



TARGET
OVARIAN
CANCER

For every woman. For life.



My care, my future

A guide for women living with incurable ovarian cancer



Target Ovarian Cancer
2 Angel Gate, London EC1V 2PT



020 7923 5475



info@targetovariancancer.org.uk



targetovariancancer.org.uk



TargetOvarianCancer



@TargetOvarian

**Be the first to find out about news, information and events.
Register now at targetovariancancer.org.uk/signup**

We would like to thank everyone who has contributed to this guide:

- The women who shared their experiences – Annette, Gabrielle, Gina, Jan, Julia, Mary and Fi Munro.
- The writers and reviewers – Dr Sarah Russell and Dr Ros Taylor from Hospice UK, Lynn Buckley, Dr Josie Butcher, Dr Alison Farmer, Lynn Hill, Julia Merrigan, Gina Simpson and Dr Sarah Yardley.
- Dr Philip Lodge and all of the team at Marie Curie Hospice, Hampstead.

Contents

1. Introduction	5
2. Understanding the terminology used	7
3. Dealing with the news	15
4. Relationships	25
5. Support for you	31
6. Living with your condition	39
7. Looking after your wellbeing	43
8. Thinking about the future – advance care planning	57
9. Families, children and creating precious memories	65
10. Helpful organisations	71

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

There may come a time when you are told the news that your cancer is no longer responding to oncology (cancer) treatment and is not 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 will 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 professionals, 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 are 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 on **020 7923 5475** or through **support@targetovariancancer.org.uk**





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 are not ones that we hear regularly and you may feel uncomfortable reading them.

We don't want to distress you, but instead hope that defining what we mean when we use these words will provide an opportunity to think and talk about some of the more difficult or less discussed things in life.

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

In this guide, we've used the word 'incurable' to mean that your cancer is not responding, or is no longer responding, to treatment that could cure you. At this stage 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 symptoms and side effects. Be sure to discuss any concerns with your Clinical Nurse Specialist (CNS) and wider medical team as often they will be able to help. You may be offered symptom control treatment (also called palliative care) to help manage or ease any

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

The word 'palliative' and occasionally the word 'terminal' may be used to describe this phase of your treatment, so try not to be alarmed if you hear these words. It's important to remember that people may live with an incurable, palliative or terminal illness for weeks, months or even years. Supportive and palliative care specialists see people according to their needs and symptoms, not because they necessarily only have a short life expectancy.

"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



You might also hear the term ‘end of life’. This is often used in healthcare systems when someone may have a year or less left to live or if health professionals would not be surprised if someone were to deteriorate significantly in the next year. It is 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 ensure people with cancer that cannot be cured are prioritised for the help and support they need.

Additionally, the terms ‘hospice care’ and ‘palliative care’ are used. It can be daunting to hear these words but they simply mean the holistic and total 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.

Hospice care and palliative care focus on you and your concerns. These could be physical (eg 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 referred to as ‘symptom control teams’.

It is important to 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?

When you and your medical team understand that your cancer is incurable, you may be referred to a symptom control or specialist palliative care team. The intention of a referral to palliative care or a hospice is to provide additional support to your existing cancer treatment team to ensure you live as well as possible with your 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 to provide you with the care that you need.

It is 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 are ill. The following chapters offer insights into looking after yourself, understanding symptoms you may have, and your relationships with others.

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

People often want to know what symptoms to expect when they have cancer that is no longer responding to treatment, and are particularly concerned about being in pain or short of breath. We have included strategies to help you manage these symptoms.

Some women ask about their prognosis and how their quality of life can be maintained, while others do not feel ready for this

information. For many, knowing what to expect can help them to make the most of each day, but others feel overwhelmed by thoughts of the future. Everyone is different, there is no right or wrong and we hope this guide offers some help to each of you.

We have also included some information about hospice and palliative care teams within this guide. These teams can be involved at all stages of an illness, working with your cancer treatment team and GP. They are often a valuable source of information and support for you and your loved ones. Having a serious illness can make you feel that you are 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. Many women are often not good at putting themselves first, so we hope this guide gives you some hints on how to do just that!





Dealing with the news

Receiving the news that your cancer is not curable

When you find out that your cancer is incurable, it is not unusual to feel frightened, angry or shocked about what is happening to you. Some people might find out that their cancer is incurable when they are 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 might live with the knowledge of their incurable cancer for a long time. This might mean having lots of different treatments to control the cancer, and during this time many women carry on with their day-to-day lives, spending time doing things that they love. 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 clinical team may be reluctant to give you any timescale, even if you ask them. You may

"Suddenly, everything I had identified as 'me' came to a standstill. In one moment, after months of pain, tests and assurances that it was 'nothing to worry about', my instinct had proved right and my worst fears had been realised."

Fi Munro

be told that you 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. But you have the opportunity to make the most of your future however long that might be. You 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 spoil yourself.

"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

For many women, although the future seems uncertain, it is 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 is not uncommon to feel like you are experiencing a rollercoaster of emotions such as anger, sadness and fear about what is 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 are feeling overwhelmed. Although many of us keep our feelings to ourselves for fear of upsetting others, talking about what you are feeling or thinking can

also be useful to help process your thoughts and feelings.

Give yourself permission to do the things that give you pleasure. This doesn't have to mean going on a spending spree or redecorating your home from top to bottom. It can be about simple pleasures like going for a walk in your favourite place, sitting in the sunshine, arranging some candles around the bath tub and having a soak in a luxurious bubble bath. Perhaps it's putting a chore to one side and watching a film or reading a book instead. You may want to travel and take a trip you have been putting off.

"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

It's OK and natural to try to enjoy your life right now. Give yourself permission to feel as good as you can. You are still you, the same person you have always been who loves some things and hates others, a human being with a life to lead.

So try taking a break from thinking about your cancer. It does not have to dominate every waking moment and you can decide, "Today, I am not going to think about ovarian cancer, I am sending it away

in my mind. I am putting it to one side to enjoy my day. Ovarian cancer, you are not controlling me today.” Make a plan of things you want to do and things you would 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. Have a go.

“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 your 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 your cancer was progressing. It is not unusual to feel both shocked and unsurprised by the news. Some people might want to be alone at this time to help them absorb and process the news. Others might wish to spend more time with the people who are closest to them to talk about what is happening. Or you might not know how you feel. There is no right or wrong way to share this news with others, or what you choose to share. You might want to wait a few days or weeks before you tell others, and you might then only want to tell close family and friends. You might even want to ask someone to 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 be a great help in coming to terms with what is happening to you. But perhaps this is a frightening thought and you are worried about the reactions of your friends and relatives. People who love and care about you might feel shocked and upset at hearing that your 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.

Some women find that talking to a professional – a counsellor or their Clinical Nurse Specialist (CNS) – helps them feel more able to prepare for these conversations. You might also want to encourage those close to you to speak to your CNS to help understand your diagnosis and some of their own anxieties. Target Ovarian Cancer and your CNS can provide information about where family and friends can find additional support.

"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

Spending time with people you love or care about and doing the things that mean a lot can help to make this time special. 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.

"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

"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

"Recently a friend said that they would look after my partner when I'm gone. The acceptance, the acknowledgement of the reality of my disease, were the most comforting words I'd ever heard. They didn't depressingly insinuate that my death was imminent, neither did they ignorantly suggest I was healthy. No, what they did was reassure me. With those words they also silently said, 'I hear your fears, I love you, I support you, I'm here.'"

Fi Munro





Relationships

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 are 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 are 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 are looking after those around you, by protecting them from the reality of your situation. This is quite likely when you have been the centre of your family, or if you are 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 others you can turn to. Try speaking to your Clinical Nurse Specialist (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 is important to you and what you want from your care is essential. Sometimes a CNS from a palliative care team or hospice is 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.

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

Gabrielle

"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



Sex and intimacy

It is normal for women to vary in terms of wants or needs for sex and intimacy. Your sexual feelings may or may not have changed and it is OK to want, or not want, to hold hands, kiss, or have sex with a partner.

Having ovarian cancer can cause emotional and physical difficulties that can impact on your sexuality and sex life. Some women might find they have an increased need for closeness and others may withdraw. 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 Clinical Nurse Specialist is helpful.

It's still OK to have sex if you want to. If you are finding sexual intercourse difficult, it is OK to ask for help and advice. Sometimes simple changes such as a different position or being intimate at times when you are 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 specialist nurse for advice about these. You should also be able to find a variety of lubricants quite easily on the shelves of the larger chemists.

Some women feel unhappy or frightened about having sexual intercourse. There are also 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 is 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.







Support for you

Recognising and seeking support for difficult feelings

Having cancer that is not curable is bound to make you feel despairing, frustrated, frightened and angry at times. It is common for women in this situation to become very sad or depressed; no one should think that you are 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 are feeling particularly upset. But if those feelings stop you living your life or make you feel so awful that you want to cry or hide most days, it is 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 Nurse Specialist (CNS) or GP about their feelings. But it's important to look after yourself emotionally as well as physically, and depression is a condition that can be treated. Talk to your CNS or GP and they will be able to help. 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

*"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*

"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

"I have moments of realisation so debilitating I can't move. Moments of panic so strong I can't breathe. My life is not consumed by these moments but rather punctuated by them. They are little reminders of my mortality and with them they bring gratitude for each day, for each moment of joy and for each breath I take."

Fi Munro

Psychological therapies

What are they?

Psychological therapies are a form of emotional support, which many people find helpful at difficult times in their lives.

How can they help?

Health professionals 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 are 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 allow 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. Many NHS Trusts and GPs offer referrals to counselling services and many cancer support centres and hospices also offer free counselling services. Ask your CNS, GP or hospital team for a referral. Alternatively if you choose private counselling you can find a registered counsellor through the British Association of Counselling and Psychotherapy (BACP). You can call directly on **01455 883 300** or visit their website: **itsgoodtotalk.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 your 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 telephone **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. 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 is happening in your life now and what has happened to you in the past that might affect how you are 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.

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

Julia

Cancer support centres

You may find that going to 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 other women 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. You can search for your local cancer support centre on the Target Ovarian Cancer website: targetovariancancer.org.uk/support-groups

"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 are 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 holistic and total 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, but 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 (holistic) experience of a woman, and their family and friends – mind, body and spirit.

There are many hospices around the UK and they are 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, 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 are 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 are near death, but many people 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 a palliative care and hospice teams who work in the community. Your GP or Clinical Nurse Specialist (CNS) will be able to refer you to this team which often will have a palliative care medical consultant, a palliative care specialist nurse (CNS) and other professionals to support you. The palliative 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 are 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

If I get involved with the palliative care team or the hospice, will my consultant and GP be informed?

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 additional practical support that may be available locally through social services. These vary from place to place, so ask your GP what help is available in your area.





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. There is no right or wrong answer and 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 is 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, and 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.

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

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

Gabrielle

Stopping work

For most women 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, such as spending time with family and friends, or it may be because they are too unwell to continue working.

If work has played an important role in your life, or if you feel you have not 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 are 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.

"The decision to leave my job was not an easy choice by any means. Not only was I leaving a career path I'd dedicated my life to but, on a more practical level, I'd been the higher earner in our household and now we would be shifting to life on one wage."

Fi Munro

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 are sitting down, to having parts of your home modified (eg widening doorways) or purchasing special furniture to make moving around more manageable. If this is something you are considering, speak to your Clinical Nurse Specialist (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 you may be entitled to some financial support depending on where you live in the UK.

Benefits and other financial support

There are different types of benefit entitlements available to you depending on your financial circumstances. 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 is 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**

It is also worth regularly checking the benefits that you are entitled to because these may change if your circumstances change.







Looking after your wellbeing

.....

In this chapter we will 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 cope with some of the effects of being unwell, such as fatigue and pain, and gentle exercise can help improve your emotional wellbeing too. You may have worries about increasing your level of activity but even small movements can be beneficial. Perhaps you could raise your legs and move your arms when watching TV or you could put on some music and dance?

There will be days when you have more energy than others so be kind to yourself and find a pace that you are comfortable with. Your Clinical Nurse Specialist (CNS) will be able to recommend exercises that you can do at home, or you may want to see if there are group exercise classes such as seated yoga that you could join at your local cancer centre or hospice.

"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

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 are experiencing these kinds of side effects, you may want to consider eating small, frequent meals and snacks rather than three large meals each day.

If you are 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.

"Cancer has taught me how to live a deep and fulfilling life. Rather than making me fear death, it taught me how to love life and how to live each day full of joy and laughter."

Fi Munro

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, or there is lots of information online:

- Maggie's Online Centre has a nutritional advisor who you can contact:
community.maggiescentres.org
- Penny Brohn UK has very good information on healthy eating: **pennybrohn.org.uk/nutrition**
- The World Cancer Research Fund (WRCF) has excellent guides – *Eat Well, Move More* and *Healthy Living After Cancer*: **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



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 continuity of care and offer advice on self-help plans, complementary therapies and medical management for each symptom that you are 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.

"Fatigue and tiredness are not the same thing. Not even close. Fatigue is like waking up each day with four cups of energy whilst everyone else has 20. You can choose how you spend each cup. You might choose to use two on seeing a friend, one on yoga and one on cooking dinner. Each day is about making a decision on where to spend your cups."

Fi Munro



Fatigue

Fatigue is not just a question of feeling quite 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, but it is more often due to treatments (such as chemotherapy or radiotherapy) or most commonly, the illness itself, as well as the draining emotions you are experiencing.

Although it may sound strange, a beneficial approach to managing fatigue is gentle exercise, and your Clinical Nurse Specialist (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 adapt and cope with your changing energy levels.

Experiencing fatigue can mean you have to adjust your lifestyle or limit your activities which can be 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 stool 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. You can speak to 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

This 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 easily drained using a procedure called paracentesis.

Paracentesis can often be done as a day case either in hospital or some hospices. It involves a local anaesthetic and insertion of a very thin soft tube into the abdomen. 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 clever 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 women have loculated ascites. This is when the fluid is sectioned off into smaller pockets of fluid and drainage might not be possible. You will be given advice if this occurs by your GP and CNS and if you are finding this painful then they will be able to help with painkillers.

“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

This leads to weight loss and reduced energy. You can help by eating 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 or CNS can recommend. Try not to get obsessed with your weight as this can fluctuate throughout your illness with fluid retention (see ascites, left). If your appetite is really poor and you are very tired, a short course of steroids can be recommended to enhance 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 dietician who can advise on the best way to keep up your food intake when your appetite is small.

Indigestion

This 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 (eg ibuprofen), ascites and oral thrush (a fungal infection in the gullet or mouth). If thrush has been ruled out, you can help by trialling 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, and

avoiding hot drinks, alcohol and foods that are acidic or spicy. If these measures do not work, your GP or palliative care nurse can prescribe medication to reduce stomach acid.

Nausea (feeling sick) and vomiting

These symptoms can be caused by ascites, indigestion, constipation and medication (eg 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 sea sickness bands and crunching ice can also reduce nausea, and there are many medications which help to alleviate 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 are vomiting frequently and unable to keep food and drink down it is really important to alert your CNS or GP as you can quickly become dehydrated and quite unwell without treatment.

"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!"

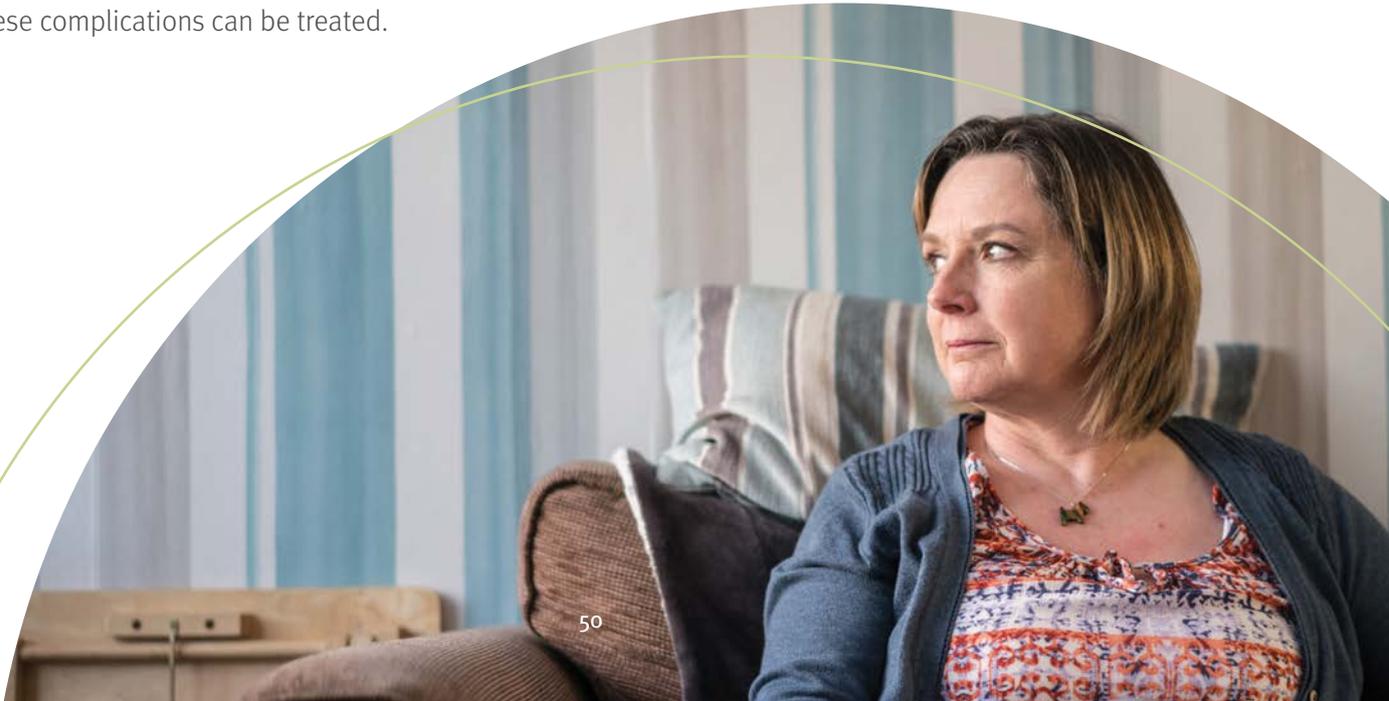
Gina

Shortness of breath

Managing this symptom depends upon the cause of your breathing problems. For instance, it may be due to ascites fluid pushing up the diaphragm, which can be eased by draining the fluid, or 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 will feel calmer. Tell your GP or CNS if your breathing is getting worse. It is 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

This is an excess of fluid in body tissues caused by a blockage of the lymph system (which clears excess body fluid). In women with ovarian cancer, this fluid is most likely to collect in your legs or possibly your pelvic area. 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 bandages.



Pain

This 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 pain killer 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 (eg liquid, skin patches, tablets, a pump) and you can discuss the best one for you with your CNS or GP.

Many people are frightened of strong pain killers 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. In the right dose morphine is safe and really effective and being free of pain means you will have more energy and can do so much more.

Constipation

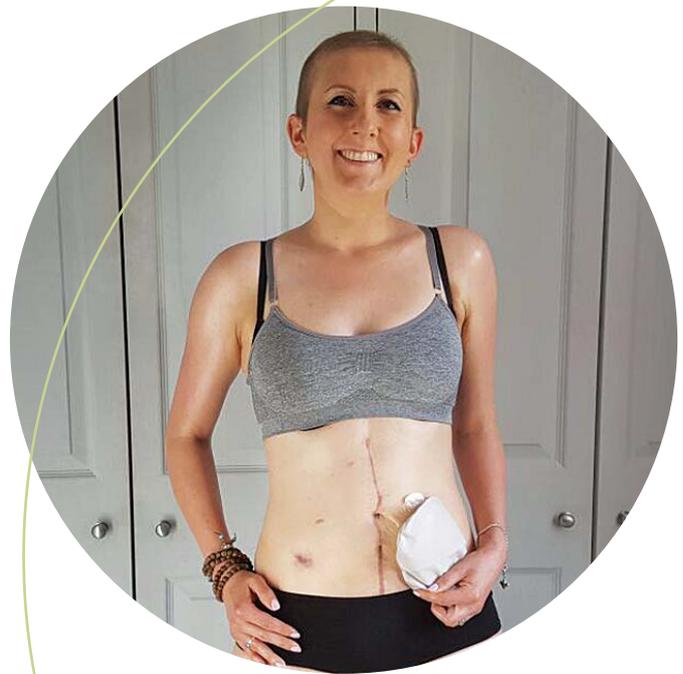
This can mean different things to different people but essentially it is a reduction in how regularly you open your bowels, or a change in the consistency of your stool (ie the stool is hard, requires lots of straining or is painful to pass). Constipation can be caused by the cancer narrowing the bowel, ascites or some medications. Not drinking enough water, a poor diet and inactivity can also contribute to constipation. It is very important that you take an active role in managing your bowels with regular drinks, fruit and vegetables and gentle exercise such as a short walk. Most importantly if you do become constipated and the above measures do not help, then you must seek advice from your CNS. Laxatives can be very effective in the right dose and should not cause loss of control or explosive bowel actions. If the oral route is not successful then suppositories or an enema (an injection of fluid or gas into the lower bowel by way of the rectum) administered by yourself or a nurse may 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 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 (eg cancer or faeces), something compressing it from the outside (eg cancer or ascites fluid) or irritation to the nerves of the bowels causing them to 'go on strike'. Often the obstruction can be eased by resting the bowel, giving steroids, draining the ascites or using laxatives. 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 are absorbed properly. A nasogastric tube may also be used to alleviate nausea and vomiting. This is a tube that is inserted from the nose into the stomach and allow fluid to drain away. You can say no to this if you do not want one – it is easily removed once the bowel starts working again.

Sometimes the bowel can move in and out of obstruction. If this does occur, it is important to actively manage your bowels and reduce the likelihood of constipation and obstruction with lots of fluid and a soft, easily digestible diet and the right laxatives to keep the motion 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.



"My surgery involved a radical hysterectomy, and the removal of my appendix, spleen, omentum and part of my liver, pancreas and diaphragm. Because I had part of my bowel removed, I was also given a colostomy bag. I didn't even know what a colostomy was.

In the days following surgery, I faced an 18 inch scar, drain sites, drips, syringe drivers and a stoma. As the days turned to weeks, slowly these additions diminished. The drains were removed, the scars started to heal, the drips were wheeled away but one thing remained; the colostomy wasn't going anywhere. It was a permanent feature.

Whilst it was hard to come to terms with at first, I began to realise that this was a result of life enhancing surgery. I posted a picture of me with my colostomy bag on social media. I used to really care what I looked like, but recently I feel much more confident in my body. Treatment made me think about how amazing the human body is."

Fi Munro

Surgical options for bowel obstruction

If your episode of bowel obstruction doesn't clear with the measures discussed in this section, and there is 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 alleviate 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 is 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 your ovarian cancer.

The surgical options for bowel obstruction depend on where the blockage is within the bowel. If the blockage cannot be removed, then a bypass operation may be required in order to minimise 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 is not possible and so your body will need a new way for your stool 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 is 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 is open is sewn directly onto the skin and is called a stoma. In order to ensure that the stool 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, in conjunction with a Clinical Nurse Specialist sometimes called a stoma nurse. Although having a stoma is not uncommon, having a stoma in addition to an ovarian cancer diagnosis is a huge event for any woman, 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, please visit targetovariancancer.org.uk/stoma, colostomyassociation.org.uk or stomawise.co.uk

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 will not know whether you are receiving the new or the standard treatment. However, research has shown that taking part in a trial can improve long-term survival, even if you do not have the drug/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, and not all treatment centres are involved in trials. Your oncologist should know what is 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 is available at another centre?
- What is the aim of the trial?
- What is the evidence that this new treatment might be effective?
- What are the possible risks and benefits of taking part?
- What would taking part involve 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 are suitable, it is your decision whether or not to join a clinical trial. The Target Ovarian Cancer Clinical Trials Information Centre available on the website

targetovariancancer.org.uk provides a search facility to find out about trials taking place in your hospital or other centres you may wish to consider.





Thinking about the future – advance care planning



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 your 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 a person 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?”

Advance care planning

Finding the answers to these questions is often known as 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 is often helpful for your friends, family or the doctors and nurses, as well as you, to know what your future wishes and decisions are about care, so that they can support and help you as much as possible.

Advance care planning could include several things:

- Advance statement – this is a way for you to write down and tell others your future wishes and decisions. This could include anything from whether you would want to be treated in hospital if you were unwell, who is important to you and you would want to be involved

in decision making, and whether you would want hospice care at the end of your life, to 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.

- Advance decision to refuse treatment (ADRT) – this is a document where you write down specific medical treatment that you do not want in the future, which might include treatment to keep you alive. This is used if in the future you cannot say what you want yourself. Previously often known as a ‘living will’, it must be signed and witnessed, and is considered to be a legal document to ensure that your wishes are upheld. An ADRT may become invalid if you go onto make a Lasting power of attorney (LPA, below) and if you give your LPA the authority to accept or refuse treatment on your behalf.
- Lasting power of attorney (LPA) – this is a person nominated by you to speak on your behalf. 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 but not in Northern Ireland) – 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 are 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 will act on your behalf if you become seriously unwell. This might include accepting or refusing medical treatment on your behalf. It is very important to choose someone who understands your wishes for treatment, especially if you know that there is specific treatment that you do not want in the future or have thought about making an advance decision to refuse treatment (ADRT, above). An ADRT and LPA can't exist at the same time so the most recent one will be the one that is used.

For more information about setting up power of attorney and the different types across the UK, please visit

[gov.uk/power-of-attorney](https://www.gov.uk/power-of-attorney) or search 'attorney' on **[mariecurie.org.uk](https://www.mariecurie.org.uk)**

- Best interests - this is the decision making process for taking any medical or care action on your behalf if you are unable to contribute to the decision making process. Advance care planning activities such as advance statements, an ADRT and LPAs are very useful to ascertain what would be the best decision to make in a person's best interests (if they cannot say so themselves).

- Do not attempt cardio pulmonary resuscitation (DNACPR) – this is a specific discussion between you and your doctors to decide that you do not want your heart to be restarted if it should stop. This can be a really difficult decision. Sometimes the doctors may advise you that resuscitation would be unsuccessful or some people feel as they near the end of their life that they do not want this medical treatment. You may wish to initiate this discussion, or sometimes a doctor or nurse may discuss it with you if they feel that it is 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](https://www.resus.org.uk/faqs/faqs-dnacpr)**

- 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 is 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)

- Digital legacy - for some people it is 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. Websites such as **deadsocial.org** provide a variety of ways to think ahead for your digital legacy. For some people it can be comforting to think that they have organised this.

There are clinical handover systems which ensure that this important information is communicated to doctors, nurses and paramedics who might be called unexpectedly to see you at the weekend or at night. This means that they are aware of all the important decisions you have made about the next steps in your treatment or care. It is worth asking your GP or specialist palliative care nurse about this if you would like specific information about you shared in this way.



Talking about advance care planning

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

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 is 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 are 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, there is no right or wrong.

"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

"As an optimist, I can't become a pessimist overnight, not even living with incurable ovarian cancer. I've become a pragmatist. How do I deal with the knowledge that my life expectancy has been dramatically shortened? With difficulty, inevitably, but I have developed a coping mechanism to greet it. I have accepted I cannot beat it, that there is no miracle cure and if I want to give myself a present then it's the joy of life, the joy of today."

Gina

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 specify 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, 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:

- Dying Matters - **dyingmatters.org** - is a coalition across England and Wales which aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life.
- Macmillan Cancer Support has very good information about planning for the future with advanced cancer including a booklet called *Your life and your choices*, available at **macmillan.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.

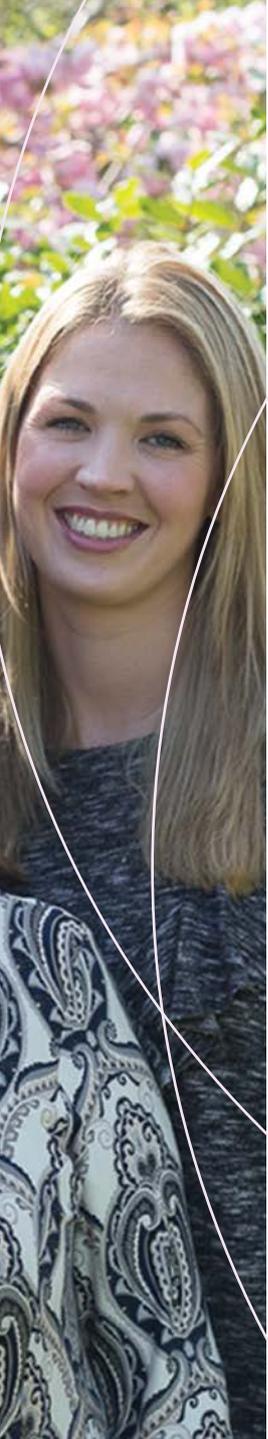


With good communication with the medical professionals, we were able to prevent any suffering by strong painkillers and a local charity sent in palliative nurses to sit through the night giving the family much needed sleep. With further good advice, we became aware of Carer's Allowance which covered 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

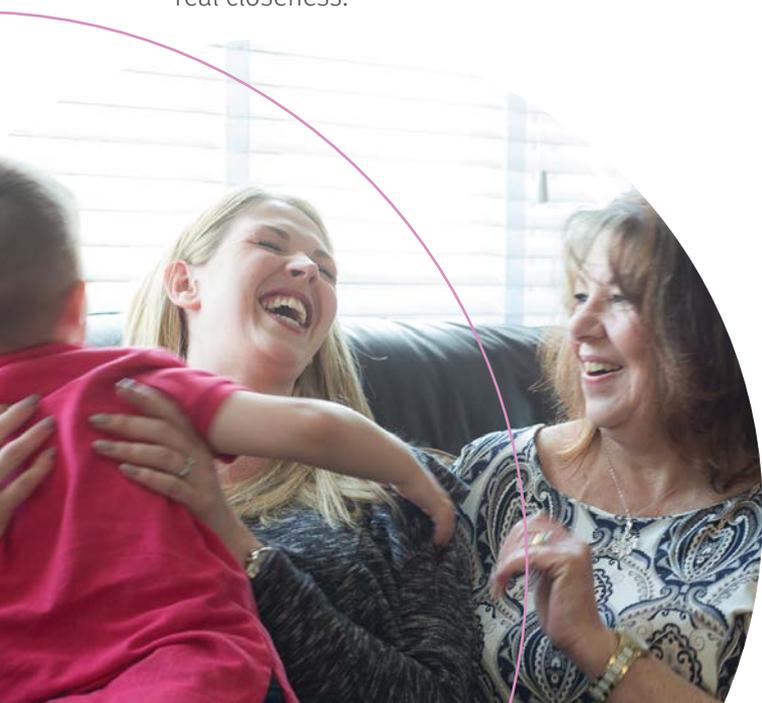


Dr Ros Taylor shares some insights from her work with families during her time at the Hospice of St Francis in Berkhamsted and The Royal Marsden Hospital.

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 is also sad and emotional. We have often found that it is 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.

There are so many simple, creative ways to capture memories. 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 their mother how important this is. Children often talk about the creative times when mum was ill – times of real closeness.



Memory boxes

.....

If you have young children you may want to consider creating a memory box for them – a special box filled with photographs, memories, treasured objects or souvenirs from trips – whatever you want your children to remember about you and your relationship with them. This can be heartbreaking to do, and easy to put off, but is really treasured by children.

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 is 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.

There are a growing number of mobile apps that can help you collect photos, messages and music on your phone. There are also guides as to how to manage your online assets, to ensure that your messages, photos and social media accounts are saved. The website **deadsocial.org** can help advise you about digital end of life planning.

Planning a future for your children

There are often huge practical concerns about your children's future care, particularly if you are a single parent. These may feel like unbearable conversations, trying to imagine your child's life without you – but it is 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 is your husband, partner, sister, whoever – there is 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 is these routines, that perhaps only a mum 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 – riprap.org.uk – for teenagers who are facing the loss of someone special.
- 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 are not getting too exhausted by all the attention you are receiving though. Your family and friends will not mind if you set some boundaries, for example asking them not to call between 2pm and 4pm because you are 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. This is something that women in particular tend to do.

Wondering why you got cancer and how it has 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 is 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 are likely to be better able to cope with your 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.



"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

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

Julia

"We all face adversity. Each and every day brings new challenges and sometimes despair. But life is a gift and an adventure waiting to be embraced and enjoyed. It is possible to live a fulfilling and grateful life through adversity."

Fi Munro





Helpful organisations

.....

Target Ovarian Cancer

Worried about anything you've read in this guide? Or want more information? Contact the **Target Ovarian Cancer Support Line**. This is a nurse-led advice, information and signposting service for anyone concerned about any aspect of ovarian cancer, from symptoms, diagnosis and treatment to clinical trials, practical and emotional concerns.

Call **020 7923 5475** or email
support@targetovariancancer.org.uk

If you have any questions about your diagnosis, treatment or how you're feeling, you can also search through our directory of frequently asked questions or ask one of your own at **targetovariancancer.org.uk/experts**

Our website **targetovariancancer.org.uk** brings you insights from women who have had a diagnosis of ovarian cancer and how they feel. You might want to become a guest blogger too and write about your experience to help others.

We also have a Clinical Trials Information Centre on our website which has a search facility to find out about trials taking place in your hospital or other centres you may wish to consider.

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

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. Search **hospiceuk.org** to find a hospice near you or get in touch on **info@hospiceuk.org** or **020 7520 8200**.

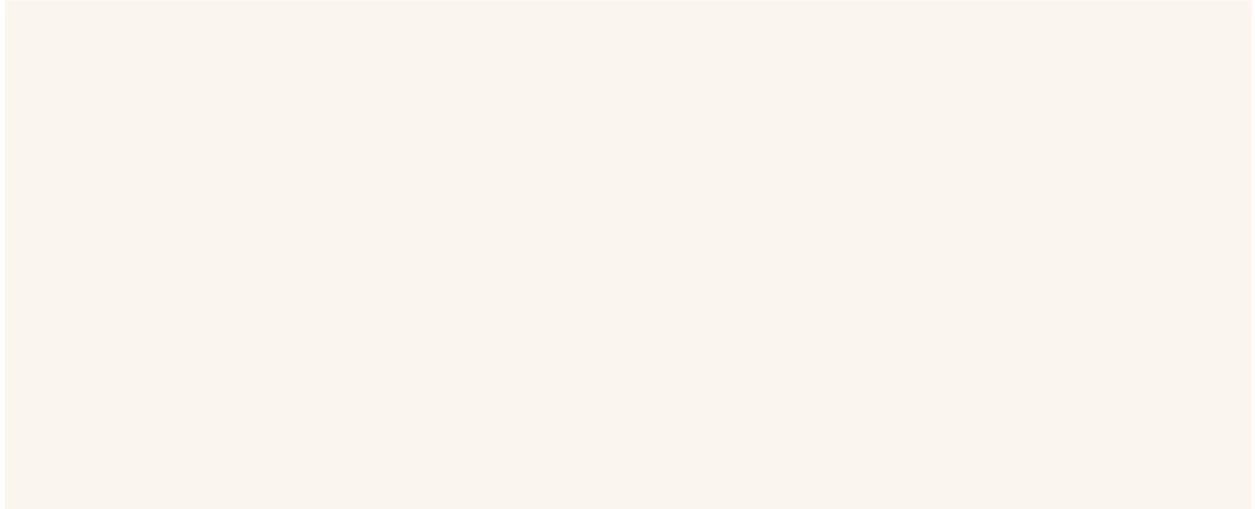
Marie Curie

Marie Curie offer care, guidance and support to people living with any terminal illness, and their families. You can call the Support Line on **0800 090 2309** (Monday – Friday 8am – 6pm and Saturday 11am – 5pm) or visit the website: **mariecurie.org.uk**

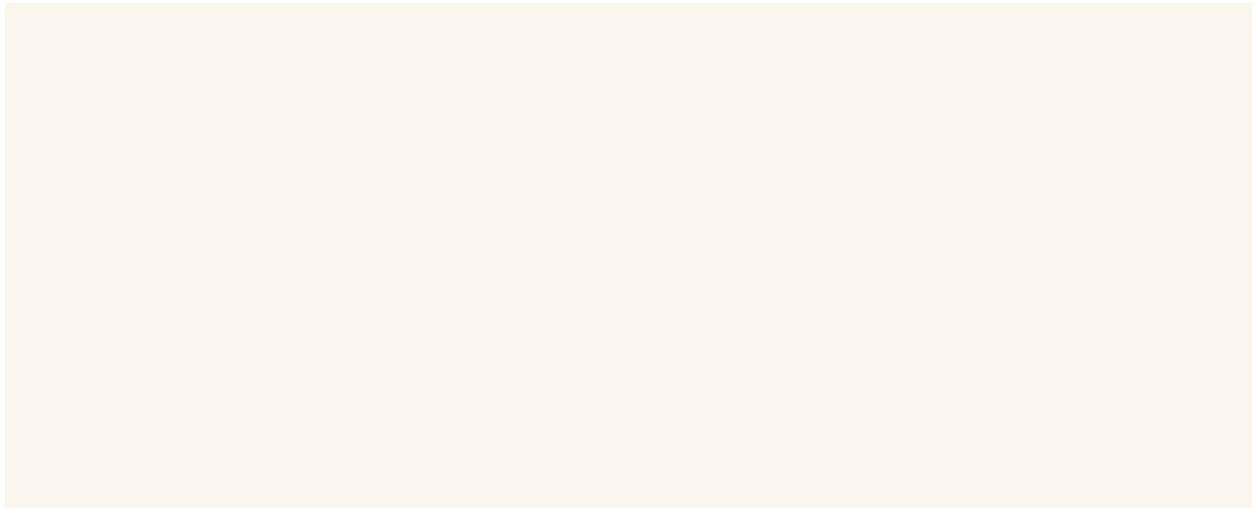
Notes

.....

Useful contacts You can use this space to record useful contacts such as your nurse 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 to women with 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 women, family members and health professionals to ensure we target the areas that matter most for those living with ovarian cancer.

As an Information Standard accredited organisation 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.



Target Ovarian Cancer
2 Angel Gate, London, EC1V 2PT



020 7923 5475



info@targetovariancancer.org.uk



targetovariancancer.org.uk



TargetOvarianCancer



@TargetOvarian

Copyright ©Target Ovarian Cancer 2017

This edition (third edition): May 2017

Next planned review: April 2020

Target Ovarian Cancer is a company limited by guarantee, registered in England and Wales (No. 6619981). Registered office: 2 Angel Gate, London EC1V 2PT.

Registered charity numbers 1125038 (England and Wales) and SCo42920 (Scotland).