:

- Reflexology, a type of therapy that applies gentle pressure to the feet or hands and that can be used for relaxation or to ease tired and strained muscles. Some people who have reflexology on their feet have said that this helps with **peripheral neuropathy** to the feet. This is damage to nerve endings, which causes numbness and tingling.

- Acupuncture, which can be given to ease symptoms of nausea (feeling sick) and vomiting (being sick) and also for pain.
- Group relaxation, which can be very helpful when you are feeling stressed or anxious. When we are anxious our brain finds it difficult to take in information. Often we just can't focus or think straight and may not sleep well. Relaxation can help you to deal with the range of emotions you may experience and gives the body time to recover.

Find out what your local cancer support centre and hospice offer and try different therapies to decide which one is best for you. A professionally qualified therapist can talk to you about what therapy options there are and what might suit you best.

How do I find out more?

- Read our online information at **targetovariancancer.org.uk/complementary-therapies** or download our information sheet called *Ovarian cancer and complementary therapies* at **targetovariancancer.org.uk/guides**

5 Living with your condition

In this section

- Choosing to stop work is a personal decision. Your work's Occupational Health or Human Resources department can support you in speaking to your team or manager.
- Adapting your home with specialist equipment can help you to feel more comfortable and make it easier to do things.
- There are different benefits available to you depending on if you can't work, need help with housing costs or have extra costs because of the cancer. You may also be able to claim your pension early.

Work

When you find out that you have incurable cancer, if and when you choose to stop working is a very personal decision.

You might have taken time off work for treatment in the past. You might have made a full return to your role, or you might have chosen to stop working. Some people want to continue working for as long as possible. For others, continuing to work may seem financially necessary. You may also come to a point when you feel too unwell to work.

It's important that your work is understanding and flexible to your needs. You should feel respected and supported by them as you decide what you would like to do.

You may want to talk to someone who is not in your team or management. If your workplace has an Occupational Health or Human Resources department then these are the ideal people to talk to. They can then represent your needs to your team or manager.

Working with Cancer has more information and support: **workingwithcancer.co.uk**

> "I have always been very open at work about my diagnosis. I gave them the letters from the hospital so they were informed. Last year I went down from working full-time to three days a week. My work has been incredibly supportive."
> **Sarah**

Your rights

Everyone living with or beyond cancer is protected against unfair treatment in the workplace now and in the future. This is under the Equalities Act 2010 in England, Scotland and Wales. This is under the Disability Discrimination Act 1995 in Northern Ireland.

Whether you have had symptoms or side effects or not, the law still applies. It also applies when you have finished treatment. Your work must make changes to help you work through treatment or return to work after treatment. This is as long as they know, or should reasonably know, that you have or had cancer. This might include:

- changing some of your duties
- agreeing different work hours
- allowing time off for appointments.

These changes are called **reasonable adjustments**. For more information search reasonable adjustments at **macmillan.org.uk**

This law also protects you from unfair treatment by future employers.

If your work ends your employment

Your work may be able to end your employment because of long-term health issues or because there are no reasonable adjustments that can be made.

Citizens Advice can help you understand any rights or support available to you: **citizensadvice.org.uk**

Stopping work

Most people with incurable cancer will choose to stop working altogether at some point. You may choose to stop work to spend more time doing things that you enjoy. Or it may be because you're too unwell to continue working.

Stopping work may feel particularly difficult to cope with if it has played an important role in your life. Stopping work can also be hard to cope with if you feel you haven't had a choice in the decision.

It can be helpful to talk to your friends and family, CNS or GP about how you're feeling. You can also speak to a therapist or counsellor about how you feel. Take a look at the **Help for you** section of this guide for details of how to find professional support.

If you choose to stop working you may be able to get your pension early. There's more information about this later on in this section of this guide.

For more information visit **targetovariancancer.org.uk/work-and-education**

What if there is a problem?

If you feel that your work is making unreasonable demands of you, you can get advice from:

- Citizens Advice: **citizensadvice.org.uk**
- Advisory, Conciliation and Arbitration Service (ACAS) for free employment advice: **acas.org.uk** or **0300 123 1100**
- If you are a member of a trade union, you can speak to your local representative.
- If your workplace runs an employee assistance programme you can use this service to speak with a trained professional about a range of issues including health and legal matters.

Adapting your home

You may consider adapting your home or getting some specialist living equipment to make day-to-day life a little easier for you. This could include:

- a hot water bottle or foam cushion to feel more comfortable when you're sitting down
- changing parts of your home, such as widening doorways or installing a stairlift
- buying special furniture to make moving around more manageable
- stairs often become more of a problem as an illness worsens. Downstairs living is a good option to consider.

Occupational therapists can help make home life easier. Speak to your district or community nurse, CNS or GP about what support is available.

You might be able to get some free equipment from your local social services department or on a long-term loan from the NHS or your local hospice.

Marie Curie has more information about adapting your home. Search **adapting your home** at **mariecurie.org.uk**

Financial help

Benefits

There are different types of benefits available. These depend on the impact the cancer has had on you and your finances. These include:

- benefits if you can't work
- help with housing costs
- extra costs because of the cancer.

Some of the benefits you may be eligible for are:

- **Attendance Allowance** or **Personal Independence Payment (PIP)** if you need help looking after yourself.
- **Universal Credit (UC)** or **Pension Credit** if you are on a low income.
- **Employment and Support Allowance (ESA)** if you can't work because of your illness or disability.

Anyone who is caring for you for at least 35 hours per week may also be able to claim **Carer's Allowance**.

There are special rules for sickness and disability benefits that might apply to you if you have an incurable diagnosis. For instance, you might be able to get benefits more quickly and at a higher rate.

For more information search **benefits and financial support** at **macmillan.org.uk** or **benefits** at **gov.uk**

Getting your pension early

You may be able to retire from work and get your personal or workplace pension early because you have cancer. This depends on your pension scheme. You won't be able to get your State Pension until you reach State Pension age.

There are different ways to get your personal or workplace pension early. You may want to speak to a financial adviser to consider your options. The Personal Finance Society has an online tool to help you find a qualified financial adviser in your area: **thepfs.org/yourmoney/find-an-adviser**

For more information search **getting your pension early** at **macmillan.org.uk**

How do I find out more?

- Target Ovarian Cancer has an information sheet called *Ovarian cancer and your finances* that you can download at **targetovariancancer.org.uk/guides** or you can read our online information at **targetovariancancer.org.uk/finances**
- Macmillan has a benefits calculator to find out the financial support you're entitled to: **macmillan.entitledto.co.uk** or currently (May 2025), you can call the Macmillan Support Line for specialist financial and benefits advice on **0808 808 0000**. In some areas there are benefits advisers. Speak to your CNS or GP to find out if they are available in your area.

6 Looking after your wellbeing

In this section

- You should be offered a Holistic Needs Assessment (HNA) to help you manage all areas of your life that have been affected by cancer. If you haven't been offered one speak to your GP or CNS.
- Physical activity can help you to cope with side effects such as tiredness and pain. Gentle exercise like yoga, walking and gardening can help your mental health too. Ovarian cancer and its treatment can reduce your appetite. There are things you can do to help with this.
- You may experience some uncomfortable symptoms from your treatment, medication or the cancer. Your GP, CNS or palliative care team can help.

Holistic Needs Assessment (HNA)

A **Holistic Needs Assessment (HNA)** is when you talk about your cancer care and support with a health professional to create a care plan. It is called holistic because you can talk about any area of your life that has been affected by cancer.

Having a HNA can help you get the support you need. This could be:

- symptom control for any side effects you have
- support with emotional worries
- a referral for more help and support, such as to physiotherapy or counselling
- help to plan ahead, for instance adapting your home
- occasionally a HNA can help you with advance care planning.

There are three parts to a HNA:

1. You will fill in a checklist or answer some questions about all areas of your life. This may be done in person or online.
2. You then will talk to a health professional about your answers. This is usually a member of the nursing team or a similar role.
3. Together you will create a care plan to manage any concerns you have.

If you have not been offered a HNA, speak to your CNS or GP.

Macmillan has more information about having a Holistic Needs Assessment. Download their booklet *Holistic Needs Assessment: Planning your care and support* at **be.macmillan.org.uk**

Physical activity

Being active can help you cope with side effects such as tiredness and pain. It can improve your mental health too. You may be worried about being more active but even small amounts of movement can be helpful. Gentle movement, such as yoga, walking or gardening, can help to you be more active and support your mental health.

Your CNS or a physiotherapist at your local hospice will be able to give you exercises that you can do at home. A physiotherapist is a trained professional who helps people affected by illness with movement and exercise.

Ask your healthcare team if you are not sure how much and what exercise you should do.

Many cancer centres or hospices have gentle exercise classes such as seated yoga. Instructors are trained to work with people who have had cancer treatment. Your local gym or leisure centre may also offer classes or a reduced membership rate.

> "I'm working with my palliative care team to get my hip pain under control so I can continue walking and being out in the fresh air which I love."
> **Helen**

How do I find out more?

- Target Ovarian Cancer runs free weekly online yoga and relaxation sessions for anyone with an ovarian cancer diagnosis. Sign up to take part: **targetovariancancer.org.uk/digital-events**
- Maggie's centres offer free classes for all abilities that are run by fully trained instructors: **maggies.org**
- Macmillan has more information on physical activity. Search **physical activity** at **macmillan.org.uk**

Diet and nutrition

You might find that the cancer, your treatment and medication have reduced your appetite. Foods might taste different and you may find that you can't eat as much as you used to. Try eating little and often rather than full plates at mealtimes. Liquid or soft foods such as soup and jelly can also be easier to eat.

Drinks such as fruit smoothies and milkshakes can help you build up and maintain your weight if you are finding it hard to eat. Adding a spoonful of any type of nut butter, ice cream and your favourite fruit can help you get some extra calories.

If you're feeling sick or being sick (vomiting) it can be difficult to eat three large meals a day. You may want to try:

- having more small meals and snacks throughout the day rather than three large meals each day
- eating cold foods as this helps you to avoid cooking smells which can sometimes make people feel sick
- eating slowly and sitting in an upright position
- eating at certain times of the day, for example not late at night.

> "My palliative care team have advised me with my diet to make sure I'm not constipated as bowel blockages are one of the things that can happen in the late stages. I've been reducing nuts and brown bread slowly. In the early evening I'm now beginning to find I don't want a whole meal."
> **Helen**

Ask the health professionals looking after you if you have any concerns or want to know more about whether certain foods and supplements may be right for you.

If you have to eat a different diet because of your treatment or because you have a stoma, you can ask your CNS or a dietitian for support with this. Dietitians work with people who need a different diet because of a health condition. You may also be able to access a dietitian through your local NHS.

If you would like to find a dietitian privately the British Dietetic Association has a database where you can search for dieticians who work with people with cancer: **bda.uk.com**

How do I find out more?

- Target Ovarian Cancer has an information sheet called *Ovarian cancer, diet and nutrition* that you can download at **targetovariancancer.org.uk/guides** or read our online information at **targetovariancancer.org.uk/diet**
- The World Cancer Research Fund studies the links between diet and cancer. You can download their booklet *Eat Well During Cancer* for recipe ideas and tips to manage side effects of treatment: **wcrf-uk.org**

- Maggie's offers free support for people affected by cancer and many centres have a dietician you can speak to. They also run workshops about eating well when you have cancer: **maggies.org**
- Penny Brohn UK has information on healthy eating and recipes: **pennybrohn.org.uk/resources**
- Macmillan has lots of information about diet, cancer and healthy eating, including lots of helpful videos. Search **healthy eating** at **macmillan.org.uk**

Controlling your symptoms

When you are living with incurable ovarian cancer you may have some uncomfortable or unfamiliar symptoms and side effects. They are different for everyone. Talk to your GP, CNS or another health professional caring for you about your symptoms. They can support you with symptom control.

In this section we've listed some of the common symptoms that you might experience.

Watch our recorded event about managing your symptoms: **targetovariancancer.org.uk/managing-symptoms**

Fatigue

Fatigue isn't just feeling tired but feeling exhausted most of the time. This may be due to conditions such as:

- **Anaemia**, where you have low levels of healthy red blood cells. It might be helped by iron supplements or an **iron infusion**, which is when iron is given to you through your vein. You might also be offered a **blood transfusion** to help anaemia, which is when you're given blood from a donor. For both these procedures you will have a needle in your hand or arm connected to a tube and a bag. The blood or iron runs from the bag through the tube into your vein.
- Low magnesium that might be helped by magnesium supplements or a magnesium infusion.
- Treatments, such as chemotherapy or radiotherapy.
- The cancer itself, as well as the emotions you're experiencing.

Gentle exercise can help with fatigue. Your CNS or GP should be able to tell you where you can join a **fatigue programme**. These can guide you through the right kind of activity as well as ideas on how to pace your life and cope with your changing energy levels.

Experiencing fatigue can mean you have to adjust your lifestyle or change your activities, which can be frustrating. Be kind to yourself as you find a pace you can cope with.

An occupational therapist can help you to:

- find solutions to continue or improve your independence in daily life
- manage fatigue.

They can give you tips and aids that will help you save your energy as you continue living your life. For example, you may find it useful to put a plastic seat in the shower or have a perching stool when cooking.

There are also medications that act as **stimulants**. These increase brain activity and may help your energy and alertness. Ask your CNS or GP about what might help you.

Abdominal ascites

Ascites is where fluid collects in the **abdominal cavity** and is caused by the cancer. The abdominal cavity is your tummy area. Ascites can cause:

- swelling in your tummy
- shortness of breath
- indigestion
- feeling or being sick
- reduced appetite
- fatigue.

You can have an ultrasound scan to confirm that any abdominal swelling is caused by fluid (ascites). The fluid can usually be drained using a procedure called **paracentesis**.

Paracentesis can often be done in hospital or some hospices, without the need to stay overnight in hospital. You will have a **local anaesthetic** where medicine is used to numb an area of the body. A very thin, soft tube is put into the abdomen (tummy) and connected to a bag. Ascites fluid will slowly flow into the bag over a few hours. The tube is then removed. This drainage can be repeated if the fluid collects again. Your doctor will discuss with you the right time for you to have this procedure.

If the fluid is collecting again quickly, an **indwelling drain** may be a better option for you. This is a semi-permanent tube that means you can manage your ascites at home by draining small amounts of fluid on a more regular basis to avoid a build-up of fluid. It is also known as a **PleurX** or **Rocket drain**.

Some people have **loculated ascites**. This is when the fluid collects in smaller pockets in the body and draining it might not be possible. If this happens, you'll be given advice by your GP or CNS. If you're finding it painful then they will be able to give you painkillers to help.

There may also come a time when the risks of having this procedure outweigh the benefits even if you have had it done before. For example, if you have low blood pressure. In this case, you will be given medicine to feel more comfortable rather than draining the ascites.

Loss of appetite

Losing your appetite can lead to weight loss and less energy. It can help to eat high calorie snacks little and often to avoid feeling bloated. If eating is really difficult you can try nutritional supplement drinks which your GP or CNS can recommend.

Try not to be concerned about your weight as this can go up and down throughout your illness with fluid retention. But if there is a drastic change in your weight speak to the healthcare team looking after you.

If your appetite is really poor and you're very tired, a short course of steroid tablets may be used to increase your appetite and energy. Steroids can have side effects if used for too long so a short booster course is given. Usually you will also be given another medicine to stop you from getting indigestion.

You can also ask to see a dietitian who can advise on the best way to keep up your food intake when your appetite is small.

Indigestion

Indigestion happens when your stomach acid comes back up your **gullet**. The gullet is the tube which food passes from the mouth to the stomach through. Indigestion is also called **heartburn** or **reflux**. It can feel painful or uncomfortable and can often be the cause of a cough.

Indigestion can be caused by anxiety, steroids, anti-inflammatory drugs, for example ibuprofen, ascites and **oral thrush**. Thrush is a fungal infection in the gullet or mouth. If thrush has been ruled out by your GP, palliative care CNS or district or community nurse, you can help by:

- trying over the counter antacids such as Gaviscon
- eating little and often
- eating your evening meal more than two hours before going to bed
- sitting upright when eating
- not drinking hot drinks or alcohol
- not eating foods that are acidic or spicy.

If these changes don't help, your GP or CNS can prescribe medicine to reduce your stomach acid.

Nausea (feeling sick) and vomiting (being sick)

Feeling and being sick can be caused by ascites, indigestion, constipation and medications such as strong painkillers, antibiotics and chemotherapy. It can lead to loss of appetite and weakness if not eased quickly. Things that may help ease nausea include:

- eating small, light meals such as soups
- eating cold food as this helps you to avoid cooking smells which can sometimes cause people to feel sick
- trying complementary therapies such as acupuncture or aromatherapy
- wearing 'travel sickness' bands
- crunching ice.

There are also many medications that help to reduce nausea and vomiting, depending on the cause. Speak to your CNS or GP about what might help you.

Good to know

If you're vomiting often and you're unable to keep food and drink down, it's important to tell your CNS or GP as soon as possible. You can quickly become dehydrated and unwell without treatment.

Shortness of breath

Shortness of breath has several different causes and can be managed in different ways:

- Ascites fluid can push up the **diaphragm** causing shortness of breath. The diaphragm is a muscle that separates the chest and abdomen. Shortness of breath can be eased by draining the fluid.
- Anaemia can cause shortness of breath and can be helped by a blood transfusion. Sometimes an iron infusion can help.
- Anxiety is closely linked to breathlessness. Deep breathing and relaxation can help. Pacing yourself, where you balance your activity with rest, can also help.
- Sitting near a fan or an open window will also reduce the feeling of being breathless.

Your local hospice may have clinics to help with breathlessness. A low dose of morphine liquid or medicine for anxiety can help with your breathing and to feel calmer. These medicines are usually taken as a tablet via the mouth but can also be given as an injection.

Good to know

Tell your GP or CNS if your breathing is getting worse. It's also important to contact your healthcare team if your shortness of breath is because of a new cough or chest pain. This may be due to a chest infection, fluid around the lung or a blood clot. All these conditions can be treated. But some, like blood clots, need to be treated quickly.

Lymphoedema

Lymphoedema is where there's extra fluid in the tissues of your body. This happens when your **lymphatic system** is blocked. The lymphatic system is a network of vessels and glands that clear out extra fluid in your body. If your lymphatic system becomes blocked, the fluid which it usually clears out will build up in tissues under your skin and lead to swelling.

The fluid is most likely to collect in your legs and ankles or your lower tummy, and **pelvic area**. This is the area between the lower part of the tummy and the tops of the thighs.

Lymphoedema can cause swollen heavy legs, reduced mobility and changes in your appearance which may be difficult to cope with. Your CNS or GP can give you practical advice on how best to manage lymphoedema. This includes:

- raising your legs
- gentle exercise

- good skin care, such as keeping your skin clean and moisturised. This is because skin injury or infection can make lymphoedema more likely.

If you are diagnosed with lymphoedema, you should be referred to a **lymphoedema specialist practitioner**. They will share treatments to help manage lymphoedema. These may include:

- doing a specialist massage to help drain the lymph fluid
- wearing support stockings, pressure pads and compression bandages to squeeze the legs to help trapped fluid to flow better and drain the area.

For more information about lymphoedema visit **targetovariancancer.org.uk/lymphoedema**

Pain

Pain can happen in any area that the cancer affects. For mild pain you can try:

- Paracetamol or ibuprofen. Check with your GP or CNS that you can take ibuprofen first.
- A warm bath or a heat pack.
- Relaxation techniques including specific movements or stretches.

If the pain becomes worse you should monitor where it is in your body, when it happens and whether anything makes the pain worse or better. This will help your healthcare team to prescribe the best pain relief.

If swallowing is difficult then you will be given painkillers and other medications to stop nausea and vomiting. They can be given as an injection or as a **continuous infusion** over 24 hours. This is where medication is given all the time through a needle.

For more severe pain, a stronger painkiller will be suggested such as morphine. You will need medication to avoid constipation and sickness with this type of pain relief. Strong painkillers can be given as:

- a liquid medicine that you take via the mouth
- a tablet that you take via the mouth
- a **painkilling patch**, which is stuck onto your skin to release painkillers through your skin. It may be a good option for you if nausea is a problem
- a **syringe driver**, a small battery-powered pump that gives medicine through a small tube or needle just under the skin. It also may be a good option if nausea is a problem.

You can discuss which option is best for you with your palliative care team, CNS or GP.

Some people worry about becoming addicted to strong painkillers such as morphine or that their body will get used to the medicine and need higher doses of it for it to work in future. But this is extremely rare when morphine is used in the right dose for the pain.

Palliative care teams are specialists at monitoring painkillers to make sure that they are right for you. In the right dose morphine is safe and really effective. The dose can be increased or decreased to manage the pain. Being free of pain means you'll have more energy and can do much more.

Good to know

'Just in case' medicines are medicines that are given to you to keep at home. They are prescribed for you for symptom control if your healthcare team think that you might need them at some time. They usually include:

- a strong painkiller such as morphine
- anti-sickness medicine
- medicine for breathlessness.

You may never need these medicines but it can be reassuring to have them if needed.

Constipation

Constipation is changes to how you poo, such as:

- not opening your bowels (pooing) as often
- a change in the consistency of your poo, for instance if it is hard
- finding it hard to poo, for instance if you are straining or it is painful.

Constipation can be caused by the cancer narrowing your bowel, ascites or some medications. You can help reduce constipation by:

- drinking enough water
- eating enough fruit and vegetables
- doing gentle exercise such as going for a short walk.

If these changes don't help talk to your CNS, palliative care team or GP. They can give you **laxatives**, which is a medicine that encourages movement in the bowels to help you go to the toilet. The right dose of laxatives can help you poo more regularly but shouldn't cause loss of control or explosive bowel actions.

If laxatives that you take by mouth don't help, you may need other treatment. This can include:

- **suppositories**, which is medicine that is pushed gently into the anus (bottom)
- an **enema**, where fluid is put into the lower bowel through the bottom.

These may be given by yourself or by a nurse.

Bowel blockage

If you have constipation along with nausea, vomiting, tummy pain or a swollen tummy it could mean that your bowel is blocked. This is called a **bowel blockage or obstruction** and means that the waste from digested food can't get past the blockage. Your bowel may be partially or completely blocked. This can be caused by:

- something on the inside of the bowel blocking it, such as cancer or poo
- something pressing on the bowel from the outside, such as cancer or ascites fluid
- irritation to the nerves of the bowels, which can cause the muscles to stop working.

If you have symptoms of a bowel blockage, contact your GP, CNS or healthcare team straight away.

Sometimes the blockage can be eased by **resting the bowel**. This means stopping eating and drinking until your bowel is working normally again. If you're resting the bowel, you may need fluids through a drip to stop you getting **dehydrated**. This is when your body loses more fluids than it takes in.

Your healthcare team will talk to you about how to make sure you don't become dehydrated.

Sometimes steroids can help. If you have ascites pressing on the bowel, draining the fluid can help. Laxatives can also help if there's poo blocking the bowel.

Your healthcare team can give you medicine to reduce any tummy pain or nausea you have from the blockage. These medicines may need to be given by injection or a syringe pump rather than by mouth to ensure they are absorbed properly.

A **nasogastric tube** may also be used to reduce nausea and vomiting. This is a temporary tube that's inserted from the nose into the stomach and allows fluid to drain away. It's easy to remove once the bowel starts working again.

Sometimes a bowel blockage can keep coming back. If this happens, it's important to actively manage your bowels and reduce the likelihood of constipation and obstruction. You can do this by:

- drinking lots of fluid
- eating a soft, easily digestible diet. This is usually a low residue, low fibre diet
- taking the right laxatives to keep your poo soft and the bowel open.

If you have a bowel blockage you will often need to stay in a hospice or hospital to control the symptoms you're having.

There may be surgical options to treat your bowel blockage. But sometimes there's no easy way treat the blockage with surgery or medicines. This is called **intestinal failure**. If you're well otherwise (up and about), but your bowel can't be cleared, then there may be specialist options to help with nutrition. Your team may refer you to a specialist bowel centre to consider these options.

Surgical options for bowel blockage

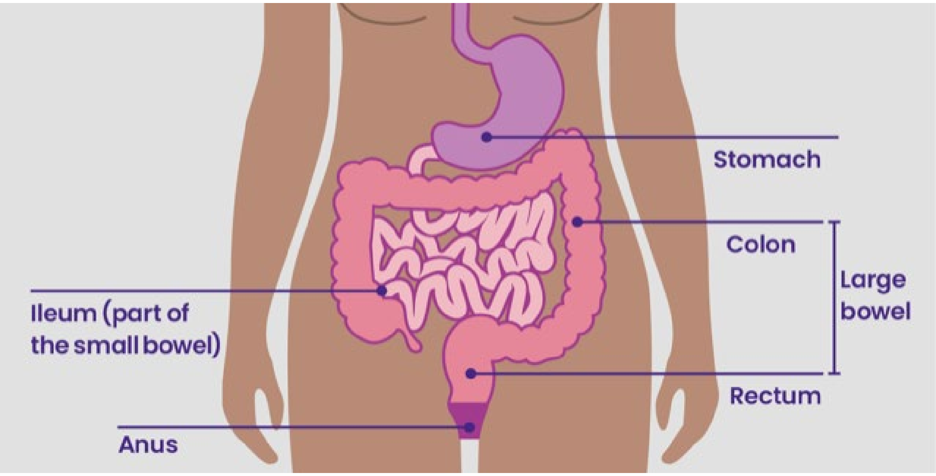
If a bowel blockage doesn't clear using the ways we explain in this section, and there's a clear single blockage, you may be offered surgery to remove a part of the bowel. This is often a difficult decision and not taken lightly.

It's important that you speak to your own clinical team and surgical team. Everyone is different and your team will know the opportunities and challenges for managing the bowel blockage.

The surgical options for bowel blockage depend on:

- where the blockage is within the bowel
- if it is possible to operate on
- what your wishes are.

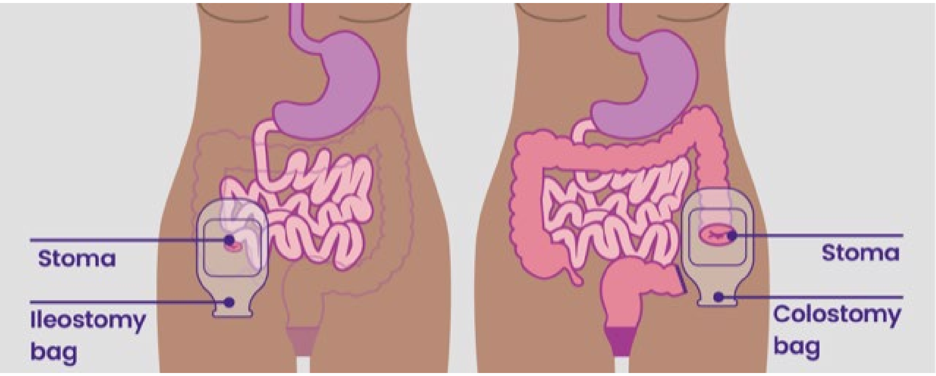
If surgery is possible then you may need a **bypass operation** to reduce potential symptoms such as pain and vomiting. In most instances the affected area of the bowel can be removed and the two ends put back together.



Sometimes it isn't possible for the affected area of the bowel to be removed and put back together. Your body will need a new way for your poo to leave your body. In this instance the surgeon will make an opening through your abdominal wall (tummy) and onto the skin and bring the end of the intestine (bowel) through it. This called the creation of an **ostomy** or a **stoma** (an artificial opening).

Whether you have a **colostomy** or **ileostomy** depends on which part of the bowel is used. It's commonly called a colostomy if it involves the large intestine (colon) or an ileostomy if it involves the small intestine. The end of the bowel that's open is sewn directly onto the skin and is called a stoma.

To make sure that the poo is contained as it leaves the body, a special appliance will be attached to the skin, along with a **stoma bag**. This bag will need to be changed and emptied.



Your surgeon should talk to you about the options before surgery, along with a type of CNS sometimes called a **stoma nurse**. Your stoma nurse will continue to support you after the surgery to help you get used to your stoma.

You can read more about the different types of stomas and how to manage them:

- Order or download our guide *Ovarian cancer and stomas* at **targetovariancancer.org.uk/guides** or by calling **0808 802 6000**
- Read our online information at **targetovariancancer.org.uk/stoma**

You can also find information about stomas at:

- Colostomy UK: **colostomyuk.org**
- Ileostomy & Internal Pouch Association: **iasupport.org**

Clinical trials

The team looking after you might suggest taking part in a **clinical trial**. Clinical trials are research studies that explore potential new drugs, new ways of giving treatment or different types of treatments. Often studies are **randomised**. This means that, like tossing a coin, you will be put into a group by chance. These groups are sometimes called the **treatment group(s)** and the **control group**. Depending on the type of trial, groups may be split in different ways:

- One group may be given the new drug being tested and the control group would be given standard treatment, so that they can be compared.
- The treatment group might be given the new treatment and the control group might be given a **placebo** as well as standard treatment. A placebo is a treatment that has no effect.
- Both groups may be given the new treatment but in different ways.

- Some trials may be comparing more than one new treatment at once so there may be a few different treatment groups.

You might not always know which group you're in, but you will be closely monitored no matter which treatment you have. This may include more regular tests and checkups during or after treatment.

Each clinical trial has strict criteria (rules) for who can join the trial. This is to make sure that the treatment is tested on similar groups of people and that we know who the results of the trial apply to.

Not all cancer centres are involved in clinical trials. You should ask your oncologist what trials you might be suitable for and where (in which hospitals) the trials are happening. You might want to ask:

- What trials are suitable for me at my local treatment centre?
- If I'm willing and able to travel, what trials are available at other centres?
- What is the aim of the trial?
- What is the evidence that this new treatment might be effective?
- What are the possible risks and benefits of taking part?
- What would taking part involve?

You may also be asked to take part in research studies, for example into your wellbeing. This may involve completing surveys or being interviewed.

You can decide if you join a clinical trial or a research study or not. You can search all live UK ovarian cancer trials on our website: **targetovariancancer.org.uk/clinical-trials**

7 Thinking about the future – advance care planning

In this section

- Advance care planning means making decisions about the care and treatment you would or wouldn't like in future, talking to your family and friends and writing your decisions down for them, your clinical team, and palliative care team.
- There are three ways to write your preferences for your future care and treatment: an advance statement, an advance decision to refuse treatment (ADRT) and a lasting power of attorney (LPA) for health and welfare.
- You can write or update your will yourself, use a solicitor or an online service. Charities like Target Ovarian Cancer also offer a free will writing service.

When you are told that the ovarian cancer is incurable, you may start to think about what's important to you before and after you die.

You may also think about the future when the cancer makes you more unwell. Or perhaps when you or your clinical team are thinking about stopping active treatment. Instead, your team will be controlling your symptoms rather than trying to control the cancer.

You may be a person who likes to plan ahead. Or perhaps a stay in hospital has made you think about the 'what ifs', such as:

- What or who is most important to me if I get more ill?
- What do people need to know about me to care for me?
- What if the people who are caring for me need help for me to stay at home?
- How do I decide and say what treatments I might not want in the future?

What is advance care planning?

Advance care planning means making decisions about the treatment or care you would or wouldn't want in future. You can talk to your family and friends about your decisions and write it down for them and for your healthcare team.

By writing down your decisions, your preferences will be known and can be followed if you're ever unable to tell the people around you. Many people feel more in control after writing down their wishes. It gives them peace of mind to continue living their life now.

Talking about advance care planning

It is important to talk about advance care planning. Take time to consider what matters to you. Is it about making specific decisions? Or is it about talking to your loved ones about what matters most to you? Take as much time as you need to.

Good to know

Some of the questions that you might want to think about are:

- If your health worsens what are your most important goals?
- What are your biggest fears or worries?
- How much does your family know about your priorities or wishes?
- What does a good quality of life look like to you?
- What would a good day look like?
- Who and what matters to you?
- What do people need to know about you to care for you?
- How do you like to talk about these things?

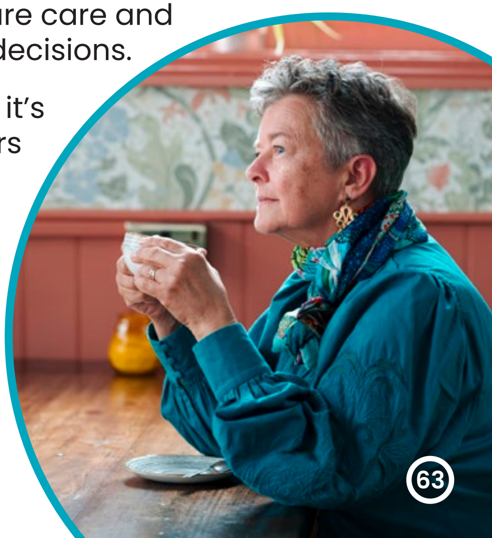
Compassion in Dying can help you talk about your wishes for end-of-life care with family, friends, doctors and nurses. Download the guide *Starting the conversation* from **compassionindying.org.uk** or call their nurse-led support line on **0800 999 2434**

Recording your care and treatment wishes

Once you've thought about your future care and treatment you can write down your decisions.

To support you as much as possible, it's helpful for your family, friends, doctors and nurses to know:

- what's important to you
- what your future wishes are
- the decisions you make about your treatment and care
- any treatments you don't want.



There are three main ways to write down your preferences for your future treatment and care:

- **advance statement** – writing down what's important for your care
- **advance decision to refuse treatment (ADRT)** – a statement written in advance about medical treatments that you don't want, if you cannot say so yourself at the time
- **lasting power of attorney (LPA) for health and welfare** – appointing someone to speak on your behalf about your care and treatments.

These documents have different names depending on where you live in the UK:

England and Wales	Advance statement	Advance decision to refuse treatment (ADRT), also called a living will	Lasting power of attorney (LPA) for property and financial affairs and/or health and welfare
Scotland	Advance statement	Advance directive, also called a living will	Power of attorney for property and financial affairs only
Northern Ireland	Advance statement	Advance decision to refuse treatment (ADRT), also called a living will	Enduring power of attorney for property and financial affairs only
What we call it in this guide	Advance statement	Advance decision to refuse treatment (ADRT)	Lasting power of attorney (LPA)

Advance statement

An advance statement is a way for you to write down what's important to you about your care. This is so that everyone involved in your care knows what care you would prefer.

An advance statement isn't legally binding, but it must be taken into account for any **best interests decision** and it does hold legal weight.

What is a best interests decision?

Making a decision in someone's best interests means considering:

- the person's past and present wishes
- their feelings, beliefs and values
- the clinical options available.

The decision should reflect the choice that the person would make for themselves if they could.

In your advance statement you could include:

- Where you want to live and be cared for at the end of your life.
- Who's important to you and who you would want to be involved in making decisions about your care. But be aware that these people won't have legal rights to make decisions if they are only named in an advance statement.
- Whether you would want to go to a hospice for care at the end of your life.
- How you like spending your time and things that bring you pleasure.
- Any spiritual, religious or cultural practices that are important to you.
- Important information about your health.
- Important people in your life.

- Your lifestyle and habits which are important to you such as your favourite fragrances, songs or music, or things like wanting to have your hair and makeup done every day.
- Your food preferences and allergies.

Advance decision to refuse treatment (ADRT)

An advance decision to refuse treatment (ADRT) is a legal document that anyone in the UK can make. ADRTs are legally binding in England and Wales. They also hold legal weight in Scotland and Northern Ireland.

In Scotland an ADRT is called an **advance directive**. In Northern Ireland it is called an **advance decision to refuse treatment**. You may also hear ADRTs called a **living will**. In this guide we call it an **ADRT**.

An ADRT must be made when you have capacity (the ability) to make decisions. It can be used to record any tests and treatments you don't want to have if you become more unwell. This can help you to stay in control of future treatment decisions and keep a quality of life that's meaningful to you. Your ADRT is used if you can't say what you want yourself in future.

An ADRT must be signed and witnessed to make sure that your decisions about treatment you don't want (refuse) are upheld, if you can't say so at the time.

If you don't make an ADRT and lose **mental capacity** to make decisions, a doctor will have the final say on decisions that need to be made about your treatment or care.

What is mental capacity?

Mental capacity is when you can make a decision for yourself. While you have mental capacity you have the right to make choices about your medical treatment and care.

Lasting power of attorney (LPA)

Lasting power of attorney (LPA) is a legal document that lets you appoint one or more people to make decisions on your behalf.

In Scotland this is called a **power of attorney** and in Northern Ireland it is called **enduring power of attorney**. In this guide we call it an **LPA**.

In England and Wales there are two types of LPA. You can choose to make one type or both:

- **Property and financial affairs (in all areas of the UK)** – you can give this person the power to make decisions about money and property, for example managing a bank account or paying bills. This person can speak on your behalf from any time that you authorise them to do so.
- **Health and welfare (in England and Wales only)** – you can give this person the power to make decisions about things like your daily routine and medical care. It can only be used if you're unable to make your own decisions or express your wishes at the time.

Having a health and welfare LPA can be reassuring. It means someone that you trust will act on your behalf if you're unable to say your wishes and decisions yourself. This might include accepting or refusing medical treatment for you.

It's very important to choose someone who understands your wishes for treatment, especially if you know that there's specific treatment that you don't want in the future or have thought about making an ADRT.

It can also be helpful to make sure you have an advance statement and advance decision in place. This is so that your LPA can evidence your wishes if challenging decisions need to be made.

In Scotland and Northern Ireland, you can only give someone power of attorney for your property and financial affairs.

In Northern Ireland, you can nominate an enduring power of attorney under the Mental Capacity Act 2016. At the time of this guide's publication (May 2025), this currently only allows your chosen person to make decisions about your property and financial affairs, it doesn't yet cover health decisions.

Good to know

Can I have both an ADRT and an LPA?

You can have both an ADRT and an LPA for health and welfare. If you do, the one that you made more recently will take priority when a decision needs to be made about your treatment or care.

How do I find out more?

- Compassion in Dying has free online and printed forms to make your advance statement and a *Planning ahead* guide to help you choose what's right for you: **compassionindying.org.uk**. They also offer a nurse-led support line to help you fill in the forms on **0800 999 2434**
- My Decisions is a free online tool from Compassion in Dying to help you make an ADRT (living will): **mydecisions.org.uk**
- For more information about setting up a power of attorney and the different types across the UK visit **gov.uk/power-of-attorney** or search **attorney** on **mariecurie.org.uk** or **macmillan.org.uk**
- MyWishes is a free online tool to document your future care wishes: **mywishes.co.uk**

How it felt for me

"The reality is that you do have to do these things, like, organise your affairs, make your will and talk about things that might be horrible to talk about. But once you've done them, you feel a bit better. Doing these things helps you get to the point where there's more acceptance. It's difficult to talk about death but it's one of life's shared experiences."

Sarah

"My hospital referred me for palliative care and my GP surgery arranged for me to have an appointment with a nurse to discuss advance care planning. My sister came to the appointment with me. I never felt rushed as we discussed my decisions and filled in the ReSPECT form (an emergency care information form) with the nurse.

I brought quite a lot of useful information with me because my sister had previously arranged to do lasting power of attorney forms with me. My sister is my power of attorney and I'm her and her husband's power of attorney. So we brought all that information with us, which was good because that all went on to the ReSPECT form.

It's helpful to make all these decisions early rather than last minute. Yes, it can be scary, but I'd rather do it when there's plenty of time to talk about my options."

Helen

Making a decision for someone else

If someone can't make a decision for themselves because they have lost mental capacity, then the decision needs to be made by someone else. This is called making a best interests decision. The responsibility for making decisions falls to health professionals not family members unless:

- you have made an ADRT
- you have appointed an LPA for health and welfare.

A best interests decision is needed for anything not covered in your ADRT if you don't have capacity to make the decision yourself. For example, if you have a medical condition, like a stroke, that isn't covered in your ADRT. In this situation, a best interests decision will need to be made for you, either by the doctor in charge of your care or your LPA for health and welfare if you have appointed one.

If an ADRT is in place for the decision that needs to be made, then a best interests decision wouldn't be needed. As the ADRT is legally binding, it takes priority over decisions made in your best interest by other people.

If you have an ADRT but it doesn't apply to the situation in which a best interests decision needs to be made, then the ADRT can be used as a guide when making the best interests decision.

Do not attempt cardiopulmonary resuscitation (DNACPR)

Do not attempt cardiopulmonary resuscitation (DNACPR) is a decision not to attempt **cardiopulmonary resuscitation (CPR)**. CPR is a treatment used to try to restart someone's heart and/or breathing.

A DNACPR is a document signed by a doctor and made in advance to guide health professionals whether to attempt to restart the heart. You may also hear it called a **DNAR** or a **ReSPECT form**. In this guide we call it a **DNACPR**.

Resuscitation can be **chest compressions**, which is when someone uses their hands to push down hard and fast on the chest. Resuscitation can also be done by using a machine to stimulate your heart with electric shocks.

Often people feel as they near the end of their life that they don't want CPR. Doctors are likely to advise you that resuscitation would be unsuccessful if you have advanced ovarian cancer. With a DNACPR, while CPR wouldn't be attempted, this doesn't mean that other treatments wouldn't be offered to you.

Sometimes a doctor or nurse may talk to you about it if they feel that it's unlikely that your heart could be restarted due to your condition. You may also wish to start the conversation with your healthcare team.

Resuscitation Council UK has FAQs where you can find out more about DNACPR: **resus.org.uk/faqs/faqs-dnacpr**

Good to know

Doctors, nurses and paramedics have clinical handover systems which mean they can know decisions about people's DNACPR if they are called unexpectedly to see them. This is the case if they are in hospital, a care home or at home.

Talk to your GP or CNS if you would like important decisions you have made about your care or any specific information about you shared in this way.

You may also choose to share your documents yourself with anyone involved with your care. This includes your clinical team, palliative care team, GP and local ambulance trust. It can give you peace of mind that they're aware of your wishes.

The ReSPECT process

The **ReSPECT process** stands for **Recommended Summary Plan for Emergency Care and Treatment**. ReSPECT records your emergency care information so that health professionals can access it quickly. This means that in different care settings they can make immediate decisions about your care and treatment in a crisis. It covers more decisions about treatment and care than DNACPRs.

The ReSPECT process is used in some areas of England and Scotland. Northern Ireland is currently working towards using it at the time of this guide's publication (May 2025).

For more information about the ReSPECT process visit **resus.org.uk/respect**

Making or updating your will

By making a will, you can make sure that when you die your assets and belongings go to those who you feel should or would benefit most. Your will should set out:

- who you want to benefit
- who should look after any children under 18
- who your **executor** is. This is who's going to sort out your **estate** (everything you own) and carry out your wishes after you die.

You can write your will yourself, but you should get advice if your situation isn't straightforward. You also need to get your will formally witnessed and signed to make it legally valid.

For more detailed information about making a will visit **gov.uk/make-will** or search **making a will** on **citizensadvice.org.uk**

Good to know

Whether you're updating your existing will or writing one for the first time, there are organisations or professionals that can help.

You may wish to use a solicitor or an online service to write your will. Many charities, including Target Ovarian Cancer, support you to make updates or write a will for free. You don't need to leave a gift in your will or donate to charity to write your will for free, but some people do wish to leave a gift in their will.

Visit **targetovariancancer.org.uk/legacy** or call **020 7923 5474** to speak to one of our team members about how we can help.

Thinking about your digital legacy

It might be helpful to think about what happens to your online and social media accounts after you have died. This is known as your **digital legacy**. You can write down what you want to happen to each account to help people follow your wishes.

You can keep details of what you would like to happen to your online and social media accounts in your will or in a separate digital will.

Marie Curie has more information about managing your online accounts and how to write down your wishes. Search **online accounts** at **mariecurie.org.uk**

Digital Legacy Association has information and guides to help you manage your digital legacy: **digitallegacyassociation.org**

Top tips for choosing what happens to your online and social media accounts

Online accounts and social media sites will have different options for what you can do. They include:

1. Setting up a legacy contact to manage your account after you die – Apple, Google and Facebook have this option.
2. Creating a backup and downloading a copy of your data to save photos and messages.
3. Memorialising a social media account so it can be seen by friends but no one can make changes to it.
4. Deactivating an account so it can no longer be seen but information may still be stored if someone needs it.
5. Deleting an account so that your information is permanently removed.

Thinking about a funeral

You may have been to funerals for friends or family members that you thought had aspects that you would want to include in a celebration of your life. Or you may know what you definitely don't want. Talking about these thoughts might help those close to you feel confident that they can help you carry out your wishes. Some families might find this difficult and avoid it. If this is the case, you may need to write things down for them.

How much you plan is up to you. It might be anything from the type of funeral, to every last detail – music, flowers, or even a message for those who attend.

You can also write a letter of wishes which is addressed to your executors. This is the person or people responsible for carrying out the instructions in your will. The letter of wishes can include:

- giving guidance
- listing your assets
- details of funeral arrangements
- information explaining your will.

You can include anything that makes you feel comfortable and confident that your wishes will be carried out.

How do I find out more?

There are lots of organisations that can provide practical advice and support for thinking about the topics that have been discussed in this section. The resources below might be helpful to look at now, or to keep for when you feel ready:

- Compassion in Dying help you prepare for the end of life including how to talk about it, plan for it, and record your wishes: **compassionindying.org.uk**
- Hospice UK's Dying Matters campaign aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life: **dyingmatters.org**
- Macmillan has very good information about planning for the future with advanced cancer in their booklets *Planning ahead when living with cancer - England and Wales*, *Planning ahead when living with cancer - Scotland* and *Your life and your choices: Plan ahead, Northern Ireland*, available to download at **be.macmillan.org.uk**

8 Families, children and creating precious memories

In this section

- Many hospices have teams who can support children who are facing the loss of a parent. Meeting your local hospice team before death can give continuity for your children in the future.
- Creating a memory box, writing special letters or recording videos are some of the ways you can continue your voice, hopes and dreams for your children into the future.
- For professional help to plan for your child's future or advice on how to talk with them, speak to your local hospice, your child's school or your GP or CNS for support.

In this section Dr Ros Taylor MBE, a hospice medical director, shares some insights from her work with families during her long career in hospice and palliative care.

We know that those who are left behind hugely treasure memories that have been crafted especially for them. This is especially important for children and teenagers. There are so many creative ways to continue your voice, your hopes, your dreams into the future, and your children or grandchildren will truly treasure this.

It can be really uplifting work but it's also sad and emotional. We have often found that it's best to work with a close friend or family member, or perhaps a therapist from your palliative care team who will have the skills to guide you.

Many hospices have teams who can support children who are facing the loss of a parent and a meeting with this team before you die can give some vital continuity for your children in the future. Early psychological support can really help children, even if it is difficult for you.

There are now so many simple, creative ways to capture precious memories, stories and your voice. Involving the children and the whole family will make the work even more special and keep your memory alive. We know from the work we do with children who have lost a parent how important this is. Children often talk about the creative times when mum was ill – times of real closeness that will sustain them in the times ahead.

Memory boxes and special letters

You may want to consider creating a memory box for your children – a special box filled with photographs, treasured objects or souvenirs from trips – reminders for your children of special moments with you and your relationship with them. This can be heartbreaking work to do, and so easy to put off, but it is really treasured.

You may want to leave letters to be opened on every birthday. We know a young mum who left a special sum of money in her will to buy Christmas presents for her children every year.

Your digital legacy

It's so easy now to make videos on our phones, capturing special moments, or simply sharing thoughts and hopes for your children, perhaps telling a favourite story or remembering a holiday. Recordings of your voice, or videos of times together will be treasured. Don't leave it too late. Short messages recorded on your phone when something comes to mind might be easier than one long emotional message.

Apps on your mobile phone can help you collect photos, messages and music in one place. Some hospices also have services to help with memory making such as recording your voice.

Planning a future for younger children

There are often huge practical concerns about your children's future care, particularly if you're a single parent. These may feel like unbearable conversations, trying to imagine your child's life without you – but it's so important to make your mark on these plans. You know so much about your children, what makes them tick, their likes, their hopes and their fears.

Once you know who your children's guardians will be in the future – whether it's your husband or wife, partner, family member, whoever – there's so much information you could share that would make the job of bringing up your children easier for those who have that honour.

For instance, we remember a mum who was really worried that no one could do her daughter's hair properly. Her husband had simply never learnt how to plait her daughter's hair. She was worried that this would be a source of distress after she died. Of course she taught her husband how to do it. These treasured moments can actually bring you closer and make you feel more at ease that your children's lives will perhaps be disrupted a little less.

We know how resilient children are in the face of loss. But we also know how keen they are on routine. It's these routines, that perhaps only you might know, that need passing on in a systematic way to those who are going to have a big role in your children's lives in the future.

If you need professional help to plan for your children's future, or just need advice on how to talk with them, then the local hospice may be a good place to start – many have a family and children's support team, or will know where you can get local help. If you don't have a hospice near to you, then your child's school, and your GP or CNS will know of local support services.

There are more tips for talking to children in the **Dealing with the news** section earlier in this guide.

Support for your children

Information and support to help children and young people who are facing loss:

- Ruth Strauss Foundation offers a tailored Family Support Service both before and after bereavement: **ruthstraussfoundation.com**
- Winston's Wish is a charity giving hope to grieving children and young people: **winstonswish.org**
- Child Bereavement UK supports bereaved children and young people: **childbereavementuk.org**
- Macmillan has information to help you talk to children and teenagers and to help you understand their reaction. Search **preparing a child for loss** at **macmillan.org.uk**
- Young Minds has information to help you support your child or young person with **grief and loss**. Search grief and loss at **youngminds.org.uk**
- Hospice UK has information to support someone with a bereavement. Search **support with a bereavement** at **hospiceuk.org**

Notes from Alison

“Thinking about the end of our lives, perhaps making some plans, or gaining a sense of putting your house in order, is very important. Whether this involves saying goodbye to friends and family or resolving unfinished business, it can all help give us some peace of mind.

Making plans about end of life treatment isn’t something that anyone would find easy but people have said that they find it reassuring to have these plans in place and to be able to talk to their family, friends and doctors about them.

We hope we have encouraged you to indulge yourself and let your family and friends indulge you too. Do be careful that you’re not getting too exhausted by all the attention you are receiving though. Your family and friends won’t mind if you set some boundaries, for example asking them not to call between 2pm and 4pm because you’re having a rest or going for a walk.

Do seek help from professionals and charitable organisations should you need it. Sometimes talking to someone outside your immediate circle can be very helpful, as you may be tempted to hide your true feelings from your family and friends.

Wondering why you got cancer and how it’s affected you as an individual is normal. So is thinking about the purpose or meaning of life and where the cancer fits in. Facing incurable ovarian cancer might be making you think “Why me?” and “What’s it all about?”

Finding meaning in life might be about feeling part of something that’s bigger than we are. Some people find meaning in their relationships or by feeling connected to their community. Some people find their religious beliefs helpful at this time. Spiritual wellbeing is a sense of calmness and peace which, if you don’t have a formal religious faith, can be found in nature, meditation or doing something creative like painting or listening to music. Even something simple like lying in the sun listening to birdsong can give you a sense of spiritual wellbeing and can be a great comfort.

No one can deny that this is a challenging time for all concerned. You may occasionally feel that things are pretty hopeless, but hope can be achieved in a number of ways, even the hope of keeping your quality of life as good as possible for as long as possible. Hope is the emotion you experience when you have something to look forward to. It may be the visit of a grandchild, an outing with a friend, a future wedding or finishing a book. Some people find that setting goals that are not too ambitious, can be fairly easily achieved, and can be measured, helps to give them hope. Hope is hugely important. It provides a way forward even when life looks bleak.

If you understand your medical condition and have good support from family and friends, then you’re likely to be better able to cope with ovarian cancer. All these factors contribute to your psychological and spiritual wellbeing. Even if not all these factors are present we do hope we can help you achieve some peace of mind and that the advice offered will help you to continue to enjoy your life for as long as possible.”

9 Help for you

It may take time to adjust after finding out that the cancer is incurable. It's OK if you have days when you feel upset. But if these happen more or your emotions are feeling out of control, you may need some extra help. If you're worried, speak to your CNS or GP. The following services can also help.

Target Ovarian Cancer

Support line

Need someone to talk to about ovarian cancer?

Call our nurse-led support line and you'll speak directly to a specialist nurse. Our specialist nurse team have supported thousands of people just like you. Whether you need practical information, advice or just a listening ear, we're here for you.

Call us today: **0808 802 6000**

Our support line is open Monday to Friday, 9am – 5pm, excluding bank holidays. Calls are free from UK landline and mobile phones.

If you don't feel like talking, please use our contact form or email **support@targetovariancancer.org.uk**

Facebook groups

Our Ovarian Cancer Community group is a kind, supportive, private group for everyone affected by ovarian cancer, including friends and family. You will find support to help you every step of the way.

Our In Touch group is a safe and supportive space only for those with an ovarian cancer diagnosis. This is a private community where you can talk honestly and openly about how you are feeling – and find comfort and understanding from others living with ovarian cancer.

Join us today: **targetovariancancer.org.uk/community**

> "I'm a member of Target Ovarian Cancer's online support group, In Touch. Through this and Target Ovarian Cancer's digital events, I've reconnected with a lovely lady who used to live in my village who was diagnosed with ovarian cancer at almost the same time as me. It's so nice to chat to other people with the same diagnosis and I learn so much about how the disease might progress from being in touch with people from across the country. I find it really reassuring."
>
> **Helen**

Support events

Our programme of digital events is shaped by you and the support that you have told us you need. From diet and nutrition tips to updates on new treatments, yoga and relaxation classes to having a virtual cup of tea and a chat, there is lots to explore. Our support events also offer you the chance to meet leading experts as well as others affected by ovarian cancer.

You can find out more and sign up to our upcoming support events on our website: **targetovariancancer.org.uk/support-events**

To watch our previous events back at a time that suits you, visit our YouTube playlist: **youtube.com/@TargetOvarianCancer/playlists**

Website

Our website **targetovariancancer.org.uk** has more information about ovarian cancer as well as stories from women who have had a diagnosis of ovarian cancer.

You can also download or order more of our guides for free at **targetovariancancer.org.uk/guides**

Register to receive the latest news, information and events by email at **targetovariancancer.org.uk/signup**, and follow us on Facebook, X and Instagram.

Online and telephone support

- The Macmillan Support Line is available every day, 8am - 8pm. You can contact them for free on **0808 808 00 00**. This service also offers an interpretation service in over 200 languages.
- Maggie's provide cancer support where you can access specialist advisers and meet others through online support groups. Contact your local Maggie's centre for more information: **maggies.org**
- Samaritans are also available 24 hours per day, 365 days a year and you can talk to them about anything that is troubling you. They are available by calling **116 123**, free of charge, or by emailing **jo@samaritans.org**

Support groups

Simply being around people who know what you're going through can help. Often groups have members who have had different types of cancers but there may be a group just for those with gynaecological cancers.

Support groups are for sharing experiences and for helping each other with emotional and practical support. If you have any questions about your treatment or care, speak to the health professionals caring for you.

Your CNS may run a support group locally or you can visit **targetovariancancer.org.uk/support-groups** or call **0808 802 6000** to find a group near you.

Psychological therapies

You may find professional support useful to help you deal with your feelings and emotions. Psychological therapies support your mental health during difficult times. They allow you to talk to a trained professional about your thoughts and feelings. There is more information about all these options on our website. Visit **targetovariancancer.org.uk/support** or call **0808 802 6000**

- Counselling is where you speak to someone about your worries and fears. A counsellor's job is to listen and allow you to talk. Many hospitals can refer to counselling services. Cancer support centres and hospices may also offer free counselling. Ask your CNS, GP or local support centre for more information. If you would like private counselling, you can find a registered counsellor through the British Association of Counselling and Psychotherapy (BACP). You can visit their website **bacp.co.uk** or call **01455 883 300**
- Psychological support looks at how cancer has affected your life and wellbeing. A psychologist will be able to talk to you about how cancer is affecting you. They can then decide what type of psychological treatment may help you. The British Psychological Society (BPS) can help you find a

psychologist in your area. They offer the service in different languages if English is not your first language. You can visit their website **bps.org.uk** or call **0116 254 9568**

- Cognitive behavioural therapy (CBT) looks less at the causes of your feelings and more at what to do about them. It looks at how the way you think can make you feel and act. It then works to improve your reactions to difficult situations by finding new ways to think about and deal with problems. The more specific a problem the more likely CBT will be able to help. Most clinical psychologists in the UK are trained in CBT and you can access one through your GP. The CBT Register UK allows you to search for therapists in your local area: **cbtregisteruk.com**
- Psychotherapy is like counselling but the therapist will try to find out where emotions or problems might be coming from. A therapist will help you to think about what is happening in your life now. They will also look at what has happened to you in the past that might affect how you're feeling and acting. Psychotherapy can help you to understand why you act in certain ways and how you might change this behaviour. The UK Council for Psychotherapy has a **Find a therapist** service on their website: **psychotherapy.org.uk**
- Mindfulness helps you focus on the present moment and can be done at home. It is a type of meditation that can help with your wellbeing, stress and anxiety and low mood. Mindfulness and mindfulness-based cognitive therapy is taught by applied psychologists and other registered health professionals. Meditation courses are available locally in many areas. Hospices and cancer support centres run mindfulness groups and training sessions. Search **mindfulness** at **mentalhealth.org.uk** to find out more about mindfulness. You can also search **mindfulness** at **nhs.uk** or visit **pennybrohn.org.uk/resources** for mindfulness and relaxation resources.

Search **mental wellbeing** at **nhs.uk** for more information and advice on mental health.

Other sources of support

- Hospice UK provide a wide range of information about living with an advanced illness, including a directory of hospice and palliative care services in the UK. Visit **hospiceuk.org** to find a hospice near you, email **info@hospiceuk.org** or call **020 7520 8200**
- Marie Curie offer care, guidance and support to people living with any terminal illness, and their families: **mariecurie.org.uk**
- Compassion in Dying provide information and support to help you prepare for the end of life including how to talk about it, plan for it, and record your wishes. The Compassion in Dying nurse-led support line is available Monday to Thursday, 11am – 2pm on **0800 999 2434**. You can visit **compassionindying.org.uk** or use their free tool to plan for your future treatment and care: **mydecisions.org.uk**
- Child Bereavement UK offers excellent resources and ideas to support children through difficult times. The Child Bereavement UK helpline is available Monday to Friday, 9am – 4:30pm by calling **0800 02 888 40** and live chat support is also available: **childbereavementuk.org**
- Winston's Wish has information and support for grieving children and young people. The Winston's Wish bereavement helpline is available Monday to Friday, 8am – 8pm by calling **08088 020 21** and live chat support is also available: **winstonswish.org**
- Ruth Strauss Foundation offers a Family Support Service when a parent or caregiver is living with incurable cancer. You can refer your family for tailored support: **ruthstraussfoundation.com**
- My Wishes is a free online tool to easily record your hopes, choices and wishes for the future: **mywishes.co.uk**

Notes

Useful contacts

You can use this space to record useful contacts such as your gynae-oncology CNS, palliative care CNS and GP etc.

Questions I want to ask

Use this space to write down any questions you want to ask your clinical team or palliative care team.

Symptoms tracker

Use this space to write down any new or ongoing symptoms you have in the time between appointments.

You can also record any medications you are taking, how many times a day and whether they are helping your symptoms.

Date of appointment	New symptoms	Ongoing symptoms	Medications
1.			
2.			
3.			
4.			
5.			
6.			

When you need information, friendly support or someone to talk to that understands, our specialist nurses are here.

We're open 9am-5pm, Monday-Friday.
Call us for free on: 0808 802 6000

Target
Ovarian
Cancer

Get in touch for more information, support and signposting for anyone affected by ovarian cancer:

- ☎ Support line: 0808 802 6000
- @ info@targetovariancancer.org.uk
- targetovariancancer.org.uk
- TargetOvarianCancer
- @TargetOvarian
- @TargetOvarian

To access our list of references please contact us. Target Ovarian Cancer is a company limited by guarantee, registered in England and Wales (No. 6619981). Registered office: 30 Angel Gate, London EC1V 2PT. Registered charity numbers 1125038 (England and Wales) and SC042920 (Scotland).

Disclaimer: We make every effort to ensure that the information we provide is accurate. If you are concerned about your health, you should consult your doctor. Target Ovarian Cancer cannot accept liability for any loss or damage resulting from any inaccuracy in this information or third-party information on websites to which we link.

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GSK

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