



My care, my future

A guide for anyone living with incurable ovarian cancer

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Throughout this guide we have included contributions from Dr Alison Farmer.



"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 recently decided to return to nursing and 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."



Introduction

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There may come a time when you're told the news that the cancer is no longer curable. This may not be easy to hear, think or talk about. This guide aims to help you and those you care for. Take your time in reading it.

Within this guide you'll find information on a range of concerns. The information has been divided into different coloured sections so you can pick and choose which bits you'd like to read now, and which you might wish to save until you feel ready.

While writing this guide, alongside experienced healthcare practitioners, we spoke to women with incurable ovarian cancer. We learned a great deal from them and their views and experiences are included throughout. We hope that their words will help you feel you're not alone.

If you have any questions and concerns about any of the information you read in this guide, do not hesitate to get in touch with our nurse-led support line by calling **020 7923 5475** or emailing **support@targetovariancancer.org.uk**



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



Understanding the terminology used

You might hear a variety of terms and words being used, and these might mean different things to different people. Many of the words used within this guide aren't ones we hear in everyday conversation. They may feel unfamiliar or uncomfortable to you when reading them. We don't want to distress you and hope that by explaining some of these words we will make it easier for you to deal with some of the more difficult conversations. These may be with your hospital team or your loved ones.

It's also important to understand exactly what's being said and be clear with your doctor, nurse and the team looking after you, about the words they use. If you aren't sure, or don't understand, ask.

In this guide, we have used the word **incurable** to mean that the cancer isn't at a stage where a cure is now possible. There may still be cancer treatments that can help control your disease, slow down its progression, or reduce the impact it has on how you feel physically. However, during this time you may experience some uncomfortable or unfamiliar symptoms and side effects. Be sure to discuss any concerns with your Clinical Nurse Specialist (CNS) and wider medical team. They can help with symptom control (e.g. assessing, managing or easing any physical symptoms you're experiencing) as well as support you emotionally and spiritually. Depending on

your individual needs this might mean that both a gynae-oncology CNS and a palliative care CNS are involved in your care.

There may be other words you hear to describe this phase of your treatment. Try not to be alarmed if you hear these words. They're words that can help all of us talk about living with an incurable illness.

The terms **palliative care and hospice care** may be used. It can be worrying to hear these words but they simply mean the total (holistic) care of someone who's living with an advancing or incurable illness. The aim of hospice and palliative care is to maintain and improve your quality of life and offer support to you, your family and your friends during the course of your illness.

"I'm living with and surviving incurable ovarian cancer. You may think this sounds like a bad thing but it's not. Not always, anyway. I won't pretend there aren't dark days but they must be ridden like the waves and calm waters will come once again."

Gabrielle



Hospice care and palliative care focus on you and your concerns. These could be physical (e.g. pain, sickness), emotional (how you feel and manage your feelings), spiritual (how you make sense of the world) and social (how you see yourself within your family or workplace). It can be provided by a variety of people ranging from your GP and community nursing team or hospital team, to hospice and specialist palliative care teams. Sometimes called **symptom control teams, palliative care specialists** see people according to their needs and symptoms, not because they necessarily only have a short life expectancy.

Sometimes you may hear the term **end of life**. This is often used in healthcare to describe when it's believed that someone may have a year or less left to live. It's helpful to find out what your medical team mean if they use this phrase. Although it can sound frightening, the main reason for using this term is to make sure that people with an incurable illness can be helped to live well and also to ensure that the help and support they need can be discussed, planned and prioritised.

The phrase **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.

Give yourself time to ask questions about these terms, now or in the future, and remember that

while your cancer may not be curable, there are still many things that can help you live well for as long as possible.



"When I was first told I had cancer, I found it difficult to take in. I'm not alone with this of course, but I'd just had keyhole surgery and cancer was the last thing on my mind, especially as I was going through a bad patch with my boyfriend at the time. How trivial that became moments later when I heard the news."

Gina

Who will be looking after you?

Once your medical team has explained that the cancer isn't curable you may be referred to a symptom control or specialist palliative care team. A referral to palliative care or a hospice is to provide extra support for you to enable you to live as well as possible with the cancer, for as long as possible. Several studies have shown that early referral to a hospice or palliative care team is very helpful in ensuring people feel better for longer.

You can also request a referral to palliative care or a hospice at any stage of your illness from your

GP or hospital team, whenever you feel you might need some extra support. Your palliative care or hospice nurse will usually work in partnership with your existing CNS and oncologist to provide you with the care you need.

It's important to keep in mind that the care teams and support they provide might differ depending on where you live in the UK. Talk to your CNS about what additional support you can access in your area.



SOME THOUGHTS 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. However, 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 strategies to help you manage these symptoms.

Some people ask about their prognosis and how their quality of life can be maintained, while others don't 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 cancer 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!





Dealing with the news

Receiving the news that the cancer isn't curable

When you find out that the cancer is incurable, it's not unusual to feel frightened, angry or shocked about what's happening to you. Some people find out that the cancer is incurable when they're first diagnosed, while others might have cancer that has come back after treatment or has spread. Most people experience a lot of powerful emotions when they receive this news.

Some people live with the knowledge that the cancer is incurable for a long time. This might mean having lots of different treatments to control the cancer, and during this time they carry on with their day-to-day lives, spending time doing things that they love. Some people make a conscious choice and decide they no longer want to continue active treatment. Some people might become too unwell to continue treatment, or it might not be possible to control the cancer any longer. In these cases, your clinical team will focus on making you as comfortable as possible and treating any painful or distressing symptoms.

One of the questions that you might have is, "how long will I live?" Nobody will be able to give you an exact answer to this question and your medical team may be reluctant to give you any

timescale, even if you ask them. You may be told that you could have weeks or months to live, but it's really important to remember that this is just an estimate. No doctor or nurse can be sure and you may live longer or, unfortunately, for less time than this. However 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.

"During an appointment with my oncologist, I was told that my cancer was incurable and that the treatment I would be having was palliative only. I found this very difficult."

Annette

"I knew from the beginning my cancer would never be cured. I told myself that I would let the specialists take care of my body and I would look after my heart and mind. For me the quality of my life is the most important thing."

Julia



"I have a short prayer verse I say as often as I can and it gives me strength."

Julia

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 devote your time to family and friends, or enjoy simple pleasures such as going for a walk. You might want to focus on your work. You will probably also have bad days when your energy reserves are lower and this is normal. 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 and help you cope when you're feeling overwhelmed. Although many of us keep our feelings to ourselves for fear of upsetting others, talking about what you're feeling or thinking can

also be useful to help process these thoughts and feelings.

Give yourself permission to do the things that have meaning to you or give you joy. You're still you, the same person you've always been who loves some things and hates others, a human being with a life to lead.

Try taking a break from thinking about the cancer. Try not to let it dominate 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 to have just an hour and gradually build up.

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 one day a week, then perhaps try a whole weekend.

"I personally don't consider it a gift. If it were and I could find the receipt, I would take it back, a full refund please. But it's not and I have to accept that."

Gabrielle



*"I smile at everyone I see,
I offer to do things for people
I see struggling and I try to get out
there rather than sitting at home.
Some days I look to nature to
boost my mood whilst on other
days I turn up the heating and
read a good book."*

Gina

*"Nowadays, I enjoy travelling,
going to comedy gigs and the
cinema, reading and eating out
– all the usual social stuff.
I'm a committee member,
fundraiser and home visitor for
the local RSPCA. I also do water
aerobics and water Zumba a few
times a week with friends."*

Jan

*"At the beginning of our
diagnosis, we're so busy putting
our life on hold and wrestling with
coming to terms with this
experience. We shouldn't beat
ourselves up that we haven't got
the strength or knowledge to react
effectively to start with. And
neither should we try. This is the
best time to phone a friend."*

Gina

Sharing the news

Hearing that cancer is incurable can be incredibly difficult. You may find it hard to think clearly, or may be in shock, even if you were aware that the cancer was progressing. It's not unusual to feel both shocked yet not surprised by the news. You may want to be alone at this time to help you absorb and process the news. You may wish to spend more time with the people who are closest to you to talk about what's happening. You might not know how you feel. There's no right or wrong way to feel or to share this news with others, and it's entirely your decision what you choose to share. You might want to wait a few days or weeks before you tell others, you might then only want to tell close family and friends. You might even want to ask someone close to you to let others know on your behalf.

*"I was in total shock.
It was a very surreal experience
– almost like it was happening to
someone else. I was alone at the time
and my first thought was about how
I was going to tell my family the news.
I have two sons, and I was anxious
about how they would cope."*

Annette

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 and accept what's happening. But perhaps this is a frightening thought and you're worried about the reactions of your friends and relatives. People who love and care about you might feel shocked and upset at hearing that the cancer is no longer curable and you might find yourself feeling as though you need to look after other people's emotions as they deal with your news.

You may find that talking to a professional – a counsellor or your CNS – helps you feel more able to prepare for these conversations. You might 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 anxieties. Target Ovarian Cancer's support line and your CNS can provide information about where family and friends can find additional support.

Some people find that taking control of practical things such as decisions about treatment and planning for the future also helps them to make sense of their news.

"I think the most difficult aspect of my diagnosis was having to tell my family and then worrying about how they would cope. I found it easier to deal with my own fears and worries about my diagnosis than seeing my family and friends worry. At the beginning everyone was in total shock, but when it sunk in they were unbelievably supportive. I can honestly say that I could not have got through it all without their help and support."

Annette

"It can be very difficult dealing with other people's emotions and you can feel guilty that you have caused people to be upset."

Julia

"Four years on, my husband and I regularly talk openly about what will happen. Somehow we get more out of 'now' by doing this."

Julia



Relationships

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Even if you have the support of your family, friends or partner, you may still be feeling isolated, or your self-esteem may be low. This is a common experience particularly if you feel that time may be short or you're worried about the future. Spending more time with family and friends is something that might help. If you can, talk to your loved ones about how you're feeling. Those close to you will want to support you but may just not feel confident about how to give you that support.

You may feel that people around you are trying to control your life right now by ‘wrapping you up in cotton wool’ and trying to make decisions for you. If this is happening and it’s not what you want, then you need to let them know.

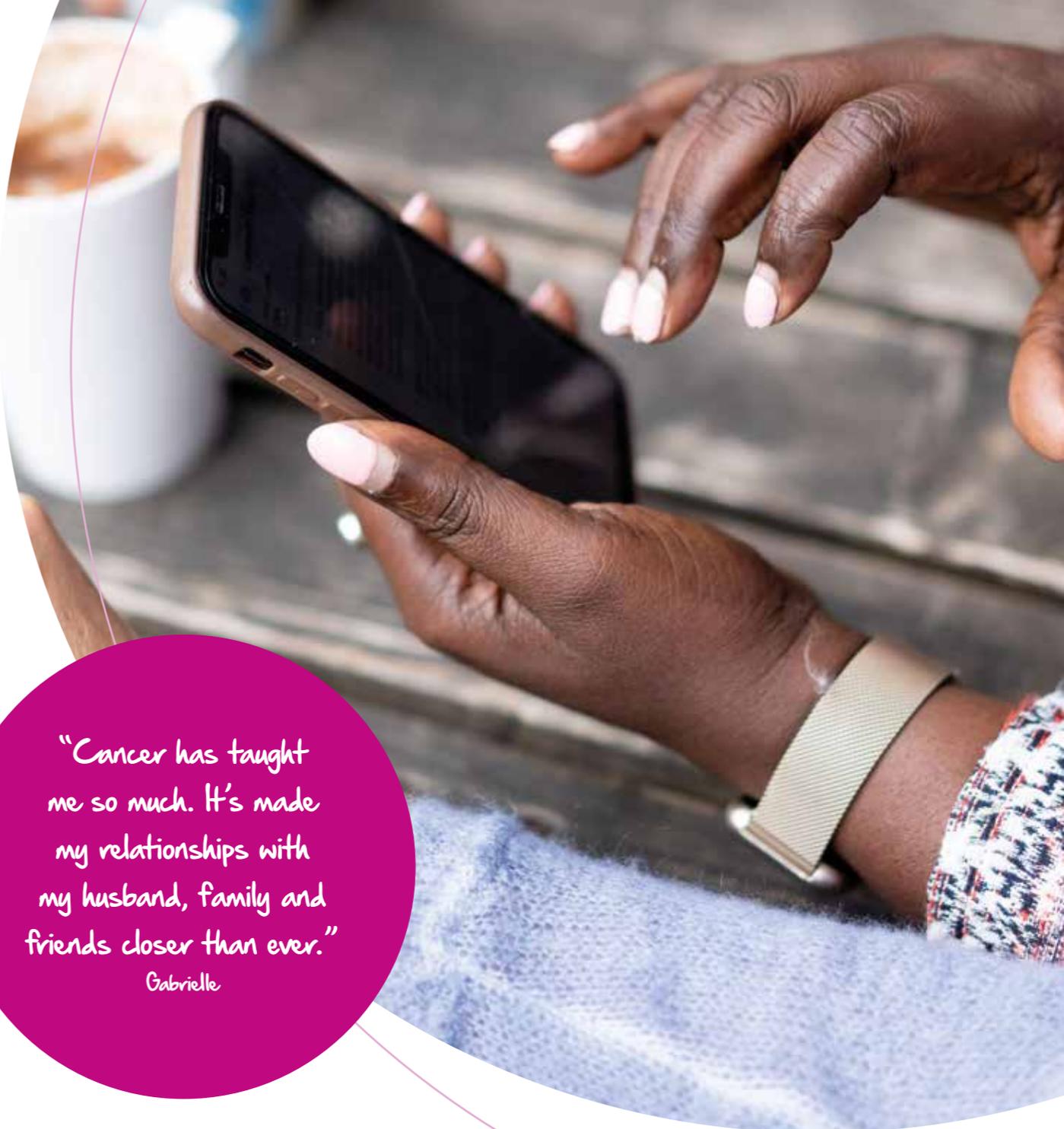
You may feel like you’re looking after those around you by protecting them from the reality of your situation. This is quite likely when you’ve been the centre of your family or friends, or if you’re used to putting the needs of others before your own. But now you need their support. If you don’t feel comfortable asking for this from those close to you, there are other people you can turn to. Try speaking to your CNS or palliative nurse, the local hospice, a counsellor, your GP, or a combination of these.

Often your partner, family members or friends will take on the role of caring for you when you need extra help. Communicating with those who care for you, including your medical team, about what’s important to you and what you want from your care is essential. Sometimes a CNS from a palliative care team or hospice will be able to support you through this conversation with your family – either by helping you to gather your thoughts and prepare some helpful phrases to use, or by being involved with a family meeting – an opportunity to bring you all together to have discussions about your future care.

It’s also important to share with those who are close to you ‘who’s who’ in your hospital team, your hospice or palliative care team and your GP. Making sure that people have this information means they can get in touch with your medical team on your behalf if you so wish.

“I doggedly battled on trying to deal with the diagnosis on my own. I should have asked for help and talked to one of the friendly experts to get medical support, and relied on my family and friends for emotional support.”

Gina



“Cancer has taught me so much. It’s made my relationships with my husband, family and friends closer than ever.”

Gabrielle

Sex and intimacy

It's normal for your wants and needs for sex and intimacy to vary. Your sexual feelings may or may not have changed and it's OK to want, or not want, to hold hands, kiss, or have sex.

Having ovarian cancer can cause emotional and physical difficulties and changes to your body can affect your confidence. All of this can impact on your sexuality and sex life. You might find you have an increased need for closeness or you may withdraw. Both of these feelings are natural. However you feel, it's important to find the right balance for you. You may find that talking your feelings over with your partner, friends or CNS is helpful.

It's still OK to have sex if you want to. If you're finding sexual intercourse difficult, it's OK to ask for help and advice. Sometimes simple changes such as a different position or being intimate at times when you're not tired or in pain can help. You may find you need more lubrication during sex than you used to need. Some lubricants are available on prescription so ask your GP or CNS for advice about these. You should also be able to find a variety of lubricants quite easily on the shelves of the larger chemists.

You may feel unhappy or frightened about having sex. There are other ways to find sexual satisfaction that don't include penetration. Sexual intimacy without penetration can be very pleasurable and rewarding both physically and emotionally. It's also not essential to have sexual

intimacy to feel closeness to a partner. Intimacy is greater than just sexual intimacy, so you might prefer to spend time relaxing in, and enjoying your partner's company.

Be kind to yourself and give yourself time to find what works for you.

How do I find out more?

Target Ovarian Cancer has produced a mini guide, *Ovarian cancer, sex and intimacy*, which you can download or order at targetovariancancer.org.uk/guides or by calling **020 7923 5475**

Macmillan has lots of information about body image, sex and intimacy on their website. Search **body image** or **sex** at macmillan.org.uk

Treatment for ovarian cancer brings changes to your body that can be difficult to cope with.

Look Good Feel Better is a UK wide charity offering free confidence boosting workshops to anyone living with cancer: lookgoodfeelbetter.co.uk

Marie Curie has more information about body image, sexuality and intimacy. Search **sexuality and intimacy** at mariecurie.org.uk





Support for you

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Recognising and seeking support for difficult feelings

Having cancer that isn't curable is bound to make you feel frustrated, frightened, hopeless and angry at times. It's common to become very sad or depressed in this situation; no one should think that you're being weak or that you should be able to cope. It's understandable if you feel very emotional and have the odd 'duvet day' when you're feeling particularly upset. However, if those feelings stop you living your life or make you feel so awful that you want to cry or hide most days, it's time to ask for help.

When we feel this way it can seem impossible to explain these feelings to others or to ask for help. Often people think that they shouldn't bother their clinical team about their feelings. But our mind and body are closely linked so it's important to look after yourself emotionally as well as physically, and depression is a condition that can be treated. Talk to your team looking after you, they will be able to help. This may be your GP, CNS or palliative care team. They may recommend medication or a referral for counselling or cognitive behavioural therapy (CBT) which will give you skills and empower you to take back control at a time when there seems to be very little control to take.

If you feel that you would like to find a therapist yourself, without professional referral, and can afford to use these services privately, the contact details listed in this section can help you find a registered professional. You can also look online at targetovariancancer.org.uk/support

"Since my treatment finished, I have suffered from anxiety, fatigue, panic attacks and constant worry about the cancer. It's like you're expected to return to normal, but I found I wasn't the same person. I had a lot of emotions to cope with. I went to counselling with a cancer support group, and I attended different courses to help me move on. I had to seek out support for myself."

Annette

"A partner struggles as much as you do, and close friends, too. But I was to discover that there are many friends in the cancer world. Friends, like your specialist nurse, who have greater knowledge, and the Target Ovarian Cancer support line."

Gina

Psychological therapies

What are they?

Psychological therapies are a form of emotional support, which many people find helpful at difficult times in their lives. They involve talking to a trained professional about your feelings.

How can they help?

Healthcare practitioners who work with people who have cancer have been trained to understand how cancer may cause difficulties for you emotionally, practically and in relationships. Just getting things off your chest can help. You can discuss the problems you're having and explore difficult feelings in a safe and confidential space. Being able to talk through frustrations, anger, sadness and fears with a trained professional can help you to feel more in control.

How do I find out more?

Counselling gives you the opportunity to speak to someone about your fears or concerns. A counsellor's job is to listen and allow you to talk. You may be able to access free counselling. In some areas of the UK you can book your own NHS counselling (self-referral) but if this isn't possible, speak to your GP to see what's available to you. Many cancer support centres and hospices also offer free counselling. Alternatively if you choose 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**

The charity Mind also provides helpful information about accessing counselling. Search **counselling** at mind.org.uk

Psychological support will look at how cancer has affected your life and wellbeing. A psychologist will be able to talk to you about the impact of cancer in more depth and they can then decide what type of psychological treatment may help you. The British Psychological Society can help you find a psychologist in your area and offers the service in different languages if English is not your first language. You can either visit their website bps.org.uk or call **0116 254 9568**



Cognitive behaviour therapy (CBT) is a very practical way of looking at emotional distress. It focuses less on the causes of your distress and more on how to improve your reactions to difficult situations. CBT examines how our ways of thinking can trigger difficult emotions and behaviours. The therapy then works to change behaviour by finding new ways to think about problems. You may be able to access free CBT. In some areas of the UK you can book your own NHS CBT (self-referral) but if this isn't possible, speak to your GP to see what's available to you. If you choose private CBT, the CBT Register UK allows you to search for therapists in your local area: cbtregisteruk.com

Psychotherapy is similar to counselling but involves the therapist trying to discover where emotions or difficulties might be coming from. A therapist will explore what's happening in your life now and what's happened to you in the past that might affect how you're feeling and behaving. Psychotherapy can help you to understand why you behave in certain ways and how you might change this behaviour. The UK Council for Psychotherapy has a **find a therapist** service available on their website: psychotherapy.org.uk

Mindfulness-based therapies help you focus on the present moment. Mindfulness is a form of non-religious meditation that can have benefits for your sense of wellbeing, help with stress and anxiety and can be practised at home. Mindfulness meditation courses are available locally in many areas and many hospices and cancer support centres are now running mindfulness groups and training sessions. The Mental Health Foundation has more information about the different types of mindfulness, just search **mindfulness** at mentalhealth.org.uk. Or try their mindfulness course at bemindfulonline.com

You can also search mental wellbeing at nhs.uk for further information and advice on mental health.

"I found using mindfulness really helped. I was calmer and could think more rationally."

Julia

Cancer support centres

You may find that contacting a local cancer support centre will make you feel more able to cope and build up your confidence. Many hospitals offering cancer treatment will have their own or a charity-run cancer support centre (such as Macmillan or Maggie's) on site, or there may be a local cancer support centre nearer to your home. These centres can be a great source of comfort for many people and will offer an opportunity to meet others in a similar situation, providing a safe environment to share experiences and deal with the emotions you may be feeling.

Cancer centres will have nurses and counsellors you can speak to and most provide complementary therapy and exercise sessions, which many people find extremely beneficial. Complementary therapies can be used alongside conventional medical treatments. Some people use them to help them relax or to ease symptoms and side effects of medical treatment. You can search for your local cancer support centre on the Target Ovarian Cancer website: targetovariancancer.org.uk/supportgroups

"I found cancer support groups very beneficial and availed myself of every support and complementary therapy available, which definitely made all the difference. I also had counselling which helped me cope with my feelings and fears."

Annette



Hospice and palliative care

A lot of people are worried about the idea of a hospice and think they're only for people at the very end of life. In fact, they offer a range of supportive services for all stages of cancer both within and beyond the hospice building. Many people are admitted to hospices for one to two weeks to get more intensive symptom control before returning home again. It may also be daunting to hear the words palliative care, but this is simply the total (holistic) care of someone who is living with an advancing illness. The aim of palliative care is to maintain and improve your quality of life and offer support to you, your family and your friends during the course of your illness.

Where can I get this care?

Every area will have a local hospice or specialist palliative care service which works in the community, in hospitals and care homes. You may already have met a Macmillan, hospice or palliative care nurse who helped you with

questions and worries during your treatment. If you haven't, you can ask to be referred to your local team by your doctor, nurse or another healthcare professional. In many areas you can also now refer yourself whenever you feel you might need some extra support.

What is hospice care?

Hospice care values the whole experience of a person, and their family and friends – mind, body and spirit.

There are many hospices around the UK and they're mainly independent charitable organisations working closely with your local health services. Most hospices offer clinics with various professionals and day services where you can visit perhaps once per week, for a few hours. They also offer inpatient care where you can stay for a short period of time if you need to. It might be a good idea to find out what your local hospice offers even if you don't feel ready, or wish to use the services yet. You can discover your local hospice by visiting hospiceuk.org

What services do hospices and palliative care teams offer?

Specific services vary from area to area but in essence all hospice teams will offer care such as pain and symptom control by experienced palliative medicine doctors, advance or future care planning, psychological and social support. They will help you stay active and independent with physiotherapy and occupational therapy, arranging complementary therapies (such as

massage, acupuncture or reflexology), spiritual care, practical and financial advice, and support in coming to terms with your future. They're often involved with education, training and research programmes. The services are usually provided by a variety of staff from highly trained professionals to experienced volunteers. All their care is provided free of charge and they may also be able to arrange transport for you to attend.

What is a hospice admission?

A hospice admission is when you may stay in the hospice for a few days for a variety of reasons. People often associate hospice admissions with dying, and of course some people choose to go to a hospice when they're near death, but many come in and out of the hospice to receive treatments such as a blood transfusion, to help manage their symptoms or to give those who are caring for them a short break. 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 have experienced it, they regret not meeting the team earlier.

Can I have palliative or hospice care at home?

Most areas have palliative care and hospice teams who work in the community. Your GP or CNS will be able to refer you to this team which will often have a palliative care medical consultant, a palliative care CNS and other professionals to support you. The palliative care CNS will come and visit you at home to support you and help you manage your

illness as well as provide support to your loved ones. They may see you in an outpatient clinic if you're well enough to attend.

There are also schemes such as Hospice at Home where nurses from the hospice or community team, or the Marie Curie charity, offer hands-on nursing care at home, particularly in the last weeks of life. Marie Curie nurses work nationwide and Hospice at Home services are now available in many areas. You can find out more about this at mariecurie.org.uk and hospiceuk.org

You may be asked by your GP or palliative care CNS about where you want to spend your final days. This is an emotional and difficult discussion, but so important to discuss. To make the best decision it's important to know what help is available in your area to support your preference and wishes.

If I get involved with the palliative care team or the hospice, will my consultant and GP still stay in touch?

Yes, all the teams keep in close contact with each other. Your GP and hospital consultant's team remain your key contacts with the hospice and palliative care teams working in partnership with them. Your GP will also be able to talk to you about any extra practical support that may be available locally. There will be a surprising variety of other local services and charities that may be able to offer additional support. For example, your local carers charity may be able to offer advice to those who are caring for you at home.





Living with your condition



Work

When you find out that you have incurable cancer, if and when you choose to stop working is a very personal decision. It's important to do what feels right for you. You might have taken time off for treatment in the past and made a full return to your role, or you might have chosen to stop working for a number of different reasons. Some people wish to continue working for as long as possible, and for others this might seem like a financial necessity. There may also come a point when you feel too unwell to work.

It's important that your employer is understanding and flexible in their response to your needs at this time, and that you feel respected and supported by them as you decide what you would like to do.

Staying at work

Everyone living with or beyond cancer is protected under the Equalities Act 2010 (in England, Scotland and Wales) or the Disability Discrimination Act 1995 (in Northern Ireland) against unfair treatment in the workplace. This means that your employer can't sack you or find an excuse to make you redundant because of your illness. They must also make reasonable adjustments to accommodate your needs at work. This might include reallocating some of your duties, altering your work hours, and allowing time off for appointments. Working remotely from home is more acceptable than ever now and may be an energy saving option for you.

However, your employer may be able to end your employment on grounds of capability because of health issues. Approaching organisations such as Citizens Advice can help ensure that you're aware of any rights or support available to you: citizensadvice.org.uk. Macmillan's **work and cancer** pages also offer comprehensive advice about work issues: macmillan.org.uk



Stopping work

For most people with incurable cancer there will come a point when they choose to stop working altogether. This may be to spend more time doing things that give them pleasure, or it may be because they're too unwell to continue working.

If work has played an important role in your life, or if you feel you haven't had a choice in the decision, stopping work may be particularly difficult to cope with. At this time it can be useful to talk to friends, family, your CNS or your GP about how you're feeling. If you would prefer to speak to someone further removed from your personal situation, take a look at the **Support for you** section of this guide for details of how to find professional support.

"Cancer has given me the opportunity to recalibrate, to set new and exciting goals. It's given me a greater appreciation of myself."

Gabrielle

Adapting your home

There may come a time when you consider adapting your home or getting some specialist living equipment to make day-to-day life a little easier for you. This could range from a hot water bottle or foam cushion to ease discomfort when you're sitting down, to having parts of your home modified (e.g. widening doorways) or purchasing special furniture to make moving around more manageable. Stairs often become more of a problem as an illness advances, and sometimes downstairs living is a good option to consider ahead of time. Occupational therapists are a great resource to advise on how to make home life easier. If this is something you're considering, speak to your CNS about what support is available to you.

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 hospice.

Benefits and other financial support

There are different types of benefit entitlements that could be available to you. These include benefits that replace your earnings, help with housing costs or extra costs resulting from your illness.

Many people are unaware of the financial help and support that's available to them during this time. This means that large sums of money go unclaimed each year. Macmillan have a benefits helpline staffed by trained advisers and can be reached on **0808 808 0000** or through macmillan.org.uk. You may also be able to access a Money Advice Unit locally, through organisations such as Citizens Advice or Macmillan benefits advisers in hospital.

It's also worth regularly checking the benefits that you're entitled to because these may change if your circumstances change.





Looking after your wellbeing

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In this chapter we'll look at how you can manage your illness and look after your physical wellbeing. This includes treatments to relieve the symptoms you may be experiencing and help manage the impact of the physical changes you might be going through.

Keeping active and eating well

Physical activity

Keeping active can help you feel more in control of your body. It can also help you cope with some of the effects of being unwell, such as fatigue and pain, and improve your emotional wellbeing too. You may have worries about increasing your level of activity but even small amounts of physical activity can be helpful. Gentle movement, such as yoga, walking or gardening, can help to ease you back into physical activity and can also help your mind.

There will be days when you have more energy than others so be kind to yourself and find a pace that you're comfortable with. Your CNS or a physiotherapist at the hospice (someone who's specially trained to help people affected by illness through movement and exercise) will be able to recommend exercises that you can do at home. You may want to see if there are group exercise classes such as seated yoga that you could join via your local cancer centre or hospice, either face to face or online. Your local gym may also offer something specific for those with low energy due to illness. Maggie's centres offer a range of classes for all abilities that are free and are run by fully trained instructors: maggies.org

Diet and nutrition

You might find that your cancer, treatment and medication have reduced your appetite or changed the way things taste and the foods that you want to eat. This is totally normal. If you're experiencing these kinds of side effects, you may want to try eating small, frequent meals and snacks rather than three large meals each day.

If you're feeling sick or vomiting you may also find cold foods help to reduce cooking smells and therefore help to limit nausea. Sucking on a boiled sweet or drinking fizzy drinks such as lemonade can also help, as can eating slowly and sitting in an upright position. Nourishing drinks such as fruit smoothies and milkshakes can help you maintain your weight, and liquid or soft foods such as soup and jelly can often be easiest to eat when food is not appealing.

Target Ovarian Cancer's guide, *Ovarian cancer, diet and nutrition*, has more information about what to eat and drink when you have ovarian cancer and practical advice for getting all of the nourishment you need, even when eating is hard. You can download or order this at targetovariancancer.org.uk/guides or by calling **020 7923 5475**

You can ask your CNS or oncologist if you have any concerns or want to know more about what diet and exercise are right for you. There's also lots of information online:

- Maggie's have nutritional therapists who can talk to you about your needs. They also run workshops where you can learn more about eating well when you have cancer: maggies.org
- Penny Brohn UK has very good information on healthy eating: pennybrohn.org.uk/resources
- The World Cancer Research Fund (WRCF) has an excellent guide called *Eat well during cancer* with recipe ideas and tips to manage side-effects of treatment: wcrf-uk.org
- Macmillan has lots information about maintaining a healthy lifestyle including a selection of simple recipes: search **healthy eating** at macmillan.org.uk

"Cancer is life altering for certain but often in the most positive ways. I live with this incurable disease with feelings of hope and happiness, with acceptance, belief and courage. I have to rejoice in what cancer has given me, I have no choice."

Gabrielle

"Since my diagnosis, I have learnt not to push myself too hard. I'm also at peace with the idea that I'm not the same person as before, and I try not to be too hard on myself. On a brighter note, I'm now a much more positive person. I embrace life and try not to worry about the trivial things."

Annette



Controlling your symptoms

During this phase of your treatment you may experience some uncomfortable symptoms. These will vary from person to person. One of the key people to support your individual needs will be a community palliative care nurse or hospice nurse, acting as part of the symptom control treatment team. Their goal is to help you feel as well as you possibly can through improving and maintaining the quality of your life. Your nurse will get to know you, provide ongoing care and offer advice on self-help plans, complementary therapies and medical management for each symptom that you're experiencing. You can request a referral to a palliative care or hospice nurse at any stage of your illness from your GP or hospital team, whenever you feel you might need some extra support.

The following are some common symptoms that women with incurable ovarian cancer experience.

"I tell myself to be well and truly sick today so that tomorrow or the next day I will feel less sick. And there is always someone else who's even sicker than me so I tell myself to stop moping!"

Gina



Fatigue

Fatigue is not just a question of feeling tired, but actually feeling pretty exhausted most of the time. This may be due to a reversible cause such as anaemia (low levels of healthy red blood cells) or low magnesium that might be helped by a blood transfusion or supplements. However, it's more often due to treatments (such as chemotherapy or radiotherapy) or most commonly, the illness itself, as well as the draining emotions you're experiencing.

Although it may sound strange, gentle exercise may actually help. Your CNS should be able to direct you to a **fatigue programme** which can guide you through the right kind of activity as well as other new 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 really frustrating. Be kind to yourself as you find a pace you can cope with. An occupational therapist can give you tips to help during this time as well as aids that will help you conserve your energy but enable you to 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 certain medications that act as stimulants and may help your energy and alertness. Ask your CNS about what might help.

"You never know how strong you are until being strong is the only choice you have and it turns out, I am strong!"

Gabrielle

Abdominal ascites

Ascites is a collection of fluid in the abdominal cavity (tummy area) which is caused by the cancer and can result in abdominal swelling, shortness of breath, indigestion, feeling or being sick, reduced appetite and worsened fatigue. You can have an ultrasound scan to confirm that any abdominal swelling is caused by fluid (ascites), and this 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 over in hospital. It involves a local anaesthetic and insertion of a very thin soft tube into the abdomen (tummy). This tube will be connected to a bag into which the ascites fluid will slowly drain 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 suitable option for you (this is called a PleurX or Rocket drain). This is a semi-permanent tube that enables you to manage your excess ascites at home. This means that you can drain small amounts of fluid on a more regular basis to avoid a build-up of fluid.

Some people have **loculated ascites**. This is when the fluid is sectioned off into smaller pockets of fluid in the body and drainage might not be possible. If this happens you'll be given advice by your GP, CNS or palliative care team

and if you're finding this painful then they'll be able to help with painkillers.

There may also come a time when the risks of having this procedure may outweigh the benefits (for example if you have low blood pressure), even if you have had it done before. In this case, it can be managed with medication to ease the discomfort, rather than being drained.

"The doctor told me that I had fluid in my abdomen and that this could be caused by me having ovarian cancer. I was shocked. I'd always been quite fit and healthy. How could this be happening to me?"

Mary

Loss of appetite

Losing your appetite can lead to weight loss and less energy. It can help to eat high calorie snacks (smoothies are ideal) little and often to avoid feeling bloated. If eating is really difficult you can try nutritious supplement drinks which your GP, CNS or palliative care team can recommend. Try not to overthink your weight as this can go up and down throughout your illness with fluid retention (see **ascites**, left). If your appetite is really poor and you're very tired, a short course of steroid tablets can be recommended to increase your appetite and energy. Steroids can have side effects if used for too long and therefore a short booster course is advised with medication to protect you from 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 is also known as heart burn or reflux and is due to the stomach acid coming back up the gullet (the tube which food passes from the mouth to the stomach). It can feel painful or uncomfortable and often be the cause of a cough. Indigestion can be caused by anxiety, steroids, anti-inflammatory drugs (e.g. ibuprofen), ascites and oral thrush (a fungal infection in the gullet or mouth). If thrush has been ruled out, you can help by:

- trying over the counter antacids such as Gaviscon
- eating little and often
- ensuring your evening meal is more than two hours before going to bed
- sitting upright when eating
- avoiding hot drinks, alcohol and foods that are acidic or spicy

If these measures don't work, your GP or palliative care CNS can prescribe medication to reduce stomach acid.

Nausea (feeling sick) and vomiting

Feeling and being sick can be caused by ascites, indigestion, constipation and medication (e.g. strong pain killers, antibiotics, chemotherapy) and can lead to loss of appetite and weakness if not eased quickly. Eating small, easily digestible meals such as soups can help, as well as trying to avoid the smells of food. Acupuncture, aromatherapy, use of 'travel sickness' bands and crunching ice can also reduce nausea. There are also many medications which help to reduce these symptoms, depending on the cause. These are definitely worth trying, so speak to your CNS or GP about what might help you.

If you're vomiting often and you're unable to keep food and drink down it's really important to alert your CNS or GP as you can quickly become dehydrated and quite unwell without treatment.

Shortness of breath

Shortness of breath has several different causes, that can be managed in different ways. For instance, it may be due to ascites fluid pushing up the diaphragm (a muscle that separates the chest and abdomen), which can be eased by draining the fluid. It could also be due to anaemia (low red blood cell count) which can be helped by a transfusion. Deep breathing, relaxation and pacing yourself can also help as anxiety and breathlessness are closely linked. Sitting near a fan or an open window will also reduce the sensation of feeling breathless. Your local hospice may have clinics to help with breathlessness. Low dose oral morphine syrup or medicine for anxiety will help with your breathing and you'll feel calmer. Tell your GP or CNS if your breathing is getting worse. It's also important to contact your medical team if your shortness of breath is associated with a new cough or chest pain as this may be due to a chest infection, fluid around the lung, or a blood clot. All these complications can be treated.

Lymphoedema

Lymphoedema is an excess of fluid in body tissues caused by a blockage of the lymph system (which clears excess body fluid). This fluid is most likely to collect in your legs or possibly your pelvic area (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. Elevating your legs, gentle exercise, good skin care and eating a high protein diet (including lots of fish, meat, eggs and cheese) can help, and your CNS can give you practical advice on how best to cope. If the lymphoedema worsens you can be referred to a **lymphoedema specialist practitioner** who may suggest massage to help drainage, together with support stockings and compression bandages. These squeeze the legs to help trapped fluid to flow better and drain the area.

Pain

Pain can occur in any area affected by the cancer. For mild pain you can try paracetamol, a warm bath, a heat pack or relaxation techniques including specific movements or stretches. If the pain becomes more severe you should monitor where it is in your body, when it occurs and whether anything makes the pain worse or better. This will help your clinical team to prescribe the best pain relief. For more severe pain, a stronger painkiller will be suggested such as morphine. Make sure you have medication to avoid constipation and sickness with this type of pain relief. Strong painkillers come in a variety of ways (e.g. liquid, skin patches, tablets, a pump) and you can discuss the best one for you with your CNS or GP. A painkilling patch may be a good option if nausea is a problem. These patches are stuck onto the skin and release painkillers through your skin.

Many people are frightened of strong painkillers such as morphine or worry about becoming addicted or immune to the effectiveness of the drug. But the dosage can be adapted to manage your pain and can be increased or decreased – and there are no additional problems when morphine is used in the right dose for the pain. Palliative care teams are specialists at monitoring these medications to ensure that they're right for you. In the right dose morphine is safe and really effective and being free of pain means you'll have more energy and can do much more. Some people worry about addiction to medicines such as morphine. This is extremely rare when used in the right doses for pain.

Constipation

Constipation can mean different things to different people but essentially it's a reduction in how regularly you open your bowels, or a change in the consistency of your stool, or poo (i.e. the stool is hard, requires lots of straining or is painful to pass). Constipation can be caused by the cancer narrowing the bowel, ascites or some medications. Drinking enough water, eating enough fruit and vegetables and gentle exercise such as a short walk can help you reduce constipation.

If you do become constipated and the above measures don't help, then you must seek advice from your CNS. Laxatives, which encourage movement in the bowels to help you go to the toilet, can be very effective in the right dose and shouldn't cause loss of control or explosive bowel actions. If the oral route (taken by mouth) isn't successful then other treatment may be needed. This can include suppositories, which is medicine that is pushed gently into the anus (bottom) or an enema, where fluid is put into the lower bowel through the bottom. These may be administered by yourself or a nurse might be needed. The important message is to keep bowels moving and if they stop seek medical advice sooner rather than later.



Bowel obstruction

If constipation develops and is associated with symptoms of nausea, vomiting, abdominal (tummy) pain or a swollen abdomen this could indicate that the bowel is blocked. This can be caused by something on the inside of the bowel blocking it (e.g. cancer or poo), something pressing on it from the outside (e.g. cancer or ascites fluid) or irritation to the nerves of the bowels causing them to 'go on strike'.

Sometimes the obstruction 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'll most likely need fluids through a drip to stop you getting dehydrated (when your body loses more fluids than it takes in). In some circumstances, giving steroids can help. If you have ascites pressing on the bowel draining them can help. Laxatives (medicine that helps to empty the bowels) can also help if there's poo blocking the bowel. Your palliative care or symptom control team will be able to explore medication to reduce any

abdominal pain or nausea associated with the blockage. These medicines may need to be given by injection or a pump rather than by mouth to ensure they're absorbed properly. A **nasogastric tube** may also be used to alleviate nausea and vomiting. This is a temporary tube that's inserted from the nose into the stomach and allows fluid to drain away. You can say no to this if you don't want one – it's easily removed once the bowel starts working again.

Sometimes a bowel obstruction can keep coming and going. If this does happen, it's important to actively manage your bowels and reduce the likelihood of constipation and obstruction with lots of fluid and a soft, easily digestible (low-residue, low fibre) diet and the right laxatives to keep the poo soft and the bowel open.

Sometimes going to a hospice or hospital can be really helpful to get this condition under control. Controlling difficult symptoms is possible with the right palliative support and will really improve your quality of life, helping you to make the most of every moment.

There may be surgical options to treat your bowel obstruction but sometimes there's no easy way to treat the obstruction 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 obstruction (blockage)

If an episode of bowel obstruction doesn't clear using the approaches discussed 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.

The following paragraphs give more detail about bowel obstruction and the way a surgeon will help with this problem. Not everyone will want to read these details. We have kept this as simple as possible and if, after reading this, you have questions it's really vital that you speak to your own medical team and surgical team. Everyone is different and your team will know the opportunities and challenges for managing the cancer.

The surgical options for bowel obstruction depend on where the blockage is within the bowel. If the blockage can't be removed, then a bypass operation may be required in order to reduce potential symptoms such as pain or vomiting. In most instances the affected area of the bowel can be removed and the two ends put back together. However sometimes this isn't possible and so your body will need a new way for your poo to exit. 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. In order to ensure that the poo is contained as it leaves the body a special appliance will be attached to the skin, along with a stoma bag which will need to be changed and emptied from time to time.

Your surgeon should discuss the options with you before surgery, along with a CNS sometimes called a **stoma nurse**. Although having a stoma isn't uncommon, having a stoma in addition to an ovarian cancer diagnosis is a huge event and can be a body image issue for many people, so your stoma nurse will continue to support you after the surgery to help you get used to this new way of life.

For a more detailed explanation and more information visit targetovariancancer.org.uk/stoma, colostomyassociation.org.uk or stomawise.co.uk

You can also download or order our free mini guide, *Ovarian cancer and stomas*, at targetovariancancer.org.uk/guides or by calling **020 7923 5475**

Clinical trials

Clinical trials are research studies that investigate potential new drugs, new ways of giving treatment or different types of treatments and compare them to the current standard treatments. Often studies are randomised, so you won't know whether you're receiving the new or the standard treatment. However, research has shown that taking part in a trial can result in better outcomes, even if you don't have the drug or procedure being tested, and that those hospitals which undertake medical research provide better treatment.

You may be eligible to take part in a trial. Each trial will have strict criteria for joining to make sure that the results can be relied upon by comparing like with like. Not all treatment centres are involved in trials. Your oncologist should know what's possible, but sometimes you may need to ask about them specifically.

You might want to ask:

- What trials are you eligible for at your treatment centre?
- If you're willing and able to travel, what's available at another centre?
- What's the aim of the trial?
- What's the evidence that this new treatment might be effective?
- What are the possible risks and benefits of taking part?
- What would taking part involve compared to not taking part?

You may also be asked to take part in research studies, for example into your wellbeing, which may involve taking part in interviews and surveys.

Remember, if you're suitable, it's your decision whether or not to join a clinical trial. You can search all live UK ovarian cancer trials at targetovariancancer.org.uk/clinicaltrials



Thinking about the future – advance care planning

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There may come a point when you start to think about the future and what preparations you want in place when you die. This is normal for everyone – some people think about the ‘what ifs’ when significant events happen in their lives such as buying a house, getting married or having children.

Thinking about the future may also happen when the cancer makes you more poorly. Perhaps you or the doctors might be thinking about stopping chemotherapy treatment, and supporting you to control your symptoms, rather than trying to control the cancer. You may be someone who likes to plan ahead, or perhaps a hospital admission has made you think about the ‘what ifs’: “What or who is most important to me if I get more ill?” “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?”

Talking about advance care (future care) planning

It’s not always easy to talk about advance care planning or any of the topics covered in this guide. There’s no right or wrong way to feel about or discuss these things. Consider what’s most important to you – is it about making specific decisions or is it about talking with those you care most about or what matters most to you?

There are lots of ways to think and talk about advance care planning. Take as much time as you need to. Some of the questions that you might want to consider are:

- What’s your understanding now of where you are with your illness?
- How much information about your illness would you like?

- 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?
- Are there any trade-offs you’re willing to make or not?
- What would a good day be like?
- Who and what matters to you?
- How do you like to talk about these things?

However you want to talk about these things will be personal to you.

Making medical and future care decisions (advance care planning)

Advance care planning is a way to think, discuss, plan, document and share (if you want to) your views, thoughts and decisions about future care. It’s helpful for you, as well as your family, friends, or the doctors and nurses, to know what’s important to you and what your future wishes and decisions are about your care. This means that they can support and help you as much as possible. Whilst there are different legal frameworks in different countries, broadly speaking, advance care planning could include several key points. All of the ways to plan ahead listed below are only used if you’re unable

to make or communicate decisions yourself. It may be that someone has capacity to make some decisions and not others so an assessment should be done for each individual decision.

Your healthcare team will always consider your ‘best interest’ when taking medical or care action on your behalf. If you’re unable to contribute to the decision-making process, your healthcare team will firstly consider any records of your wishes for treatments and care that you have made. If you haven’t left a record of your wishes, they will consider all of the circumstances to help them decide what action to take.

Advance statement

This is a way for you to write down and tell others your future wishes and decisions. It lets everyone involved in your care know your wishes if you’re unable to tell them. This could include anything from whether you would want to be treated in hospital if you were unwell, who’s important to you and who you would want to be involved in decision making, to whether you would want hospice care at the end of your life. It could also include the simple pleasures such as your favourite fragrances, songs and music, or wanting to have your hair and makeup done every day because this is important to you. Sometimes people also add in their wishes about their funeral. Nothing is too little or too big to be shared. An advance statement isn’t legally binding but will be used as a guide when making a decision in your best interests.

Advance decision to refuse treatment (ADRT)

An advance decision to refuse treatment (ADRT) as defined in the Mental Capacity Act 2005 – England and Wales, is a legal document that a person living in England or Wales can draw up. It must be made when someone has the capacity to make decisions. An ADRT can be used to indicate certain treatments that you wouldn’t wish to receive in particular situations. This can help you to stay in control of future treatment decisions and maintain a quality of life that’s meaningful to you. This is used if, in the future, you can’t say what you want yourself. Previously often known as a **living will**, it must be signed and witnessed, and is there to ensure that your decisions about treatment you don’t want (refuse) are upheld, if you can’t say so at the time.

“Most importantly, I have learned to appreciate what I do have and not focus on what has been taken. Cancer has challenged me for sure but it’s also motivated me. Right now, we are living!”

Gabrielle

In Scotland this is called an **advance directive** (or a living will). In Northern Ireland this is also called an **advance decision to refuse treatment** or an advance directive.

For more information about ADRTs across the UK search **advance** at macmillan.org.uk

If an ADRT is in place for the particular decision that needs to be made then a **best interests decision** wouldn't be needed. This is because an ADRT is legally binding and, if it's in place for the particular situation, 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 it can be used as a guide when making the best interests decision.



Capturing your hopes for the future, what's important to you and your healthcare wishes is easily done using free online tools:

- A simple website run by Compassion in Dying to help you plan your future: mydecisions.org.uk. Compassion in Dying also offer a nurse-led support line to support you with completing the forms. Call **0800 999 2434**
- Software that can help you document your future: mywishes.co.uk

Do not attempt cardio pulmonary resuscitation (DNACPR)

DNACPR is a decision not to attempt to restart the heart (cardio pulmonary resuscitation) if a person suffers cardiac arrest (when your heart stops pumping blood around your body) in future. It's made and recorded in advance, to guide those present whether to attempt to restart the heart. The doctors are likely to advise you that resuscitation (chest compressions and electric shocks) would be unsuccessful in advanced disease and often people feel as they near the end of their life that they don't want this medical treatment. You may wish to start this discussion, or sometimes a doctor or nurse may discuss it with you if they feel that it's unlikely that your heart could be restarted due to your condition. The Resuscitation Council (UK)

has excellent FAQs online where you can find out more: resus.org.uk/faqs/faqs-dnacpr

There are clinical handover systems which ensure that the above decisions are communicated to doctors, nurses and paramedics who might be called unexpectedly to see you at the weekend or at night. This means that they're aware of all the important decisions you have made about the next steps in your treatment or care. It's worth asking your GP or palliative care CNS about this if you would like specific information about you shared in this way. Sharing your documents yourself with anyone involved with your care can also help to give you peace of mind that they're aware of your wishes. This includes your treatment team, GP and local ambulance trust.

The ReSPECT process

In some areas across the UK the ReSPECT process is used to make sure that healthcare practitioners and patients and their families are involved in advance care planning. It's a very specific type of advance care planning that summarises the emergency care part of a wider advance planning process. This covers more decisions about treatment and care beyond DNACPRs. ReSPECT records your emergency care information so that professionals in different care settings who need to make immediate decisions about care and treatment in a crisis, can access it quickly. For more information visit resus.org.uk/respect/respect-resources

Lasting power of attorney (LPA)

This is a legal document in England and Wales that lets you appoint one or more people to make decisions on your behalf. In Scotland this is called a **power of attorney**. There are two types of LPA and you can choose to make one type or both:

- Property and financial affairs – 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, Wales and Scotland) – 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 as it means someone that you trust (and knows you) will act on your behalf if you're unable to say your wishes and decisions yourself. This might include accepting or refusing medical treatment on your behalf. 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 ensure you have an advance statement and advance decision in place so that your LPA can evidence your wishes if challenging decisions need to be made.

In Northern Ireland, you can nominate an **enduring power of attorney** under the Mental Capacity Act 2016. However, at the time of this guide's publication, March 2022, this currently only enables your chosen person to make decisions about your property and financial affairs, it doesn't yet cover health decisions.

For more information about setting up a power of attorney and the different types across the UK visit [gov.uk/power-of-attorney](https://www.gov.uk/power-of-attorney) or search **attorney** at [mariecurie.org.uk](https://www.mariecurie.org.uk) or [macmillan.org.uk](https://www.macmillan.org.uk).

Making or updating a will

By making a will, you can ensure that in the event of your death, 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's going to sort out your estate and carry out your wishes after your death (your executor)

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](https://www.gov.uk/make-will)

You may wish to use a solicitor, or use an online service to write your will. Many charities, including Target Ovarian Cancer, offer a free will service, supporting you to make a will for free. There's no

requirement that you make a donation to charity in order to get your will for free, although some people wish to do so. Go to [targetovariancancer.org.uk/legacy](https://www.targetovariancancer.org.uk/legacy) or call **020 7923 5474** to speak to someone about our free will service.

Digital legacy

For some people it's important to think about what happens to their social media and online accounts/presence after they have died. Others like to create online goodbye messages. There are guides that show you how to manage your online assets, to ensure that your messages, photos and social media accounts are saved. Websites such as the Digital Legacy Association provide a variety of ways to think ahead about your digital legacy: [digitallegacyassociation.org](https://www.digitallegacyassociation.org)

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.

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 do a letter of wishes which is addressed to your executors (the person or people responsible for carrying out the instructions in your will), giving guidance, listing your assets, giving general information, detailing funeral arrangements and maybe explaining your will. Whatever makes you feel comfortable and confident that your wishes will be carried out.

Finding additional support

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:

- 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](https://www.dyingmatters.org)
- Macmillan Cancer Support has very good information about planning for the future with advanced cancer including booklets called *Planning ahead for end of life: England and Wales*, *Planning ahead for end of life: Scotland* and *Your life and your choices: plan ahead Northern Ireland*, available at [be.macmillan.org.uk](https://www.be.macmillan.org.uk)
- Compassion in Dying has really useful information about planning for the future: [compassionindying.org.uk](https://www.compassionindying.org.uk)

"Recently I witnessed my father's death, also from cancer. He was 93 and my first parent to go. His passing thankfully removed some of the myths I'd subconsciously held onto. A big misconception was that cancer patients felt a great deal of pain at the end. With good communication with the medical professionals, we were able to prevent any suffering by strong painkillers and a local charity sent in palliative nurses to sit through the night giving the family much needed sleep. With further good advice, we became aware of Carer's Allowance which covered some of his costs, which was a welcome bonus. Another unforeseen wisdom I gained from my father's loss was the warmth with which he was held and the gratitude people felt towards him expressed in letters and at his memorial service. As a family we grieved at his cremation but at the memorial service it was more about a celebration of his life. It was so uplifting I plan to repeat this when my time comes."

Gina



Families, children and creating precious memories

.....

Dr Ros Taylor 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 and created especially for them – this is especially important for children. 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 hospice nurse or therapist who will have the skills to help you. Many hospices have teams who can support children who are facing the loss of a parent. A meeting with your local team before death can provide some vital continuity for your children in the future.

There are now so many simple, creative ways to capture precious memories, stories and your voice. Involving the children 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

If you have children you may want to consider creating a memory box for them – 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 heart-breaking work to do, and so easy to put off, but 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.

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.

There are a growing number of mobile apps that can help you collect photos, messages and music on your phone.

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 will be your children's guardians in the future – whether it's your husband or wife, partner, family member, or someone else – 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 and 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 or your local GP will know of local support services.

Support for your children

There are wonderful books, apps and websites that can help children of different ages, who are facing loss. These include:

- Winston's Wish: winstonswish.org.uk/serious-illness
- riprap – for teenagers who are facing the loss of someone special: riprap.org.uk
- *The Story Cure* by Ella Berthoud and Susan Elderkin which suggests stories that help children with all sorts of difficulties they might be facing.



SOME THOUGHTS 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're receiving though. Your family and friends won't mind if you set some boundaries, for example asking them not to call between 2 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 your 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 enable you to continue to enjoy your life for as long as possible.



"While we can't change what is happening, with support and guidance life can be good!"

Julia

"I don't sweat the small stuff like I used to, I enjoy simple things like going for walks, time with family and friends. I take one day at a time and I'm doing very well apart from a few side effects."

Annette



Helpful organisations

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Target Ovarian Cancer

If you're worried about anything you've read in this guide or would like more information, get in touch with our support line. You and your loved ones can call us about anything to do with ovarian cancer. Our specialist nurses are here to listen.

Call **020 7923 5475** (Monday – Friday, 9am – 5.30pm)
or visit **targetovariancancer.org.uk/supportline**

Our website targetovariancancer.org.uk also brings you insights from others who have had a diagnosis of ovarian cancer and how they feel in our **stories** section.

You can also register with us to be the first to receive the latest news, information and events in our monthly e-newsletter at targetovariancancer.org.uk/signup, and follow our Facebook, Twitter and Instagram pages.

Facebook groups

Join our private Ovarian Cancer Community on Facebook, a group for anyone affected by ovarian cancer (including loved ones) to connect, share experiences and support one another. Keep in touch with Target Ovarian Cancer and experience our digital events together with your family and friends. Hear from clinicians and our specialist nurses to learn more about ovarian cancer. To join visit facebook.com/groups/ovariancancercommunity

You can also join our private Facebook group, In Touch, which is a safe space just for those with a diagnosis, to talk to others and share experiences. To join visit facebook.com/groups/intouchtargetovariancancer

Support events

Target Ovarian Cancer runs a programme of free digital and face-to-face events across the UK to support people affected by ovarian cancer. These events offer an opportunity to meet others and provide support and information.

You can find out more at targetovariancancer.org.uk/supportevents

Support groups

Simply being around people who understand what cancer involves can help. Some groups like to share fears and worries or arrange talks about cancer from different professionals. Others arrange lunches or outings to boost people's spirits. Often groups are general, with members who have had different types of cancers, but there may be a group specifically for those with gynaecological cancers. Your CNS may run a support group locally or you can visit targetovariancancer.org.uk/supportgroups to find a group near you.

Other sources of support

Hospice UK

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 or get in touch by emailing info@hospiceuk.org or calling **020 7520 8200**

Marie Curie

Marie Curie offer care, guidance and support to people living with any terminal illness, and their families: mariecurie.org.uk

Macmillan Cancer Support

Macmillan Cancer Support provide information on all aspects and stages of cancer. The Macmillan Cancer Support free support line is also available seven days a week, 8am – 8pm. You can contact them on **0808 808 00 00**. This service also offers an interpretation facility in over 200 languages: macmillan.org.uk

Compassion in Dying

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: compassionindying.org.uk

My Decisions

My Decisions is a free online tool to help you plan ahead for your future treatment and care: mydecisions.org.uk

My Wishes

My Wishes is a free online tool to easily record your hopes, choices and wishes for the future: mywishes.co.uk

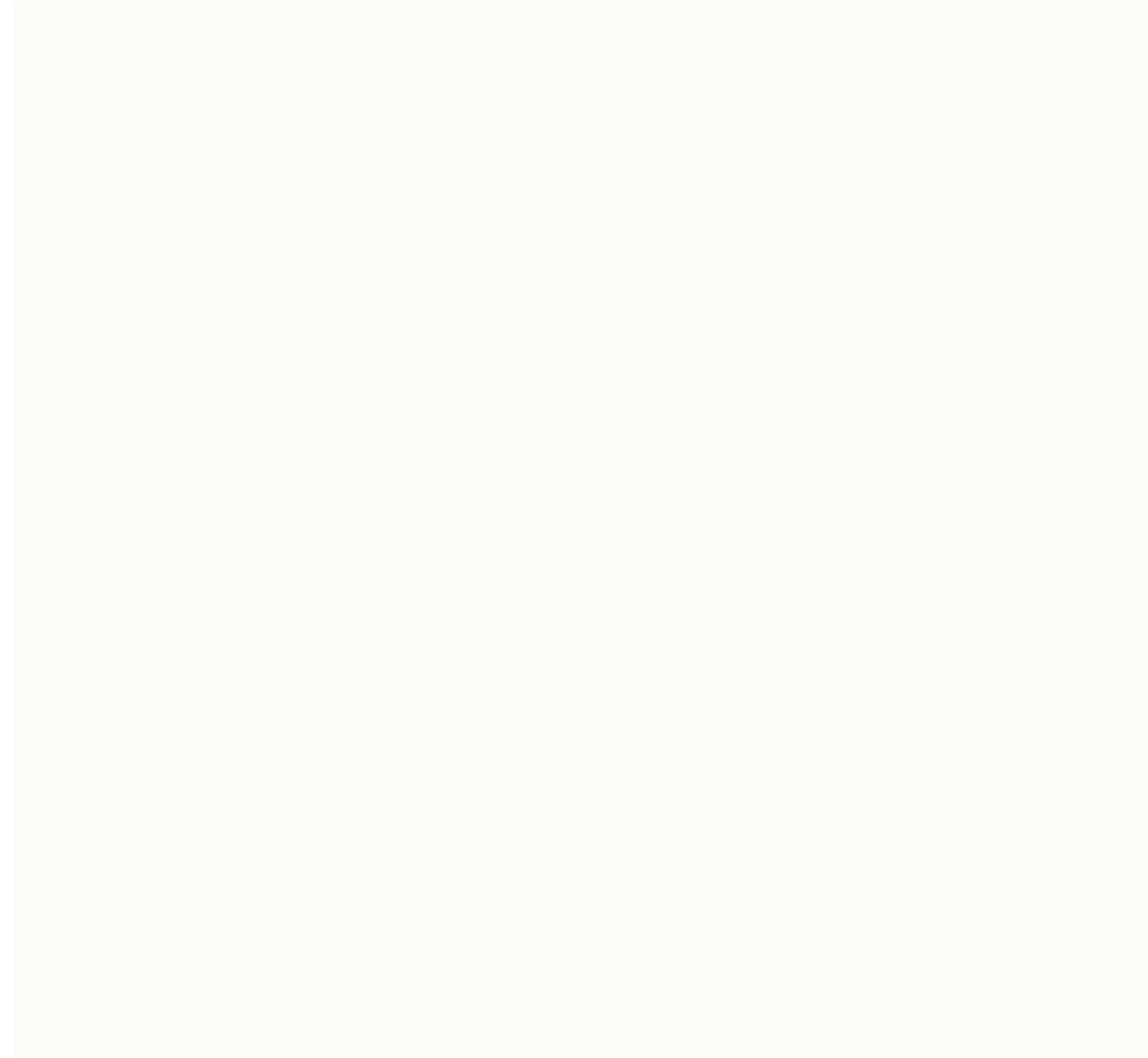
Child Bereavement UK

Child Bereavement UK offers excellent resources and ideas to support children through difficult times. The Child Bereavement UK helpline is available Monday – Friday, 9am – 5pm by calling **0800 02 888 40** and live chat support is also available: childbereavementuk.org

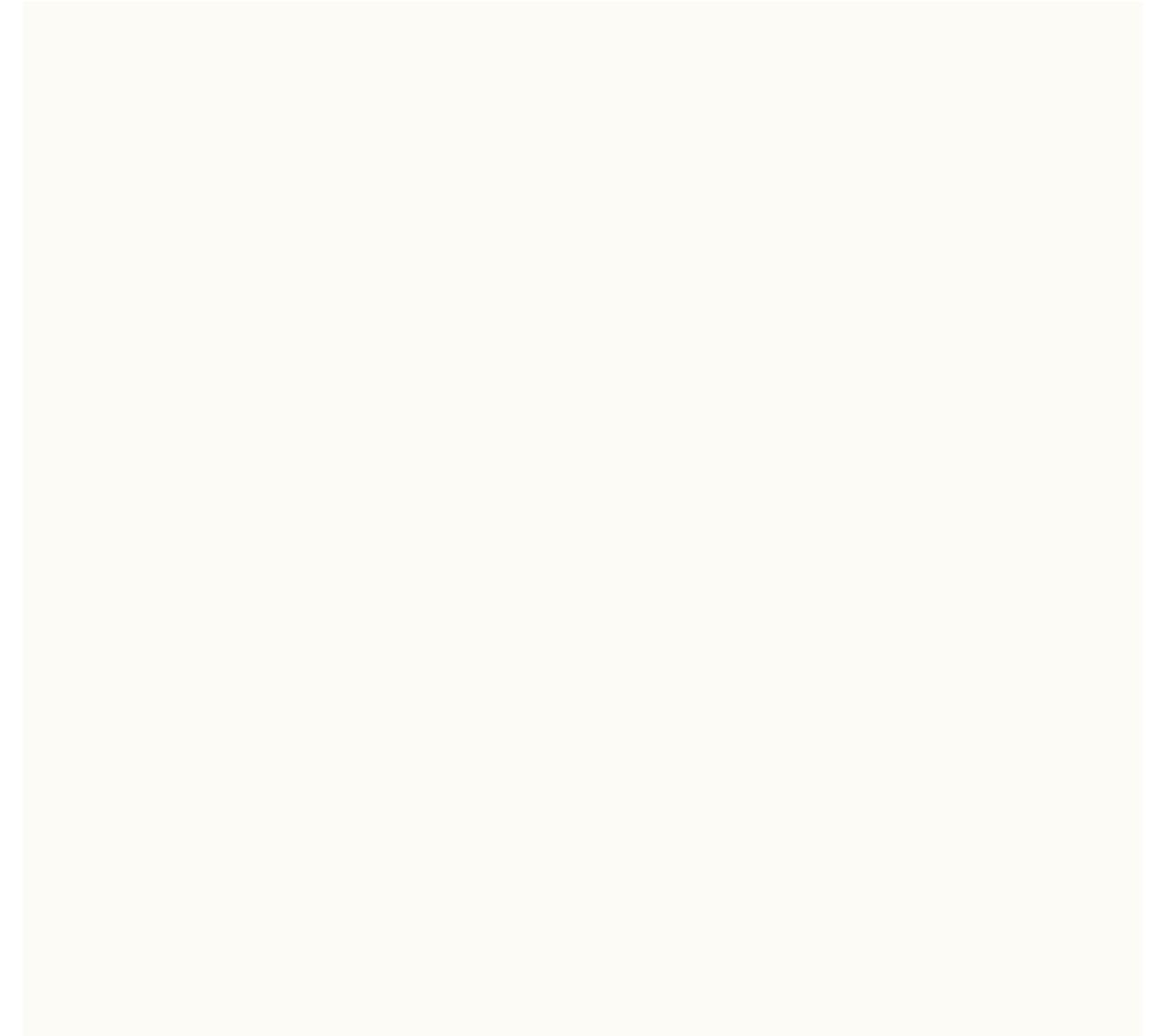
Notes



Useful contacts You can use this space to record useful contacts such as your clinical nurse specialist etc.



Questions I want to ask



My next steps

About Target Ovarian Cancer

Target Ovarian Cancer is the UK's leading ovarian cancer charity. We work to:

- improve early diagnosis
- fund life-saving research
- provide much-needed support for anyone affected by ovarian cancer.

We're the only charity fighting ovarian cancer on all three of these fronts, across all four nations of the UK. Ovarian cancer can be devastating. But there is hope – Target Ovarian Cancer. We work with people affected by ovarian cancer and health professionals to ensure we target the areas that matter most for those living with ovarian cancer.

All our publications and information are subject to an information production system that

ensures quality and impartiality. All our publications are peer reviewed by experts in their field, health professionals and those affected by ovarian cancer.

We hope that you have found this publication useful, if you have any comments or suggestions please do let us know.

To access our list of references for this publication please contact us directly.

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.

Our commitment to diversity, equity and inclusion

Target Ovarian Cancer is committed to embedding diversity, equity and inclusion into every area of the charity. We have embarked on a programme of work to make sure we're reaching and representing everyone who needs us, actively looking at how we can make sure our support reaches everyone affected by ovarian cancer, and that it reflects the communities we serve. Through this work we are taking time to learn more and think carefully about

the needs of, and challenges faced by, people we currently support, and those that we could support.

You can find out more about our immediate plans on our website at

targetovariancancer.org.uk/equity and if you'd like any more information please email us at **info@targetovariancancer.org.uk**

Our nurse-led support line is here for anyone affected by ovarian cancer – if you have a diagnosis, or if you’re a family member or a friend supporting someone living with ovarian cancer.

We’re open from 9am–5.30pm,
Monday to Friday.

Call us on **020 7923 5475**

More information and support for anyone affected by ovarian cancer can be found at **targetovariancancer.org.uk**



Target Ovarian Cancer
30 Angel Gate, London EC1V 2PT



Support line: 020 7923 5475



info@targetovariancancer.org.uk



targetovariancancer.org.uk



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