How to use this guide

Welcome to Looking after me. This guide has been written to help women deal with the challenges of living with ovarian cancer that is terminal. We refer to this as ‘life limiting’.

Each section of this guide has a tab. Before you start reading this guide, have a look at the tabs and see what information we have gathered. Then you can choose what you want to read.

There is information on a range of concerns. You may have different concerns right now, so it’s up to you whether you read about the more difficult and challenging aspects now or wait till you feel ready.

While writing this guide, alongside experienced healthcare professionals, we spoke to women with life limiting ovarian cancer. We learned a great deal from them and have reflected their views and experiences.

Thanks to Eilish and family, Pat, Sarah, Margaret, June, Chris and Paul who we feature. We hope they give you inspiration.

Warmest wishes to you,

From all of us at Target Ovarian Cancer

If there is something you wish to know about ovarian cancer that is not included here, please let us know. We also appreciate your feedback.

Dr Alison Farmer contributes to this guide: “I am currently working as an oncology nurse and remain a visiting lecturer at the University of Southampton. I was diagnosed with ovarian cancer in 2001 and my experience of surgery and chemotherapy has given me a valuable insight into the subject I teach and write about.”

We would like to thank

Dr Ros Taylor, Hospice Director; Sarah Russell, Director of Education and Research and Fay Richardson, Clinical Nurse Specialist and all the team at The Hospice of St Francis, Berkhamsted for their expert help and guidance.

Mr Richard Hutson, Consultant Gynaecological Oncologist, Leeds Teaching Hospitals NHS Trust, for his expert writing.

Thanks also to Robert Lutyens, Clinical Nurse Specialist, CNWL, Camden and Islington ELiPSe Palliative Care Teams, for his help.

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Target Ovarian Cancer would lastly like to thank Howard Webber, the Chicky Alexander Van Hay and Geoffrey Van Hay Fund and The February Foundation for their generosity in funding the development of this guide.
Some helpful thoughts from Alison

This guide aims to help you get the most from every day, while living with life limiting 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 ranked highly by people with life limiting cancer. Laughing releases all sorts of ‘feel good’ hormones and can occur during even the darkest moments. We have also included a section on touch and intimacy. These are basic human needs and are just as important now as they have always been. Preparing your family for the end of your life is something that people living with a life limiting condition have said is essential. Let them know your wishes.

People often want to know what symptoms to expect when they have life limiting cancer, and are particularly concerned about being in pain or short of breath. We have included some strategies to help you manage these symptoms and others. Most people are keen to remain mentally aware. If this is a concern of yours please discuss it with your doctor as he or she may be able to choose painkillers which are less likely to cause unwanted side effects.

Some women ask about their prognosis and how their quality of life can be maintained, whilst others do not feel ready to ask for this information. Everyone is different but, for many, knowing what to expect can help you to live in the present moment.

There is also some information about hospice care. These days the hospice team can be involved very early on when someone has cancer. They can be an invaluable source of information, support and respite for you and your loved ones. You may have contact with them on many occasions, particularly if you need help with pain relief or other symptoms. Having life limiting cancer can sometimes make you feel that you are losing your identity and are just seen in the context of your illness. Helping the doctors and nurses to get to know you, will give you more of a connection with the people who are playing such an important role in your life at the moment. Some people choose to carry a few photographs. These can be helpful in describing you as a whole person.

Finally, and most importantly, make sure you do things for you. Think about things you have always wanted to do, places you would like to visit and people you would like to see. Make a list, using the space on page 31 to help you. 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 normality. Women are often not good at putting themselves first so we hope this guide gives you some hints on how to do that.
Looking after yourself

You know that your ovarian cancer is not curable and you know that it will limit your life. These are two aspects of ovarian cancer that perhaps you have been dreading or perhaps have always known to be the case. But you have the opportunity now to try and enjoy your life, live it to the full whatever that means for you, as much as you can. This may mean spending time with the people you love or are fond of, doing things like going out when your energy levels are good, perhaps in the morning, and taking the time to spoil yourself a bit.

Give yourself permission to make things lovely, yes it’s okay, in fact it’s just what the doctor ordered! This needn’t mean going on a spending spree or redecorating your home from top to bottom. It’s about sensory pleasure like going for a walk in your favourite place, going outside in the sunshine and putting a chore to one side, arranging some candles around the bath tub and having a soak in a luxurious bubble bath without worrying about fixing the tea, and perhaps making a list of films you want to see or books you want to read.

Some of you may want to travel, perhaps to see relatives abroad or take a trip you have been putting off.

The message is that it’s okay and natural 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 with your faults and attributes who loves some things and hates others, a whole human being with a life to lead.

So try taking a break from your cancer. It does not have to dominate every waking moment and you can decide, “Right, 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 and stick to it. If it works for you try to take a break from your cancer one day a week to start with, then perhaps try a whole weekend. Eventually you may be able to put ovarian cancer in its place rather than having it dominate your life. Have a go.

Saturday

I am going to:

10 am Go for a little walk in the park this morning, try and breathe calmly and enjoy looking at the trees and feed the ducks.

11.30am Meet Anne for coffee and cake at Café Blue on the High Street.

4pm Take a nice long bath with some of that stuff Heather gave me for Christmas.

6 pm Cook a simple supper tonight – I will wrap up a salmon fillet in foil in the oven, a bit of lemon juice, salt and pepper with a jacket potato, knob of butter and peas... Ice cream for dessert if any room left.

9pm Make camomile tea and get into bed.
**Relationships**

Even if you have a family’s, friend’s or partner’s support you may still be feeling isolated. This is a common experience for women with ovarian cancer and particularly so when you know your cancer is life limiting. It might help to make some plans for doing things you enjoy with others, such as a trip or outing that will bring you together. If you can, talk to your loved ones about how you are feeling. Your family and partner will want to support you but may just not feel confident about how to give you that support.

You may feel that your family, friend or partner is 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 or by being their counsellor. This is quite likely when you have been the centre of your family, a common situation for women. But now you need support too. If it’s not from those immediately around you, you need to get it elsewhere, for instance from your clinical nurse specialist (CNS), a counsellor, your GP, or a combination of these.

Communicating with your carers and 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 a 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 conference – which although it sounds a bit formal, is just an opportunity to bring you all together to have some discussions about your future care. Together with your CNS you can decide who you feel needs to be at this meeting.
It’s important to share with your carer ‘who’s who’ from the hospital team, to GP, to hospice and/or palliative care team. Making sure your carers have this information means you do not need to worry if they need to get in touch with them rather than you.

**Intimacy**

It’s still okay to have sex. In fact having sex may lift your spirits and help you feel connected to your partner. So don’t worry about whether you should be having sex or about letting your partner know you want this closeness. You are a woman with all the desires and emotions you have always had and having sex can be a wonderful way to enjoy your body and enjoy being with someone. On a practical level you may need to experiment with different positions that are more comfortable, and simple changes such as using a pillow or cushion under your hips when you are having intercourse can really help. Don’t feel embarrassed to make suggestions to your partner and try things out – you will both benefit from this.

You may find you need more lubrication during sex than you used to need. Ask your GP or CNS for advice about this or anything else you want to check out. You should be able to find a variety of lubricants quite easily on the shelves of the larger chemists.

**The golden rules are:**

- Try not to be embarrassed, sex is a normal part of life
- Ask when in doubt – your CNS will be happy to talk about this with you
- Relax and let go – making love is a fantastic stress buster and a special way to be with someone.

Some of you may feel that sex is a no go area right now. If this is how you feel, it’s worth speaking to your CNS, trained in supporting women with these issues. It is very common to go off sex after surgery for ovarian cancer.
Your feelings may change after you speak to someone who understands what is putting you off at the moment. Try not to worry too much, speak to your partner about your feelings if you can, and get some support.

**Difficult feelings**

Having cancer that is not curable is bound to make you feel sad, frustrated and angry at times. It is common for women in this situation to become very sad or depressed, no one will think that you are being weak or that you should be able to ‘cope’. But if those feelings stop you living your life or make you feel so awful that you want to cry or hide most days, ask for help.

Depression is a condition that needs treatment. So don’t hide away, crying every day at home and feeling like nothing will ever be good again, talk to your health professional whether this is a nurse or a GP and get some help. They may recommend medication, 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. Or you may find that going to a local cancer support centre or hospice and meeting others on this cancer ‘rollercoaster’ will be enough to make you feel able to cope or more like ‘you’ again.

If you want to pay for your counselling or therapy yourself, see our website’s useful resources pages for details of professional organisations which carry registers of qualified therapists

[www.targetovariancancer.org.uk/usefulresources](http://www.targetovariancancer.org.uk/usefulresources)

If you do decide you want to have therapy privately, make sure you find a therapist you feel comfortable with. As with any relationship in life, it will only work if the chemistry between you is right.

Alternatively ask your GP for a referral to your local services or ask your local hospice or support centre for information about what is available.

**Complementary therapies**

These therapies can be really helpful to enable you to relax and let go of the tension. Women use treatments such as acupuncture, massage or reflexology to reduce anxiety and get a sense of wellbeing. These therapies are carried out by trained practitioners alongside conventional medical treatments. You should be able to access free complementary therapies at your local hospice or cancer support centre.

**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 are centres that offer a range of specialist services for all stages of cancer. Pat really brings this topic to life in her story on page 14. Like many people, she had negative associations with the word ‘hospice’ before she became a regular at her local hospice and benefited from the wonderful services they offered her.

Palliative care is the holistic and total care of someone who is living with a life limiting condition or approaching the end of their life. It aims to maintain and improve the quality of their life and offers support to the individual, their family and carers during the course of the illness.

**Where can I get this care?**

Every area will have a local hospice or palliative care service. They work in the community, hospitals and care homes. You may already have met a Macmillan 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 service by your doctor, nurse or another healthcare professional.

**What is hospice care?**

As a part of palliative care, hospice care also values the whole (holistic) experience of a patient, their family and friends (e.g. mind, body and spirit).
“I was referred by my GP to the local hospice. I was horrified.” Pat
There are many hospices around the UK and they are mainly independent charitable organisations working closely with your local health services. Most hospices offer outpatient 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, maybe 1-2 weeks. It might be a good idea to find out what your local hospice offers even if you don’t feel ready to use the services yet. Discover your local hospice by looking at www.helpthehospices.org.uk

**What is community palliative care?**

Some areas have a palliative care team who work in the community, perhaps alongside or instead of a hospice. Your GP or hospital based CNS will be able to refer you to this team which will have a palliative care consultant or senior doctor, a CNS and other professionals to support you. The 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.

**What services do hospices and palliative care teams offer?**

The services vary from location to location but in essence most will offer care such as pain and symptom control, advance or future care planning, psychological and social support, rehabilitation – helping patients to stay active and independent, arranging complementary therapies, spiritual care, practical and financial advice, and support in coming to terms with the life limiting aspect of your ovarian cancer. They often also provide education 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.

There are also schemes such as ‘Hospice at Home’ where nurses from the hospice or community team or the Marie Curie charity offer nursing care at home when people become poorly.
“I felt positive, but I needed backup and I needed somebody who could help me. I couldn’t have done it without your help. I wouldn’t have known. You’ve been there when I wanted and you made me feel good.” June
What is a hospice admission?
This means that you may stay in the hospice for a few days for a variety of reasons. People often associate hospice admissions with dying, but many people come in and out of the hospice to receive treatments, to help manage their symptoms or to give a carer respite. Hospices are often beautiful buildings, with light airy rooms and lovely gardens. Indeed people who have bouts of becoming ill may benefit from a change of environment and the reassurance that a palliative care medical team is on hand to support and care for them.

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 alongside them.
Pat from Kent was referred to her local hospice for counselling and day services. Here’s how she found it:

I was referred by my GP to the local hospice. I was horrified. Told him in no uncertain terms that I was not going “as nobody comes out of those places alive”. They sent round a CNS to explain their work to me and she assured me that their job was to very much to keep people alive, not kill them off! Finally, after much protest, I agreed to give it a go one day a week. But when I told people I was going to attend a hospice, their ignorance of how hospices worked was as bad as mine. There was always a sharp intake of breath and they didn’t know what to say. They had assumed the worst. I was going to a hospice to die. Nothing could be further from the truth and I hope the following explodes a few myths.

Not only did I come out very much alive but also invigorated and refreshed having had the time of my life. So that was Myth No1 exploded! I have never felt so pampered and cared for as I did during those days I attended the hospice. The staff and volunteers were so friendly and welcoming that
my fears immediately began to subside. I cannot commend these wonderful places highly enough, they are run by truly inspiring people whose dedication to the support, encouragement and understanding of the people who pass through their doors is utterly amazing.

The mood was upbeat and happy with lots of chat and laughter. Tea, coffee and biscuits were cheerfully served by a couple of the volunteers. There were art classes and card making classes which you could attend if you wished. These patient people managed to help me produce some very presentable cards using some hot wax and a steady hand. There was aromatherapy and massage on offer. This I particularly enjoyed along with having a manicure. There was a hairdresser who could give advice on wigs if you had lost your hair through chemo, or cut and style your hair if you hadn’t or it was growing back. Or if you preferred you could just sit and read one of the daily newspapers or books or magazines from the library. You could take a walk through the vast and beautiful gardens with a volunteer to make sure you were okay – or just snooze if that was what you felt like doing. The choice was yours, you could do whatever you felt like. No pressure to do anything you didn’t feel comfortable with. Aperitifs if you felt like one were served before lunch.

During the course of the day each patient was seen by a CNS for an informal chat when you could discuss any worries and seek advice on any aspect of your physical and mental wellbeing. There was immediate access to one of the hospice doctors if it was needed. No waiting for an appointment. You were treated as if you were the most important person on their caseload. Their whole manner was so calm, reassuring and caring. This contributed greatly to my recovery because you come out of hospital in a bit of a daze not knowing what to expect either physically or mentally. They helped me to get everything into perspective and it was reassuring to know that each week when I attended the day centre I would be able to chat to the medical team about any worries.

From my chats with the CNS it became clear that I would benefit from seeing the hospice counsellor to help me get over the changes and subsequent losses that I had incurred due to my illness. This wonderfully patient lady helped me to come to terms with what had happened and helped me to move on.

Wherever you are on the cancer journey, if you are offered a place at a hospice please do not fear it but grab it with both hands as they are truly inspiring places, full of love and laughter and most of all hope.

For more information on hospice care and for links to other organisations that can help see our website www.targetovariancancer.org.uk/usefulresources
Understanding your condition

In this chapter we will look at how you can manage your condition. This includes treatments to relieve the symptoms and impact of your ovarian cancer on your life.

Options may include clinical trials. We detail information about trials in another publication Back here again, a guide for women with recurrent ovarian cancer. You can order this from us by telephone or by detaching the slip in this guide. You can also look at our website www.targetovariancancer/clinicaltrials You may be interested in accessing non-standard drugs through the Cancer Drugs Fund. For information about this go to our website www.targetovariancancer.org.uk/cdf Your CNS or doctor may also be able to advise.

Symptom control

Symptoms will vary from person to person. The aim of symptom control is to help you feel as well as you possibly can, while living with life limiting cancer. One of the key people to support you will be a community palliative care nurse. This nurse will provide continuity, get to know you, offer advice on self-help plans, complementary and medical management for each symptom, and monitor the response and any side effects. The goal will be to improve and maintain the quality of your life. You can request a referral to a palliative care nurse at any stage in your illness from your GP or hospital team. Each hospice will have its own guidelines for how you can get benefit from their services.

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

Fatigue – this can result in you having to limit your activities, which is likely to be frustrating. In time, with help from family, friends and professionals, you will adjust to having to pace yourself. You will discover ways of conserving your energy but still getting enjoyment from life.

You may find it useful to consider putting a small plastic stool in the shower or use a stool to ‘perch’ on when cooking or ironing. These kinds of household ‘aids’ can be obtained with help from an occupational therapist who may also be able to give you other tips for living as independently as possible.

Fatigue may be due to treatments such as chemotherapy or to the illness itself. There may be a treatable cause such as anaemia that might be helped by a blood transfusion, but often there is no specific cause. Modern approaches to dealing with fatigue include gentle exercise, and many hospices have fatigue programmes to give you new ideas on how to cope.

Abdominal ascites – this is a collection of fluid in the abdominal cavity. It can cause abdominal swelling, shortness of breath, indigestion, feeling or being sick, reduced appetite and extreme tiredness (lethargy). Some women feel very self-conscious about this symptom and worry about their body image. An ultrasound test will confirm if fluid is present and this can usually be easily drained in hospital or at some hospices, often as a day case.

The most common treatment is a one-off procedure called paracentesis. Following an injection of a local anaesthetic, a small cut (approx 0.5 cm) will be made in your abdomen and a narrow tube inserted, you might have a secure dressing or a couple of stitches to hold the tube in place. The tube will be connected to a bottle or bag into which the ascites fluid will slowly drain. You will be monitored during the procedure. Once drainage is complete, the tube will be removed. This drainage can be repeated if the fluid collects again and sometimes medication can slow down the further production of fluid.

The PleurX® catheter system is a safe, simple and effective longer term alternative for women who want to avoid regular hospital visits and manage their ascites at home. A small flexible tube will be inserted under the skin of the abdomen.
“The biggest difference this time around is my palliative doctor. The pain relief has been unbelievable. She is so on the ball”
One end of the tube will remain outside of the body, but can be discreetly hidden under clothes when not needed. The tube is connected to a collection bottle, and ascites fluid drained into it. Because it is semi-permanent, PleurX® allows a woman to quickly drain small volumes of fluid on a regular basis. This helps to reduce the build up of fluid and the impact of symptoms. PleurX® was recently approved for use by the NHS in England and Wales by the National Institute of Health and Clinical Excellence (NICE). Check with your CNS to find out if PleurX® is suitable for you and if you can access PleurX® in your area.

**Loss of appetite** – this leads to weight loss and reduced energy. You can help by eating nutritious 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 nurse can recommend. Try not to get obsessed by your weight, as this can fluctuate throughout your illness with fluid retention (see ascites, above). If your appetite is really poor and you are very tired, a short course of steroids may 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.

**Indigestion** – this can cause pain and discomfort in the gullet from reflux of stomach acid. This can be caused by anxiety, steroids and anti-inflammatory drugs (e.g. ibuprofen) or thrush (a fungal infection). You can help by eating little and often, sitting upright and avoiding foods that are too acidic or spicy. Your GP or palliative care nurse can prescribe medication to reduce stomach acid and treat thrush.

**Nausea (sick feeling) and vomiting** – these are troublesome symptoms and lead to loss of appetite and weakness if not helped quickly. Nausea can be caused by ascites, indigestion, constipation and medications e.g. pain killers. Try to relax and avoid the sight and smell of food in between meals. There are many medications which help nausea, depending on the cause and these are definitely worth trying. Eating frequent, small, easily digestible meals such as soups can help. Crunching ice can also reduce nausea. If severe vomiting occurs, when you are repeatedly vomiting, then it is important to alert your GP or nurse, as you can become quickly dehydrated without treatment.

**Shortness of breath** – management depends on 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, which can be helped by 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 make you feel calmer and help your breathing. Tell your doctor or palliative care nurse if your breathing is getting worse.

**Lymphoedema** – this is an excess of fluid in body tissues caused by poor lymph node drainage. In ovarian cancer this fluid is most likely to collect in your legs or possibly your pelvic area. Lymphoedema causes swollen heavy legs, reduced mobility and difficult changes in your appearance. Your palliative care nurse can give practical advice e.g. elevation of legs, gentle exercise, good skin care and high protein diet (fish, meat, eggs and cheese). If the lymphoedema worsens, you can be referred to a lymphoedema specialist practitioner who may suggest massage to help drainage together with support hosiery and bandages.
**Pain** – this can occur in any area affected by the cancer, or may be indirectly linked (e.g. low back pain from abdominal pressure caused by ascites). For mild pain, you can try paracetamol, a warm bath, a heated wheat bag or relaxation techniques. If pain becomes more severe, you should monitor where the pain is, when it occurs, and whether anything makes the pain worse or better. This will help the doctor to prescribe the best pain relief. For more severe pain, a stronger painkiller will be suggested e.g. codeine or morphine but make sure you have medication to avoid constipation and sickness with this type of medication. Strong painkillers such as morphine can be started by mouth but other options e.g. fentanyl, can be used as a patch on the skin. Sometimes, a battery operated pump (a syringe driver) is used to give the medication, especially if you are being sick. Many people are frightened of strong painkillers such as morphine, or worry about becoming immune to the effectiveness of the drug. However the dosage can be adapted to manage your pain and can be increased or decreased so you do not need to worry about ‘saving’ the option. In the right dose, morphine is safe and really effective and being free of pain means you can do so much more.

**Constipation/sluggish bowel** – this can be caused by the cancer narrowing the bowel, ascites or certain medications e.g. codeine or morphine. 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 exercise such as a short walk. Most importantly, if you do become constipated i.e. bowels not open for more than 3 days (if your normal routine is daily) then you must seek advice from your nurse. Laxatives can be very effective in the right dose. If the oral route is not successful then suppositories or an enema administered by a nurse may be needed. So 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, and a swollen abdomen, this could indicate that the bowel is obstructed. This can be caused by the cancer blocking a narrowed section of the bowel, or ascitic fluid pressing on the bowel or formation of hard impacted faeces blocking the bowel. Sometimes the obstruction can be eased, for example by drainage of ascites or laxatives. Medication to reduce abdominal pain and nausea should be explored with the palliative care team. Medicines may need to be given by injection or in a pump (syringe driver) rather than by mouth to ensure maximum effect. 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 allows fluid to drain away.

If the blockage is more permanent and doesn’t clear with medication, you may need further surgery if you are well enough. This is often a difficult decision. 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 into the 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 life, helping you to make the most of every moment.

**Bowel obstruction and surgical options in life limiting ovarian cancer**

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; everyone is different and the team know the opportunities and challenges for managing your ovarian cancer.

**Bowel obstruction – the surgeon’s perspective**

Bowel obstruction is a common complication for women with life limiting ovarian cancer.

Surgery has a role to play in some women and the surgical options to some extent depend on where the blockage is within the bowel. If the blockage cannot be removed, and the site is in the large or small bowel then a bypass operation may be required in order to minimise potential symptoms such as pain or vomiting. Most often a loop or segment of the bowel is brought out onto the skin, through an opening called a stoma. The bowel contents then empty into a stoma bag, rather than trying to get past the obstruction. This procedure is called a colostomy.

For those women where the obstruction is high up in the small bowel this can be more problematic. This is because the small bowel is normally important for absorbing nutrients and fluid. If the small bowel is bypassed by a stoma, your doctor might recommend that you should receive nutrients and hydration through a tube. A jejunostomy is the insertion of a tube through the tummy directly into the small bowel, lower than the site of obstruction so that nutritious liquids or medicines can be introduced through the tube and be sure of being absorbed.

Clearly, once the bowel obstruction is overcome the medical oncology team may want to consider administering chemotherapy, providing the tumour is still sensitive and responding to treatment.
Margaret’s thoughts on bags... not the designer sort

I was diagnosed with stage 3c ovarian cancer in September 2009. After chemotherapy and a debulking operation I appeared to be clear in March 2010 but, by November of that year I had another tumour which was impinging on my rectum. I was not experiencing pain but constipation was beginning to be a problem and made me feel really ill. The tumour did not respond to chemotherapy and I was told that it was operable but that I would, almost inevitably, have a colostomy.

I was rapidly referred to a colorectal surgeon and had a sigmoidoscopy. This was not a pleasant experience but I have always found that the unpleasantness and discomfort of such intrusive procedures is minimised if one can relax. So my approach is to treat it like having Dyno Rod in, unpleasant but necessary. I try to think of other things and relax as far as possible, for which Yoga relaxation techniques are invaluable, as is my iPod!

I had the operation on December 5th 2011 and woke up with a stoma. I cannot say that it is a ‘must have’ accessory and it is taking its time to settle down.

Managing the bag is not a problem in itself and I have excellent support from a specialist nurse, but the low position of the colostomy means the product is thick and can push the bag off with inevitable problems. A walk-in shower is a boon when dealing with this situation which, luckily, usually occurs at night. I also suffer from flatulence on a couple of days a week and this can be inhibiting but the deodorant supplied with my bags is a great help in maintaining my social life.

I am especially vigilant when staying with my children but, so far, I have managed to deal with emergencies without embarrassing myself.

I wear incontinence pads to deal with the mucous secretions still produced by my remaining rectum. It would be so embarrassing to leave damp patches on other people’s chairs and my rectum does not seem to have got the message that it is no longer attached to the remainder of the digestive system! I also carry a ‘go straight in’ card for toilets and a key for disabled ones so that I can deal with emergencies during the day. My specialist stoma nurse helped me to obtain both. My next step is going to be to learn to irrigate, which should give me further control over the stoma and enable me to avoid further embarrassing leakages.

I am divorced and live alone so I do not have to deal with the possible consequences for an existing relationship but I have had to resign myself to the fact that starting a new one has moved from ‘not very likely at my age’ to well-nigh impossible! I cannot imagine a situation in which, having met someone with whom the chemistry appeared to exist, I had to find a way to reveal that I have a colostomy. At what point does one say “oh by the way, before we go any further I should tell you...”? I presume that it would be different in a long standing relationship but enough to frighten off any but the noblest of new partners.
“The deodorant supplied is OK but one cannot exactly get out the spray and squirt down one’s trousers in the middle of a hand of cards or discussion of the shortlist for the Booker prize.”
"I want to know the full picture. My mum has to deal with what she is dealing with, whereas I want to know the bigger picture." Emma
Thinking about the future

There may come a point 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 if I get more ill and can’t be at home”; “What if my carer needs professional support to help me stay at home?”

Finding the best answers to these questions is often known as advance care planning, a process where you explore, discuss and plan future possibilities. It is often helpful for your friends, family or the doctors and nurses – as well as you – to know what your future thoughts and wishes are about care, so that they can support and help you as much as possible.

There are several parts to advance care planning:

- **Advance statement** – a way for you to write down and tell others your future choices and preferences. This could include anything from, for example, wanting hospice care at the end of your life, to having your nails and makeup done every day because this is really 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)** – a document where you write down specific medical treatment that you do not want in the future. 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.

- **Do not attempt cardio pulmonary resuscitation** – this is a specific aspect of ADRT, where you and the doctor discuss, and you decide, that you do not want your heart to be restarted if it should stop. This can be a really difficult decision to make but 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.

- **Lasting power of attorney (health and welfare or property and financial affairs)** – where you choose to give someone else legal authority (power of attorney) to make decisions on your behalf if a time comes when you are unable to do so yourself.

- **Making or updating a will** – This is something that everyone should do, whether or not they have a terminal illness, yet many people never get round to making one. 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 benefit most.
Dr Ros Taylor shares some insights from her work with families at The Hospice of St Francis, Berkhamsted:

We do know that those who are left behind hugely treasure memories that have been crafted and created especially for them – this is particularly 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 appreciate this.

It can be really uplifting work but it is also sad and emotional. We have found at the hospice that it is best to work with a close friend or family member, and perhaps a therapist and nurse from the hospice or community palliative care team who will have the skills to help you.

At our hospice we have discovered many interesting and simple ways to work with families. Often it’s best to involve children. The fact that they have been involved, if they are old enough, 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 mum, how important this is.

**A memory box**

If you have young children you may want to consider creating a memory box for them. This would be a box filled with photographs, memories, treasured objects or mementos from trips – whatever you want your children to remember about you and your relationship with them.

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!

**A digital legacy**

Some people also make a video, capturing themselves when they are well enough, perhaps telling a favourite story to their children or grandchildren or describing a holiday they all went on.

In our world of technology there are new tools to
use to capture memories. The Legacy Organiser iPhone App can help you collect photos, messages and music on your phone.

**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 them.

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 then a hospice or community palliative care social worker might be a good place to start.

It can really help to have conversations with your children about the future, but it can also be painful and again having the support of a palliative or specialist nurse or social worker can make a big difference. Together you can decide “what daddy needs to know”.

Eilish having fun with Louis and Jemima
Sarah’s thoughts on her plans

Nine months ago I was told I might have six months left to live. I was thirty eight years old. I had to come to terms with my news, but how? I turned to my family and friends and with their support we talked about things that people very rarely discuss – planning my funeral and writing my will.

The one thing every living person has in common is that they are going to die, but we never speak about it. It’s that topic that is never mentioned or discussed. It’s morbid, it’s upsetting, it’s unthinkable, but it’s going to happen to all of us at some point. So in a strange way I guess I can count myself lucky that I know my fate. I am able to discuss my wishes with my loved ones – a lot of people aren’t able to or are too frightened. I can make sure my will is up to date and I have written a letter of wishes to my executors setting out things that need to be done. I can plan my police funeral, who I want as my pall bearers, and what music I want played.

I’m even tempted to write a list of people I want to be invited! The only things I’m unable to plan are when it will be and what people will say about me (I hope it’s all good!). I have some input into the celebration of my life, many people don’t have this option.

I’ve seen the effect grief has on people, as a police officer. I was the person on the doorstep breaking the bad news. By putting things in place and talking about it I believe I can make things just that little bit easier for those I leave behind. I can make sure everyone I love is looked after and my belongings go where I want them to, maybe I’m lucky in that respect.

It’s hard, trust me it’s very hard, but after doing this I know my house is in order and I can relax knowing that whatever happens to me in the future everything and everyone is looked after. I might not be in control of my cancer, but I can be in control of what I want and how I want it.

Once I’ve got everything in place I can relax, I’ve got a lot more living to do yet!
My plans and thoughts
We hope that you have found this guide helpful and that we have given you some food for thought.

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 a life limiting diagnosis of 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 tips and advice offered will enable you to continue to enjoy your life for as long as possible.
My top 5 things I want to do in the next months
“At one point last year my whole life was just cancer. I decided I’d had enough. I went to New York and to see the Northern Lights. I realised that I could think about other things besides the cancer. One day in New York I said to myself: “Blimey I haven’t thought about my cancer and dying for a couple of days. That’s fantastic.”
Target Ovarian Cancer is the national ovarian cancer charity working to save lives and help women diagnosed live their lives to the full, wherever they are in the UK.

We do this by:

- improving early diagnosis
- finding new treatments
- providing support for women

We provide support for women with ovarian cancer via our website, our publications, and our programme of events and courses. We work with women, their families and friends, to campaign for improving early diagnosis and finding new treatments.

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 we used 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.