

Understanding

Ovarian cancer

Caring for people with cancer

Understanding

Ovarian cancer

This booklet has information on:

- Treatment for ovarian cancer
- Side-effects and how to manage them
- Coping with the emotional side of cancer
- Practical and financial matters

Useful numbers

Specialist nurse

Family doctor (GP)

Gynaecological oncologist

Surgeon

Medical oncologist

Medical social worker

Emergency

Hospital records number (MRN)



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Fast facts

What kind of treatment might I have? Page 37

A combination of surgery and chemotherapy is the main treatment for ovarian cancer. Some patients may benefit from targeted therapy drugs.

Are there side-effects from treatment? Page 71

Any side-effects will depend on your cancer and the type of treatment you have. For example, chemotherapy side-effects include tiredness, hair loss and infection. Most treatments have side-effects but they generally go away after treatment.

There are treatments to help with most side-effects so tell your doctor or nurse. Don't suffer in silence.

Will I be OK? Page 35

What is likely to happen you (your prognosis) is hard to predict. The best thing to do is to ask your consultant about your own situation.

Clinical trials Page 70

Clinical trials are research studies that try to find new or better ways of treating cancer or reducing side-effects. Ask your consultant if there are any trials suitable for you.

We're here for you Page 111

If you or your family have any questions or worries, want to know where to get support, or if you just need to talk, you can talk to one of our cancer nurses.

Ways to get in touch

- Call our Support Line on 1800 200 700
- Drop into a Daffodil Centre.
Email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.
- Email us: supportline@irishcancer.ie

See page 111 for more about our services.



Reading this booklet



This booklet is to help you throughout your cancer treatment and afterwards. You will probably find different sections useful at different times, so keep it for reference.

If you need more information or don't understand something, ask your doctor or nurse. You can also ask one of our cancer nurses:

- Call our Support Line on Freephone 1800 200 700
- Visit a Daffodil Centre
- Email the nurses at supportline@irishcancer.ie

About our information

While we make every effort to ensure the information in this booklet is correct and up to date, treatments and procedures in hospitals can vary.

You should always talk to your own medical team about your treatment and care. They know your medical history and your individual circumstances. We cannot give advice about the best treatment for you.

We use the term 'woman/women' in this booklet, but we understand that not everyone who has ovaries identifies as a woman.

Whoever you are, wherever you come from, we are here for you. For confidential advice, information and support, contact our Support Line on Freephone 1800 200 700.

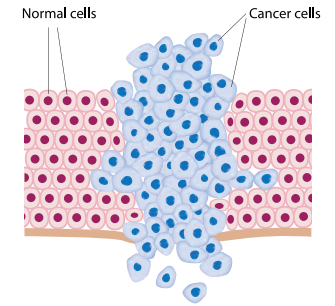
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What is cancer?

- **Cancer is a disease of the body's cells**

Cancer cells are abnormal cells that grow without control. They can form a lump (tumour).



- **Cancers are named after the organ or cell where the cancer starts**

Ovarian cancer starts in cells in the ovaries.

- **Cancers sometimes spread**

If a tumour is cancerous (malignant), a cell or group of cells can be carried by your blood or lymph fluid to another part of your body, where it can form a new tumour. This is called metastasis.

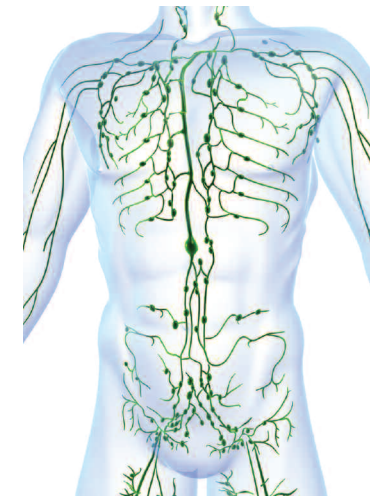
What is the lymphatic system?

- The lymphatic system protects us from infection and disease and removes extra fluid and waste from the body's tissues.

- It is made up of lymph nodes connected by tiny tubes called lymph vessels.

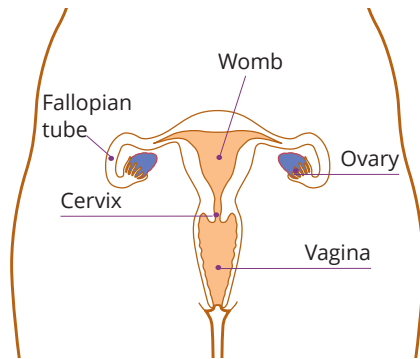
- Lymph nodes are found mainly in the neck, armpit, groin and tummy.

- If cancer cells spread into lymph nodes or cancer starts in the lymph nodes they can become swollen.



What are the ovaries?

The ovaries are part of the female reproductive system. They are two small oval-shaped organs on each side of your womb in your lower abdomen (pelvis). Each month, if you are fertile, an egg is made in one of your ovaries. The egg leaves your ovary and passes down a tube called the fallopian tube to your womb. If the egg is not fertilised by sperm, it leaves your womb with the lining of the womb. This happens as part of a monthly cycle known as a period (menstruation).



The ovaries make the female sex hormones, oestrogen and progesterone, which control your periods. You are fertile from when your periods start (puberty) to when they stop (menopause). During the menopause, fewer hormones are made, so your periods gradually stop.

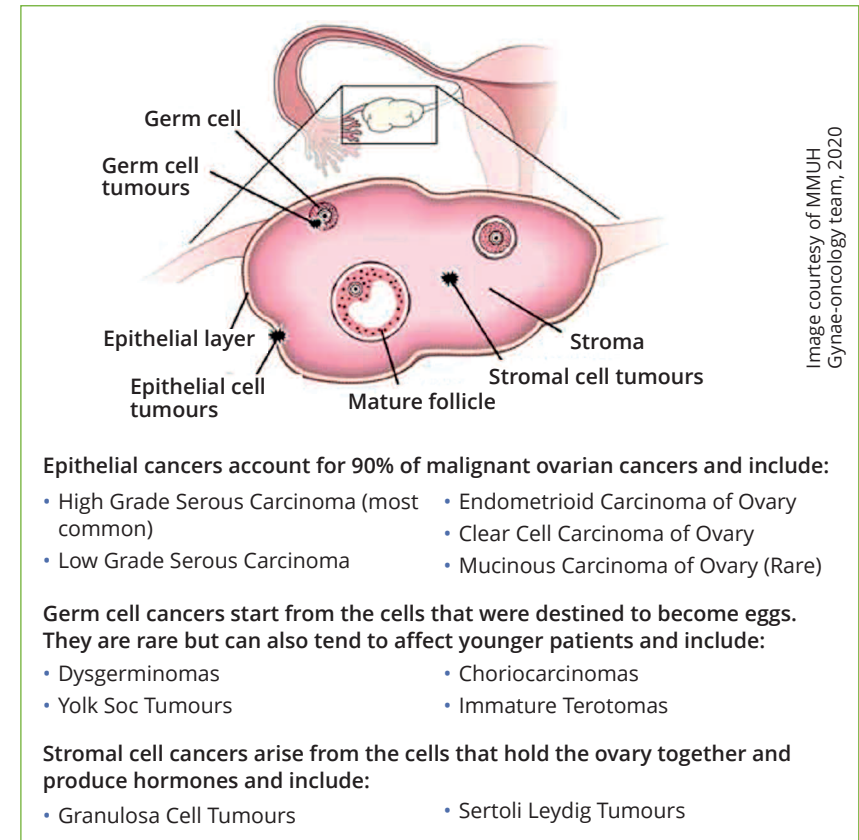
What is ovarian cancer?

When cancer occurs, cells in the ovary change to form a tumour. Because the ovaries are deep in your pelvis, the tumour may cause very few symptoms in the early stages. As the tumour gets bigger it may affect tissues and organs nearby – such as your bladder or bowel – and upset the way these tissues and organs normally work. This in turn can lead to symptoms. When the tumour is malignant, cells may break away from it and spread to other parts of your body.

The term 'ovarian cancer' describes several different types of cancer that affect the ovaries. Each type has a different biology and so behaves differently.

Each type is classified according to the type of cell from which it starts. For more information, see the next page.

What are the types of ovarian cancer?



Epithelial cancers account for 90% of malignant ovarian cancers and include:

- High Grade Serous Carcinoma (most common)
- Low Grade Serous Carcinoma
- Endometrioid Carcinoma of Ovary
- Clear Cell Carcinoma of Ovary
- Mucinous Carcinoma of Ovary (Rare)

Germ cell cancers start from the cells that were destined to become eggs. They are rare but can also tend to affect younger patients and include:

- Dysgerminomas
- Yolk Sac Tumours
- Choriocarcinomas
- Immature Teratomas

Stromal cell cancers arise from the cells that hold the ovary together and produce hormones and include:

- Granulosa Cell Tumours
- Sertoli Leydig Tumours

Ovarian cancer is divided into epithelial and non-epithelial ovarian cancer. Epithelial is by far the most common type. Non-epithelial cancer is very rare. The information in this booklet mainly applies to epithelial cancers.

Epithelial cancers

The cancer is found on the surface of the ovary, rather than inside the ovary. Epithelial cancer is further divided into different types: High-grade serous, low-grade serous, mucinous, endometrioid, clear cell and undifferentiated.

Non-epithelial cancers

These include germ cell tumours and stromal cell tumours. Germ cell tumours start in the part of the ovary that produces eggs and tend to affect very young women. Stromal tumours affect the tissues that support and keep the ovary in place and are extremely rare.

Borderline tumours

Borderline tumours have cells that are similar to the normal cells in your ovary. They are classed as tumours of low malignant potential. This means that most of these tumours are not a cancer and can be treated by surgery. However, in some cases they can recur and have the ability to transform into cancer. They are generally diagnosed at an early stage.

Ask your doctor if you want more information about your cancer type and what it means for you and your treatment.

See page 30 for information about staging and grading of ovarian tumours.



What caused my cancer?

We don't know exactly what causes many cancers, but there are things that can increase your risk of getting cancer. If you want to know more about why cancer happens or to learn about risk factors for ovarian cancer, see our website www.cancer.ie or talk to a cancer nurse – call our Support Line or visit a Daffodil Centre.

Family history of cancer

10-20% of the most common type of epithelial ovarian cancers are caused by a faulty gene. Your team may advise you to have genetic testing done, depending on the type of epithelial ovarian cancer that you have been diagnosed with.

Faulty genes that have been linked to ovarian cancer include BRCA1, BRCA2, Lynch Syndrome and Peutz-Jeghers Syndrome.

If any of your close family members are concerned about developing ovarian cancer, they should talk to their family doctor, who can advise them if they might benefit from genetic testing.

How common is ovarian cancer?

Around 400 women are diagnosed with ovarian cancer in Ireland each year.

Support Line Freephone 1800 200 700



Preparing for your hospital appointments

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Preparing for your hospital appointments

Preparation is key to getting the most out of your hospital appointments. Being prepared also helps the doctors and nurses get all the information they need – and plan the next steps in your care accordingly.



Before your appointment

- **Write down a list of questions** and things you would like to discuss.
- **Know where you are going and plan your journey** (build in extra time for unexpected delays).
- **Dress in warm comfortable clothes and shoes** – sometimes you can be waiting around for a while. Layers are best, as the temperatures in hospitals can vary a lot. Remember too, loose-fitting clothing will be easier to manage if you are having your blood pressure taken, blood tests or a physical examination.
- **Try to drink clear fluids** (water or juice without pulp) if you are having a blood test and are not fasting. This can make it easier for the nurse or doctor to find a vein. If you are told to fast, you may only drink water.
- **Check with the hospital if it is okay to bring someone with you.** Ask a friend or family member to go along for extra support.

What to take to your appointment

Put together a list of things you might need to bring for your visit, including:

- **Your medical card**, if you have one
- **Your private health insurance details**, if you have insurance
- **The appointment letter from the hospital**, if you got one
- **A referral letter or GP letter**, if you got one
- **Your GP's name and contact details**
- **Your medical history** – your doctor will likely ask you lots of questions so it's a good idea to have everything written down beforehand
- **Your list of questions**
- **A notebook and pen to take notes.** (Some healthcare professionals/nurses may be happy for you to record the meeting, but make sure you ask for their permission before doing so)
- **A list of your medications or the medication itself** – ask your pharmacist to print off a list of your medication. Hand-written lists can be hard to read or inaccurate
- **Be aware of when your prescription is due**, so you can ask for a prescription before you leave, if needed
- **Medications and medical supplies you may need that day**, in case you are delayed
- **A light snack and drink** if you are likely to have to wait for some time. Make sure you're not meant to be fasting – check with the hospital before if you're not sure
- **Your phone**
- **Details of your own phone number and the contact details of your person to call** in an emergency.
- **Your glasses and hearing aid**, if you use them
- **A book or something to listen to** (including headphones) to pass the time while you wait

Before leaving the appointment

- **Make sure you feel satisfied that your questions were answered** and that you have written down what you need to know
- **Make sure you know what will happen next**
- **Ask for the name or number of someone you can contact** in case you have further questions
- **Make sure you're booked in for your follow-up appointment** before you leave, if required

After the appointment

- **Arrange any tests in advance of your next appointment as soon as you can**, for example, a blood test – if your healthcare professional has asked for it

Note

If you have to cancel your appointment...

If you are unable to attend your appointment, contact the hospital in advance and they will try to arrange a new appointment for you. If you don't go to your appointment or contact the hospital, you may have to return to your GP and go back on the waiting list for a new appointment.



Diagnosis and tests

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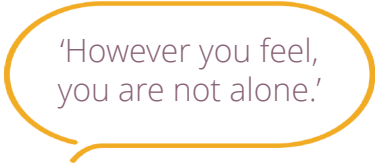
Being diagnosed with ovarian cancer

Hearing that you have ovarian cancer can be a huge shock. You may be feeling:

- **Upset** and overwhelmed by your emotions
- **Confused** by all the information being given to you
- **Worried** about what will happen next
- **Angry** that this is happening to you

If you need to talk to someone, or if you want support or advice:

- **Ask to speak to the cancer (oncology) liaison nurse or the medical social worker at the hospital.** They can help you and your family to cope with your feelings and advise you about practical matters
- **Talk to one of our cancer nurses in confidence** – visit a Daffodil Centre or call our Support Line on 1800 200 700. You can email the nurses at supportline@irishcancer.ie
- **Speak to an Irish Cancer Society Peer Support volunteer who has had an ovarian cancer diagnosis** and really knows what you are going through. Our cancer nurses can put you in touch with a volunteer
- **Talk to other people affected by cancer.** Join our online community at www.cancer.ie/community
- **Go to your local cancer support centre.** For more information, see page 118.



'However you feel,
you are not alone.'

Telling people about your diagnosis



Telling people about your diagnosis can help you to get support from friends and family. But you may feel you don't want to tell people straight away. You may be unsure how to break the news. You may also worry about how other people will react. For example, they may fuss over you or be upset.

If you would like to talk things over with a cancer nurse, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also ask for a copy of our booklet *Coping with the Emotional Effects of Cancer*. It can help you find ways to talk about your cancer and to ask for the help and support you need.



What tests will I have?

- Tests you may have include ultrasounds, blood tests, CT scan, MRI, biopsy and laparoscopy.
- The tests will tell your medical team more about your cancer and help them to decide on the best treatment for you.

After being diagnosed with ovarian cancer, you may have more tests to find out about your cancer and your general health.

Chest X-ray

This is taken to check your general health.

Blood tests

Blood tests may be done to check your general health and how well your liver and kidneys are working. A blood test called CA125 will also be done. This tests for a protein called CA125 in the blood. CA125 is known as a tumour marker for ovarian cancer, because it is sometimes released from ovarian cancer cells into the blood.

Not all women with ovarian cancer will have high levels of CA125 in their blood. But if there is a high level, it may give your doctor extra information. He or she can use it in planning your treatment. It will also help your doctor to measure how well you are doing during or after treatment.

Transvaginal ultrasound scan

This test is carried out in the X-ray department of the hospital. Before the test you must empty your bladder. You will then be asked to lie on your back. A small metal device called a probe is put into your vagina. It looks like a microphone and gel is placed on it. By doing the test in this way clear pictures of your womb, fallopian tubes and ovaries can be built up using sound waves. This test may be uncomfortable but is not painful.

Ultrasound of abdomen (tummy area)

This is a scan that uses sound waves to look at your abdomen. The scan is painless and only takes a few minutes. Having a full bladder helps to give a clearer picture, so you will need to drink plenty of clear fluids before the test and not pass urine (pee) until afterwards. Some gel is put on your tummy and then a small hand-held device is passed over the gel on your tummy.

CT scan (CAT scan)

This is a special type of X-ray that gives a detailed 3D picture of the tissues inside your body. You might be asked to fast (not eat) for a few hours before the test. You may also be given an injection or a special drink to help show up parts of your body on the scan. The injection may make you feel hot all over for a few minutes. During the scan you will lie on a table which passes through a large doughnut-shaped machine. The scan is painless and takes between 10 and 30 minutes. You'll probably be able to go home as soon as the scan is over.



MRI scan

This is a scan that uses magnetic energy to build up a picture of the tissues inside your body. During the test you will lie inside a tunnel-like machine. Some people are afraid they will feel claustrophobic inside the tunnel. Tell the radiation therapist if you're feeling anxious.

An MRI can also be noisy, but you will be given earplugs/headphones to wear. You might get an injection before the scan to show up certain parts of your body. You can't wear metal jewellery during the scan. If you have any medical device in your body, like a pacemaker or metal pin, you may not be suitable for the test.

Usually you can go home soon after the scan. You shouldn't need to stay in hospital.

For most scans you will be alone in the treatment room, but the medical staff can still see you, hear you and speak to you. If you need anything, just speak or raise your hand.

Image-guided biopsy

This involves taking a biopsy (tissue sample) from your ovaries and possibly from the omentum, a fatty pad of tissue inside your stomach. Image-guided means that the doctor will use an ultrasound or CT scan to guide the needle into the stomach to where the tumour is. The doctor will use local anaesthetic to numb the area where the needle is inserted. You may also be given some sedation. The procedure can take between 10 and 20 minutes.

You'll need to stay in hospital for a couple of hours after the biopsy, and possibly overnight. This is because there is a risk of bleeding afterwards. If you've been given sedation, you'll need someone to take you home and stay with you for 24 hours until the effects have completely worn off.

Diagnostic laparoscopy

This test allows your doctor to look at your ovaries and nearby tissues. It can help the team confirm the stage of the cancer, plan surgery or other treatments and decide how best to manage your cancer. It is a small operation done in theatre under a general anaesthetic.

While you are asleep, your doctor makes a small cut in your lower abdomen, near your belly button. They then put a thin mini telescope called a laparoscope into the wound. By looking through the laparoscope your doctor can see your ovaries and take a small sample of tissue (biopsy) and have it examined.

Abdominal fluid aspiration

If you get a build-up of fluid in your abdomen (ascites) a sample can be taken to see if it has any cancer cells. Your doctor will first numb an area of your abdomen before putting a small needle through your skin. This needle can be inserted with the help of ultrasound. Some fluid is taken and then examined under a microscope. This procedure can be referred to as paracentesis.

Laparotomy

Sometimes cancer cannot be diagnosed until a full operation called a laparotomy is done. See page 56 for more information.

Other tests

Some people may need extra tests, depending on their symptoms. These include:

Colonoscopy

This is a test on your bowel using a tiny camera. It can check the lining of your bowel to see if cancer cells are present.

Gastroscopy

This is a test on your stomach using a tiny camera. It can check the lining of your stomach to see if there are cancer cells present.

Waiting for test results



It usually takes a week or two for all the test results to come back. Naturally, this can be an anxious time for you. It may help to talk things over with the specialist nurse or with a relative or close friend. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.



Support Line Freephone 1800 200 700

How is ovarian cancer staged and graded?

- Staging cancer means finding out its size, where the cancer cells are and if the cancer has spread.
- Grading means looking at the cancer cells to see how they might grow.
- Staging helps your doctor to decide the best treatment for you.
- Your prognosis is what your doctor expects to happen with your cancer.

The tests you have after diagnosis help the doctor to give your cancer a stage and grade.

Staging means finding out the size of the cancer and if it has spread. Grading describes the cancer cells – what they look like and how they might grow.

Knowing the stage and grade of your cancer helps your doctor to recommend the best treatment for you.



How is ovarian cancer staged?

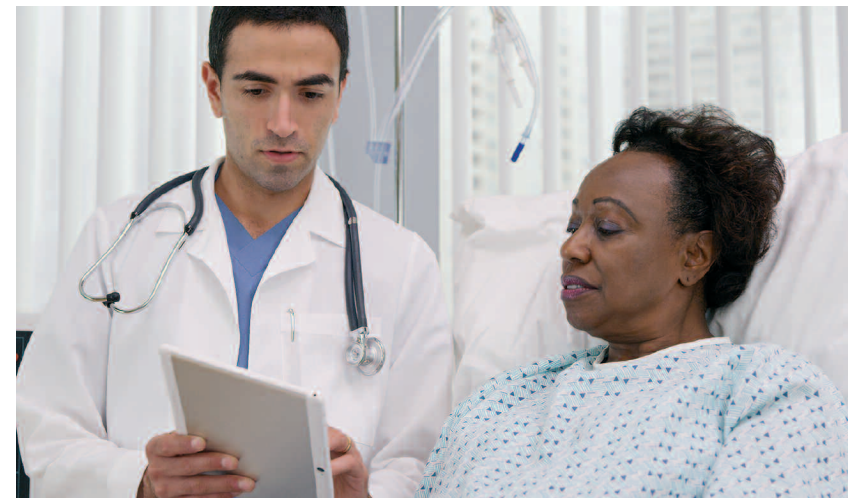
Staging normally refers to the size of the tumour (T), if there is cancer in your lymph nodes (N), and if the cancer has spread to other parts of your body (M for metastasis).

Your doctor often uses this information to give your cancer a number stage – from 0 to 4.

In general, the lower the number, the less the cancer has spread.

A higher number, such as stage 4, means a more advanced cancer. Most ovarian cancers are diagnosed at stage 3 or 4. This is because with early-stage ovarian cancer there may be few or no symptoms. Staging can be hard to understand, so ask your doctor and nurse for more information if you need it.

Sometimes you may need surgery to find out the exact stage. This means that your treatment plan may only be decided or may change after you have had surgery.

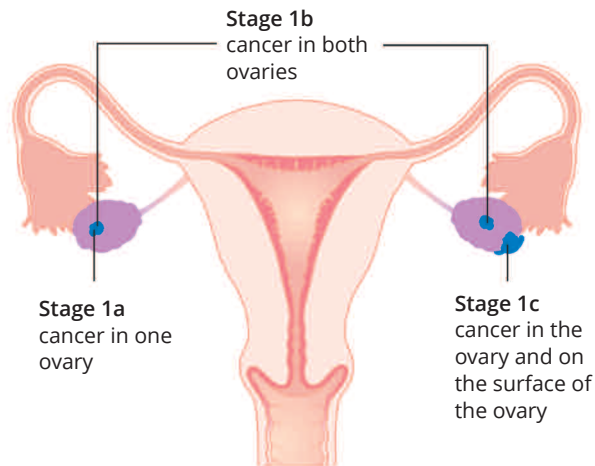


What are the stages of ovarian cancer?

Stage 1

Here the cancer affects only your ovaries.

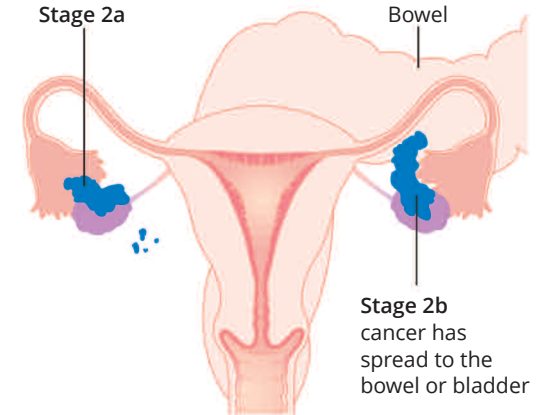
- 1a** The cancer is in one ovary only. The capsule around the ovary is intact (not broken).
- 1b** Like stage 1a except the cancer is in both ovaries.
- 1c** Tumour is in one ovary or in both ovaries, along with one of the following:
 - 1c1** The capsule around the ovary breaks (ruptures) during surgery. This is called surgical spill.
 - 1c2** The capsule breaks before surgery OR there is cancer on the surface of 1 or both ovaries.
 - 1c3** There are cancer cells in the fluid in your abdomen (ascites) OR there are cancer cells in the peritoneal washings. Peritoneal washings refers to liquid used to wash the area around the organs in your abdomen and pelvis during surgery. The liquid is checked for cancer cells.



Stage 2

The cancer has spread outside your ovary / ovaries but is still within your pelvis.

- 2a** The cancer cells have spread to organs near your ovary, such as your womb or fallopian tubes.
- 2b** The cancer has spread to other organs in your pelvis, such as the lining of your lower bowel or bladder.



Stage 3

The cancer has spread outside your pelvis and into your abdominal cavity. It can affect the lining of your abdomen or lymph nodes there. These are called retroperitoneal lymph nodes. When lymph nodes have cancer in them they are called positive lymph nodes.

- 3a1** The cancer has spread to the retroperitoneal lymph nodes.
- 3a2** Cancer cells affect the lining of your abdomen but they are very tiny and can only be seen under a microscope. May or may not have positive retroperitoneal lymph nodes.
- 3b** The cancer in your abdomen can be seen with the naked eye but is smaller than 2cm across. May or may not have positive retroperitoneal lymph nodes.
- 3c** The cancer in your abdomen can be seen with the naked eye and is larger than 2cm. May or may not have positive retroperitoneal lymph nodes. May have spread to the capsule around the liver or spleen.

Stage 4

The cancer has spread to other organs away from the pelvis.

- 4a There are cancer cells in the fluid between the membranes that cover the lungs (pleural fluid).
- 4b The cancer has spread to the inside of other organs such as the lungs, the liver, the spleen, the brain. Also includes when the cancer has spread to lymph nodes outside the pelvis, such as the groin, the neck, the armpit or the chest.

Recurrent ovarian cancer

This means that the cancer has come back (recurred) after you have finished treatment. A cancer is only staged once. If it comes back, it is not re-staged but is called cancer recurrence.

Staging means finding out the size and extent of the ovarian cancer so it can be treated fully.

What are the grades of ovarian cancer?

The grade of the cancer can help the doctor to predict how quickly the cancer will grow. You can have a low-, moderate- or high-grade cancer. Lower grades are slower growing. Different grades may need different treatments.

- **Grade 1 or low grade (well differentiated):** The cancer cells are very like normal cells in your ovary. They usually grow slowly and are less likely to spread.
- **Grade 2 or moderate grade (poorly differentiated):** The cancer cells look less like normal ovarian cells.
- **Grade 3 or high grade:** The cancer cells are very unlike normal ovarian cells. They usually grow quicker and are more likely to spread.

Asking about your prognosis

Your prognosis is information about how your cancer is likely to progress, including average survival times or life expectancy. It's not always easy for doctors to answer a question about life expectancy. Everyone is different, so what happens to you might be quite different from what the doctor expects.

Should I ask about my prognosis?

If your prognosis is better than expected, you may feel more hopeful about your illness and your future. You may feel more in control by having as much information as possible. Or you may not want to know about your prognosis. You may prefer not to think about the future too much or you may worry how you will cope if you get bad news.

If you decide you want information on your prognosis:

- **Think carefully about how you will cope with the information** before asking for your prognosis.
- **Get information on prognosis from your doctor.** They know your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- **Ask a friend or family member to go with you**, if you would like some support.
- **Be careful with online information.** It may be hard to understand or it may be incorrect. Also, the information may not really apply to your situation or to your particular cancer type. Ask your doctor or nurse specialist for recommended websites.
- **Accept that you will need time to think about what you have been told.** You may forget or not have understood some things. You may need to talk to your doctor or nurse again after you have thought about everything.

If you feel upset or anxious about your prognosis you can get support from friends, family or your hospital team. You can also call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie. Our cancer nurses can give you support, information and advice. They can also tell you about free counselling and other services that can help you.



Treating ovarian cancer

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How is ovarian cancer treated?

- A combination of surgery and chemotherapy is the main treatment for ovarian cancer. Some patients may benefit from targeted therapy drugs.
- A team of healthcare professionals called the multidisciplinary team (MDT) will look after you.

The type of treatment you receive will depend on:

- The size of your tumour
- The type of ovarian cancer (histological subtype)
- If it has spread or not
- Your general state of health
- Your preferences and lifestyle
- The stage and grade of the cancer

Treatment pathways

There are 2 main treatment pathways for ovarian cancer when it is first diagnosed:

1 Primary cytoreductive surgery and adjuvant chemotherapy

Surgery first (primary cytoreductive surgery)



Chemotherapy after surgery (adjuvant chemotherapy)

2 Neo-adjuvant chemotherapy and interval cytoreductive surgery

3-4 chemotherapy treatments first (neo adjuvant chemotherapy)



Surgery (interval cytoreductive surgery)*



Further chemotherapy

Your multidisciplinary team will decide the best treatment pathway for you.

**Some patients may have HIPEC chemotherapy during surgery (see page 53)*

Types of treatment

Surgery

Surgery is one of the main treatments for ovarian cancer. Your doctor will discuss with you the most appropriate type of surgery, depending on the stage and grade of your cancer.

Usually surgery for ovarian cancer involves removal of the ovaries, womb (uterus), cervix (neck of womb) and fallopian tubes. This is called a total abdominal hysterectomy and bilateral salpingo-oophorectomy.

If you have a borderline ovarian tumour or a low-grade very early stage cancer (stage 1a) you may have just the affected ovary and fallopian tube removed. If your cancer is more advanced, other tissues may need to be removed. This is called cyto-reductive surgery. See page 53 for more details on surgery.

Chemotherapy

Chemotherapy is the use of drugs to kill or control the cancer cells. You may have chemotherapy:

- After your surgery (adjuvant chemotherapy)
- Before surgery (neo-adjuvant chemotherapy) and again after you recover from surgery. See page 62 for more about chemotherapy.

Targeted therapies

Targeted therapies are drugs that can help your body to fight cancer. They target the parts of cancer cells that make them different from healthy cells. See page 67 for more information.

Radiotherapy

This involves using high-energy X-rays to kill the cancer cells. Radiotherapy is not routinely used in the treatment of ovarian cancer. Occasionally it may be considered if the cancer has recurred in one area that may not be suitable for surgery.

Your doctor will discuss your treatment options with you.

Specialist cancer centres

Ovarian cancer is treated in specialist cancer centres in Ireland. The staff at these centres have great expertise in managing patients with ovarian cancer. As a result, you may be transferred to another hospital from the one where you received your diagnosis.



Deciding on treatment

Multidisciplinary team

A multidisciplinary team (MDT) is a team of specialists involved in caring for your type of cancer. For example, a gynaecologist, specialist nurse and oncologist (cancer doctor). The team will meet to discuss your test results and your suggested treatment plan.

Understanding your treatment

Your doctor and nurse will explain your treatment options. Ask as many questions as you like. You could write down any questions you have in advance, so you don't forget anything. If you do forget something or need more explanations, ask your specialist nurse or talk to one of our cancer nurses – call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Time to think

It may feel as if everything is happening too fast. You may feel under pressure to make a decision. You can always ask for more time to decide about the treatment, if you are unsure when it's first explained to you.

Second opinion

You might also find it reassuring to have another medical opinion to help you decide about your treatment. Your treating doctor or GP will refer you to another specialist for a second opinion if you feel this would be helpful.

Accepting treatment

You have the right to find out what a treatment option means for you, and the right to accept or refuse it. If you want to refuse a particular treatment, let your doctor or nurse know your concerns first. It may help to talk to your GP as well. The important thing is that you are fully aware of the benefits and risks.



Who will be involved in my care?

Some of the following health professionals may be involved in your care.

Consultant An expert doctor. They are in charge of your treatment. They have a team of doctors working with them.

Surgeon A doctor who specialises in surgery and who can remove a tumour from your body.

Gynaecologist A doctor who specialises in treating problems with the female reproductive organs and functions.

Gynaecological oncologist This is a gynaecology surgeon who specialises in cancer.

Medical oncologist A doctor who specialises in treating cancer patients using chemotherapy and other drugs.

Oncology liaison nurse/clinical nurse specialist A specialist nurse who works in a cancer care unit. She or he gives information and reassurance to you and your family from diagnosis and throughout treatment.

Medical social worker A person trained to help you and your family with your social issues and emotional and practical needs. They can give advice on social welfare benefits and financial matters and on practical supports and services available to you.

GP (family doctor) Your GP is still very much a part of your care and can be a great support to you. You can talk to your GP about your medication and any side-effects you have. You can also contact your GP about any worries you have or if you are finding it hard to cope.

Physiotherapist A therapist who treats injury or illness with exercises and other physical treatments related to the illness.

Dietitian An expert on food and nutrition. They are trained to give advice on diet during your illness and use diet to help symptoms.

Psycho-oncology team These are specialists in psychological care and support for cancer patients. Usually the team includes psychiatrists, clinical psychologists and nurses.

Psychologist A specialist who can talk to you and your family about emotional and personal matters and can help you to make decisions.

Counsellor A person specially trained to give you emotional support and advice when you find it difficult to come to terms with your illness.

Pharmacists In hospital and in your local pharmacy – dispense chemotherapy and other cancer drugs. They can give advice on cancer drugs, such as how to take them, side-effects, and possible interactions between your cancer drugs and other medicines, food and drink, and supplements such as herbs and vitamins.

Community health services These include family doctors, public health nurses (who can visit you at home), community welfare officers and home-help organisers. Your local health centre or the medical social worker in the hospital can advise you about these services.

Palliative care team This team is specially trained in managing pain and other physical symptoms. They can help you and your family cope with any emotional distress. They are sometimes known as the symptom management team. A specialist palliative care service is available in most general hospitals. Palliative care teams also work in the community.

Individual treatment

You may notice that other people with ovarian cancer are not getting the same treatment as you. Their cancer may not be the same type or at the same stage as yours. Everyone's treatment needs will be different. Don't be afraid to ask your doctor about your treatment.

Giving consent for treatment

Before you start any treatment, you should be asked to sign a consent form saying that you understand what the treatment is for and that you give permission for treatment to be given. Before treatment, you should have been given full information about:

- What the treatment is for
- The type and amount of treatment you will have
- The benefits and risks of the treatment
- Possible side-effects from treatment
- Any other treatments that may be available

If you are confused about the information given to you, let your doctor or nurse know straight away. They can explain it to you again. Some treatments can be hard to understand and may need to be explained more than once. You can still change your mind after you have started treatment. Talk to your doctor or nurse if you have any worries about your treatment plan.

Waiting for treatment to start

Planning cancer treatment takes time. Most people want to start treatment right away. You may worry that the cancer will spread during this time.

Cancer treatment should start soon after diagnosis. But for most cancers, waiting for scans or treatment for a few weeks does not usually affect how well the treatment works.

If you are worried, talk to your doctor. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

While you're waiting for treatment, you might like to focus on your own health. This can help you prepare for your treatment and feel more in control.

How can I help myself?

It can be very difficult to cope with a cancer diagnosis and all the changes that this can bring. Your healthcare team can offer you different types of support, but there are also things you can do yourself to prepare for treatment and feel better.

Eat well



Eating well when you have cancer can help you feel better. It can help to:

- Make you feel stronger and help you to maintain a healthy weight
- Cope better with the side-effects of treatment
- Reduce the risk of infection
- Help your recovery

Ask to talk to the dietitian at the hospital for advice on the best diet for you. You can also read our booklet *Diet and Cancer*. To get a copy, call our Support Line on 1800 200 700, visit a Daffodil Centre or download it on our website www.cancer.ie

Be active

Being active has many benefits. It can help to:

- Reduce tiredness and some treatment side-effects
- Reduce anxiety and depression
- Improve your mood and quality of life
- Strengthen your muscles, joints and bones
- Reduce the risk of other health issues



Talk to your doctor or nurse before starting or increasing the amount of exercise you take. They can advise you on the type and amount of exercise that is safe for you. Be careful not to overdo it at the beginning, but build up gradually.

Ask your specialist nurse or visit a Daffodil Centre for information on our pre-treatment education workshops. The workshops give information on certain treatments, including what to expect and how to manage side-effects.

Quit smoking

If you are coping with a cancer diagnosis, you may find it stressful to quit smoking.

However, research tells us that:

- Non-smokers may have fewer or less severe side-effects during cancer treatment. For example, it reduces the risk of chest problems such as chest infections
- Smoking can reduce how well chemotherapy or radiotherapy work
- Not smoking can help you to heal better after surgery
- Quitting reduces your chances of further illness

If you would like advice or support on quitting, go to www.quit.ie, call the HSE Quit Team on CallSave 1800 201 203 or Freetext QUIT to 50100. Some hospitals have a stop-smoking service, with advisors who can help and support you.

Other ways to help yourself

Get information about your cancer and treatment

Understanding cancer and its treatment and knowing what to expect can help to relieve anxiety and stress for some people. If it makes you anxious, you could ask a friend to do the research for you and tell you anything important. Make sure you get your information from trustworthy sources like your medical team, the Irish Cancer Society and the HSE.

For more information on ovarian cancer, you can also look at the **This is GO** website, www.thisisgo.ie. This is GO gives tailored information for people diagnosed with ovarian cancer and for friends and relatives. **This is GO** is part of the Women's Health Initiative, a research project supported by the Irish Cancer Society.



Involve your family and close friends

Don't keep any worries or physical problems secret from the people closest to you. Ask someone close to you to come with you when you are visiting the doctor and when treatments will be discussed. Your friends and family will be affected by your diagnosis too, so try to talk openly and find ways to support each other.

Use your support network

Don't be shy about asking for help. Family and friends may not know the best way to help you, so tell them what you need. For example, lifts to the hospital, practical help at home, child-minding or just some company or support. Telling people what you need and how they can help means you will get the right amount of support to suit you.

Try relaxation and stress management techniques

Therapies like meditation or yoga can help you to cope with stress. Some cancer support centres provide groups to help you learn these techniques.

Accept change in your life

Accept that you may not be able to carry on exactly as before. Give yourself time to adjust to your new routine.

Know that there will be ups and downs

Sometimes people feel they have to be brave or positive all the time, but it's normal to have bad days. Get help if you are finding it hard to cope.

Try to cope day by day

Don't think about the future too much. Concentrate on the present and getting through each day of tests or treatment. That way, you may find it easier to cope with your illness.



Types of treatment

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Surgery

- Surgery aims to remove all of the tumour that is visible, if it is safe to do so.
- There are different types of surgery for ovarian cancer. The extent of the surgery depends on the stage and type of ovarian cancer.

Surgery and chemotherapy

You may have:

Surgery as your first treatment (primary cytoreductive surgery), followed by chemotherapy (adjuvant chemotherapy)

Chemotherapy before and after surgery. This is called interval cytoreductive surgery.

Chemotherapy during surgery

Some patients may have a type of chemotherapy called HIPEC, which involves giving a solution of heated chemotherapy direct to the surfaces inside the abdomen. Not every patient is suitable for HIPEC. There are trials ongoing to help decide which patients benefit the most. Your consultant will explain if HIPEC may be appropriate for you.

Type of surgery

The type of surgery you have will depend on:

- The type of tumour
- The size of the tumour
- If the cancer has spread to other tissues and organs

Sometimes your surgeon may only find out this information during the operation.

Sometimes a diagnostic laparoscopy (minor surgery, see page 28) is done first to see if the cancer has spread or to help plan a bigger surgery.

Extent of your surgery

To achieve the best outcome for you, surgery aims to remove all visible cancer. This can mean that the surgery required can be extensive.

Along with removing the ovaries and womb, there may be a need to operate on:

- The bowel, which sits directly behind the ovaries
- The lining of the abdominal wall, called the peritoneum
- Around the organs at the top of your abdomen.

All of this will be explained in detail when you meet your consultant and specialist nurse. Ask any questions you have about possible options and what the surgery will mean for you.



The thought of extensive surgery can be daunting, but your team will take time to go through everything and explain the benefits and risks and what to expect after your surgery.

Getting ready for surgery

Your surgical team and specialist nurse will tell you about your surgery. It is natural to feel anxious about having surgery. Talk to your doctor or nurse if you're feeling anxious. If there's anything you don't understand, ask again. They will be happy to answer your questions. You can also call our Support Line on 1800 200 700.

Before surgery

You may have some extra tests to make sure you are strong enough for surgery. These tests include a chest X-ray, heart test (ECG) and blood tests.

You will probably have to fast (not eat) from midnight before your surgery. You may get an anti-clotting injection like heparin, and elastic stockings may be put on your legs to prevent blood clots. Before you go to theatre, you may be given medication that will make you feel more relaxed and sleepy. If your team feels that an operation on your bowel may be necessary you will be asked to take a bowel-preparation drink the day before the surgery and you may also need to meet the specialist stoma nurse.

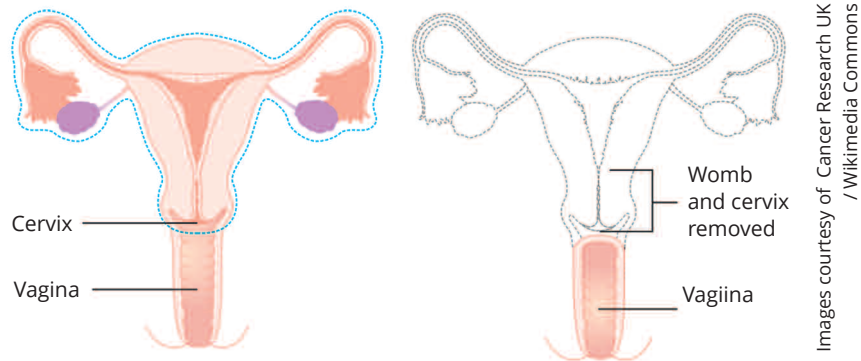
Enhanced recovery programmes

Some hospitals follow an enhanced recovery programme, which aims to reduce the time you spend in hospital and speed up your recovery. You will also play an active part in your recovery. For example, you will be given information about diet and exercise before surgery.

Types of surgery

Laparotomy

Laparotomy is an operation to let your surgeon look inside your abdomen. The surgeon will carefully examine the organs and tissues, and biopsies (tissue samples) are taken. If the samples are tested during surgery and cancer is found, the surgeon may continue with surgery to remove as much of the cancer as possible. Your surgeon will discuss this with you before your laparotomy. They will only continue with additional surgery if you have given permission (consent) before your laparotomy. In most cases, surgery will involve a total hysterectomy and bilateral salpingo-oophorectomy. If the biopsy samples are tested after the laparotomy, you may have a separate surgery to remove the cancer.



Hysterectomy and bilateral salpingo-oophorectomy

This is an operation where your two ovaries, fallopian tubes and womb (uterus) are removed. If the cancer has spread, your surgeon may need to operate on other organs in the abdomen to remove all the cancer. Commonly the omentum is removed. The omentum is a fatty tissue that surrounds your stomach. Removing cancer in the abdomen in this way is known as cyto-reductive surgery. Your surgeon may also take samples from other tissues, such as lymph glands, to see if the cancer has spread further.

Sometimes it may not be possible for the surgeon to remove all of the cancer. This may be because it would be unsafe for you or because the cancer has spread to your chest. For this reason, you may have chemotherapy first. The aim is to shrink the cancer so that it is then possible for the surgeon to remove it. You will have the rest of your chemotherapy after the operation. This is called interval cyto-reductive surgery.

Colostomy

Sometimes if the tumour has spread to your bowel, a small piece of bowel may be removed and the two cut ends joined back together.

In some cases, it is not possible to join up the bowel again. Instead, the bowel is brought out onto the surface of your tummy (abdomen) through an opening (stoma) made in your skin. This is called a colostomy. Your bowel motions (poo) will come out through the stoma, so you will need to wear a bag over the opening to collect them.

A colostomy can be temporary or permanent. If it is temporary, the bowel can be rejoined inside at a later stage.

In most hospitals there are specially trained nurses called stoma care nurses who will teach you how to care for your colostomy. You may also find it helpful to talk to someone who has had the same operation. They can give you first-hand advice and tips on how to care for your stoma in an easy and practical way. You are not alone – there are thousands of people in Ireland living with a stoma.

There are also specially trained people and support groups that can help you at this time. Talk to your doctor or nurse about them. You can also contact our Support Line on 1800 200 700 or visit a Daffodil Centre for more information.

After surgery

You may stay in an intensive care or high dependency unit (HDU) where the staff will keep you under close observation for a day or two, or you may go straight to the ward.

Drips, drains and tubes

When you wake up, you will have some tubes attached to your body. Don't be alarmed as they are normal after an operation like this.

- You will have a drip in a vein in your arm. You will be given fluids through this until you can drink again.
- A thin plastic tube may be up your nose. This is called a nasogastric tube and leads down into your stomach. By removing the fluid in your stomach through this tube, your nurses can keep your stomach empty. This will stop you from feeling sick and let your wound heal. It is usually removed after 48 hours.
- One or more thin tubes called drains may be coming out of your tummy (abdomen) near your wound. These help to drain blood, bile and fluid from the operation site to let your wound heal.
- A thin tube called a catheter may be put into your bladder to drain any urine. It is usually removed after 48 hours.
- You may have a thin tube called an epidural catheter in your back to help with pain relief.

Pain

You may have some pain after the operation, especially when you cough or move. Your nurse can give you medicine to control the pain and stop you feeling or getting sick, if you need it. You may have an epidural tube in your back to relieve pain after the surgery. If you have a patient controlled analgesia pump (PCA), your nurse will show you how to use it. Always ask for help if you have any pain or feel sick.

Vaginal bleeding

You may have some bleeding through your vagina after your operation. It can be similar to a light period. It usually changes to a red/brown discharge and then stops. It can last from a few days to a few weeks.

Tell your doctor or nurse if the bleeding starts again after stopping or if you notice that there is a green, yellow or smelly discharge.

Eating and drinking

It will take a few days before you can return to normal eating and drinking. You will soon be able to take sips of water again. The amount of fluids you can take will then be increased. Most people can manage a light meal within 2 or 3 days of surgery. As you begin to drink again, the drip giving you fluids will be removed.

Bowel function

You may have difficulty passing wind or opening your bowels after the surgery. Your nurse can give you medication to help get your bowels back to normal. Things will also improve when you are up and moving about.



Getting up and about

A physiotherapist will visit you regularly after surgery. These visits are to help you with breathing and leg exercises. Even when you are in bed, you will be encouraged to move your legs and do deep breathing exercises at least once an hour. On the day after surgery, the physio or nurse will help you get out of bed and take you for a short walk. These walks will become more frequent and longer as you get better.

It may take a few weeks before you can get back to normal physical activity. Your surgical team will advise you about this. You will not be able to drive for at least 6 weeks after surgery.

Going home

You will probably go home about 8-10 days after surgery. If you live alone or have problems getting around the house, talk to your nurse or the medical social worker on your ward as soon as you are admitted to the hospital. The medical social worker can organise community services you may need. For example, organising a public health nurse to visit you and give you support at home with wound dressings or colostomy bags. The medical social worker can also advise you about social welfare benefits or entitlements you can apply for.

On the day you go home you will be given a date to come back for a check-up in about 6 weeks' time.

If you have a worry or symptom that is causing you concern before your check-up date, contact your doctor, cancer nurse specialist or hospital ward for advice.

Possible side-effects of surgery

Bleeding

You will have some blood loss during your operation. Sometimes you may need a blood transfusion. There is a small risk of internal bleeding after surgery. It is rare and if it happens you may need another operation.

Your nurse will check you regularly for signs of blood loss.

Risk of clotting (DVT)

Surgery in your pelvis puts you at risk of clotting in the deep veins of your legs and body. This is called deep venous thrombosis (DVT). You may be given an injection to prevent this. Usually you will have injections for about four weeks after surgery. So, when you go home, you or a member of your family will be invited to learn how to give the injection. It is very easy and is given with a very fine needle just under the skin. Keep the injection well away from the surgical wounds. You may also wear special elastic stockings while you are on bed rest. Getting up and about and exercising your legs is most important in preventing DVT.

Infection

You are at risk of getting an infection in your chest, wound or urinary tract after surgery. Antibiotics will be given during your surgery. You may also be prescribed antibiotics after surgery.

Your medical team will keep a close eye on your wound to make sure you are healing well. They will also check the tubes and drains. Tell your nurse if you feel hot or unwell or if you notice any leakage from your wound or drains.



Lymphoedema

Lymphoedema or swelling in one or both of your legs may happen in the long term if your lymph glands are removed during surgery. When the glands are removed, they can no longer drain away excess fluid in your body, so there is a build-up of fluid in your legs. Ask your physiotherapist for more information about lymphoedema. For a factsheet on lymphoedema, call our Support Line on 1800 200 700. You can also pick up a copy from a Daffodil Centre or download one from www.cancer.ie

Chemotherapy

- Chemotherapy uses drugs to kill cancer cells
- Chemotherapy can cause a range of side-effects
- Side-effects normally go after treatment ends

Chemotherapy is a treatment that uses drugs to kill cancer cells. The doctor who specialises in chemotherapy is called a medical oncologist.

Chemotherapy drugs may be given:

- Before surgery to shrink the cancer and reduce the risk of it coming back. This is called neo-adjuvant treatment.
- After surgery to reduce the risk of the cancer coming back. This is called adjuvant treatment.
- Both before and after surgery (interval surgery).
- As a treatment on its own.

How often will I have chemotherapy?

Chemotherapy is given in cycles with a rest period between treatments. This rest period allows your body time to recover from the side-effects of treatment. The number of treatments and cycles can vary, depending on your cancer type and how well it is responding to treatment.

How is chemotherapy given?

Chemotherapy may be given directly into a vein as an injection and/or through an intravenous infusion (by drip or pump). It may also be given in tablet form. You may have a central venous access device fitted. This is a thin tube (line) which goes directly into a vein and stays in place until your treatment is over. This saves you having repeated injections. Usually your treatment will be given in the chemotherapy day unit.

Some patients having surgery may also have a type of chemotherapy called HIPEC. HIPEC gives chemotherapy directly to the surfaces inside the abdomen during surgery. See page 53.



What kinds of drugs are used?

There are several chemotherapy drugs used to treat ovarian cancer. These include carboplatin, paclitaxel (Taxol®), cyclophosphamide, topotecan, liposomal doxorubicin (Caelyx®), cisplatin, gemcitabine and etoposide.

There are also other chemotherapy drugs that can be used to treat ovarian cancer. Talk to your doctor, who will explain your treatment options to you. New drugs and different ways of treating ovarian cancer are being developed all the time. For more information on research and clinical trials, see page 70.

Understanding your drug treatment



It's important that you understand the drugs you have been given. Ask your doctor or specialist nurse for more information about your drug treatment and any possible side-effects. They should give you a printed sheet to take home with you.

If you know the name of your drug you can visit the Health Products Regulatory Authority's website at www.hpra.ie where you will find more information about:

- What the drug is
- How it is given
- Possible side-effects

If you have any questions or need any more information, ask your team. You can also speak to our cancer nurses by calling our Support Line on 1800 200 700.

What are the side-effects of chemotherapy?

The side-effects of chemotherapy vary from person to person and depend on the drugs used and the amount of chemotherapy given. Side-effects happen because chemotherapy can affect both healthy cells and cancer cells.

Most side-effects can be helped by medication. Usually the side-effects go away when the treatment ends or soon after. Side-effects may include:

Fatigue Fatigue is very common. It can make you feel tired and weak. For more information see page 73.

Nausea and vomiting Chemotherapy can cause nausea (feeling sick) and vomiting (being sick). There are treatments that work well to prevent nausea and vomiting.

Infection Chemotherapy drugs make you more likely to get infections. You will be asked to watch out for signs of infection at all times. These signs include feeling shivery and unwell, having a high or low temperature, having a cough, or pain passing urine. If you have any of these symptoms, it's very important to call the hospital straight away - never delay. Check with your hospital about the temperature advice to follow.

Anaemia Chemotherapy can cause the bone marrow to make fewer red blood cells. Having fewer red blood cells is called anaemia. Anaemia can make you feel tired and breathless. Regular blood tests to measure your red cell count will be done during treatment. You may need a blood transfusion to treat your anaemia.

Bleeding and bruising Chemotherapy can stop your bone marrow from making enough platelets. Platelets help make your blood clot and stop bleeding. With fewer platelets you may bleed or bruise very easily. Tell your doctor if you have any bruising or bleeding that you can't explain, such as nosebleeds or bleeding gums.

Mouth and throat problems Chemotherapy can cause mouth and throat problems including a dry mouth, ulcers and gum infections. There are many mouthwashes and medications to help, which your doctor can prescribe for you.

Hair loss (alopecia) Some chemotherapy drugs can cause hair loss from all over your body. This can be very distressing. It can affect your confidence and make you feel self-conscious about your cancer. How much hair falls out depends on the drug given, the dose and your own reaction to it. Your hair will grow back after you stop chemo.

Constipation and diarrhoea Chemotherapy can cause constipation (not having a bowel movement often enough) and diarrhoea (frequent loose or watery bowel movements).

Skin and nail changes Skin may become dry, flaky and itchy. Nails may become dark, yellow or brittle.

Peripheral neuropathy Some drugs can affect your nerve endings. Tell your doctor if you have numbness or a tingling or burning sensation in your hands and feet. This is known as peripheral neuropathy.

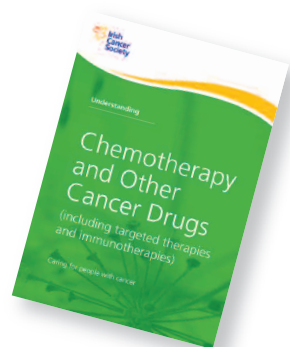
Changes in kidney or liver function Some drugs can irritate or damage kidney and liver cells. Decreased urination, swelling of the hands or feet (oedema) or headaches are some of the signs of kidney damage; yellowing of the skin or eyes (jaundice) can be a sign of liver problems. Tell your doctor if you have these or any other changes in your body. Blood tests will check your kidney and liver function regularly.

Allergy On rare occasions, people can have a reaction to certain chemotherapy drugs. Reactions can include rash, itching, low blood pressure and shortness of breath. Contact the hospital if you have these side-effects.

Blood clots Chemotherapy and having cancer can both increase your risk of blood clots. A blood clot may cause pain, redness and swelling in your leg, or breathlessness and chest pain. Contact your hospital immediately if you have any of these symptoms, as blood clots can be serious. Usually they are treated with medication to thin your blood.

If you have any symptoms that are troubling you or you feel unwell, tell your doctor or nurse straight away. You will be given contact details of who to contact before you start your treatment.

For more information on the side-effects of chemotherapy or a copy of the booklet ***Understanding chemotherapy and other cancer drugs***, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also look at our website www.cancer.ie for tips on coping with different side-effects.



Targeted therapies

- Targeted therapies target certain parts of cancer cells that make them different from other cells.
- Side-effects depend on the drugs being used and vary from person to person.

Targeted therapies are drugs that target certain parts of cancer cells that make them different from other cells. In other words, they take advantage of differences between normal cells and cancer cells. Your consultant will tell you if targeted therapies might be helpful with your particular cancer.

Various targeted therapies work in different ways, working to:

- Block or turn off chemical signals that tell the cancer cell to grow and divide
- Change proteins within the cancer cells so the cells die
- Stop new blood vessels growing to feed the cancer cells
- Carry toxins to the cancer cells to kill them

Some drugs are given in tablet form. Others are given into a vein through a drip.

Types of targeted therapies used in ovarian cancer

PARP inhibitors

These drugs stop PARP from working. PARP is a protein that helps damaged cells to repair. By blocking PARP, the damaged cancer cells cannot repair and therefore cannot grow. Olaparib and niraparib are examples of PARP inhibitors.

Bevacizumab (avastin)

This drug blocks a protein called VEGF or vascular endothelial growth factor. This protein helps cancer cells to develop their own blood supply. When VEGF is blocked, cancer cells are prevented from growing their own blood supply, which they need to survive.

Side-effects

Side-effects depend on the drugs being used and vary from person to person.

Your doctor and nurse will explain your treatment to you in more detail and tell you about any likely side-effects. Always tell your doctor or nurse if you don't feel well or if you are having any symptoms that are troubling you.

For more information on targeted therapies and their side-effects, or a copy of the booklet *Understanding chemotherapy and other cancer drugs*, call our Support Line on 1800 200 700 or visit a Daffodil Centre.



New targeted therapies



New targeted therapies are being developed all the time and existing therapies are being used in new ways. You may also be offered a targeted therapy as part of a clinical trial (see page 70). Ask your doctor if there are any targeted therapies available to treat your cancer or if there are any trials that are suitable for you.

Treatment for recurrent ovarian cancer

Ovarian cancer can come back again (recur), even if your initial treatment has gone well. This is why it is important to tell your team if you have any symptoms that are bothering you and to go to all your follow-up appointments. Your specialist nurse will explain the symptoms to look out for. If you experience these symptoms, you may need further tests, such as a scan, to check if the cancer has returned.

If your cancer does return, there are many treatments now available. Second surgeries can be considered in some cases, but repeat chemotherapy and newer targeted treatments are commonly used. Immunotherapy drugs may also be considered for some women.

Because recurrence of ovarian cancer is common, it is often now regarded as a chronic illness requiring multiple lines of treatment. Many of the clinical trials are focused on this area.

Palliative care



Palliative care helps you to manage your symptoms and improve your quality of life. Palliative care includes end-of-life care, but your doctor may also recommend palliative care to relieve symptoms earlier in your illness.

The palliative care team can include specially trained doctors, nurses, social workers, physiotherapists, occupational therapists, complementary therapists, chaplains and counsellors. Palliative care can be arranged by your family doctor (GP), public health nurse or by the hospital. Palliative care is a free service for all patients with advanced cancer.

Clinical trials

Clinical trials are research studies that try to find new or better ways of treating or diagnosing cancer or reducing side-effects.

Patients with cancer are sometimes asked to take part in a clinical trial. This means that instead of the standard treatment you get a new trial drug. Or you may be given existing treatments used in different ways. For example, you may be given a different dose of a drug or you may be given two treatments together.

Drugs that are used in a clinical trial have been carefully tested before they're given to patients. Because the drugs are still in trial, you'll be very closely monitored and may have extra tests and appointments.

Trials often investigate very specific features of a particular cancer or treatment, so you may not be suitable for a trial, even if it is researching your particular cancer. Your doctor can advise you about this.

More information

It's best to talk to your doctor if you're interested in taking part in a clinical trial. For more information, you can read our factsheet *Cancer and Clinical Trials*.

It's available to read or download on our website, www.cancer.ie. You can also get a free copy by calling our Support Line on 1800 200 700 or by dropping into a Daffodil Centre.



You can see a list of current cancer trials at www.cancertrials.ie

Email: supportline@irishcancer.ie

Managing side-effects and symptoms

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How can I cope with fatigue?

- Fatigue means feeling extremely tired.
- There are things that can improve fatigue, depending on what's causing it.

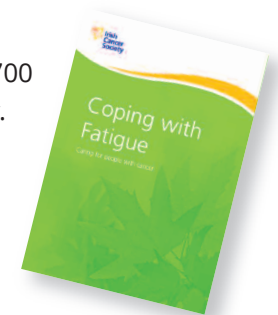
It's common to feel fatigue when you have cancer. This extreme tiredness can be caused by many things, including:

- The cancer itself
- Tests and treatments for cancer
- Not eating well
- Low levels of red blood cells (due to the cancer or its treatment)
- Dealing with difficult emotions and feeling anxious or depressed
- Not sleeping well
- Symptoms like pain, breathlessness or fluid retention

Usually fatigue starts to improve once treatment is over, but it can carry on for some people. Tell your doctor or nurse if fatigue is affecting you, so that they can help you.

Finding out what is causing your fatigue makes it easier to treat. For example, if you have a low red blood cell count, a transfusion can make you feel better. If you are not eating well, a dietitian may be able to give you some advice to help you.

Our booklet *Coping with Fatigue* has more advice. Call our Support Line on 1800 200 700 or call into a Daffodil Centre for a free copy. It's also on our website www.cancer.ie



Hints and tips: Fatigue



- **Ask your doctor about exercising.** Being active can help with fatigue. Your doctor may also be able to recommend an exercise programme for you.
- **Plan your days:** Get to know when your energy levels tend to be better. You may have to decide which tasks are important to finish and do them over the course of the day or when you have most energy.
- **Ask for help at work or at home** with any jobs that you find tiring.
- **Try to eat a well-balanced diet.** Eat little and often. If your appetite is poor. Our booklet *Diet and Cancer* has tips to help.
- **Try to avoid stress.** Talk to friends and family about any worries you have and take time to enjoy yourself. Counselling (see page 95) may help too.
- **If you are not sleeping well, try to get a good bedtime routine and try relaxation techniques.** Avoid stimulants like caffeine and alcohol in the evening and try not to use electronic devices for an hour before bedtime.
- **Short naps (less than an hour) and rest periods can be helpful,** as long as they don't stop you from sleeping at night.
- **Try complementary therapies** like meditation, acupuncture or massage, if your doctor says they're safe for you.

Will treatment affect my sex life?

Going through treatment for ovarian cancer can affect you physically and mentally when it comes to sex.

Sex and your emotions

Cancer can affect how you feel about sex and your relationships. Coming to terms with the fact that you have cancer can take quite a while. It can be hard to relax as well when you have a lot of worries on your mind. You may also be feeling tired from the effects of treatment and lose interest in sex as a result.

There is no right or wrong way to feel about your sexuality and sex life. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner. Touching and holding each other can help you to stay physically close.



You may find that talking about your feelings may ease any worries you have. If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. Our Support Line 1800 200 700 and our Daffodil Centres can help you to find supportive information and accredited therapists if you would like to talk to someone. This can help you and your partner deal with a change in your sexual relationship and find ways of being close again.

There is no set time for you to be ready to have sex again. It varies from person to person.

Sex and your body

Some treatments can affect your sex life.

If you have a hysterectomy, it is best to wait at least 6 weeks before having sex again to allow your wound to heal properly. Many women have no problem resuming intimacy and sex after this time.

If you haven't been through the menopause and you have your ovaries removed, you will go through early menopause. This can affect your desire for sex (libido) and cause vaginal dryness, which can make penetrative sex uncomfortable. Vaginal creams, moisturisers and lubricants can help. These can be bought in your local pharmacy. Your doctor or nurse can advise you about the best products, or may recommend hormonal creams.

Other menopausal symptoms such as difficulty sleeping and hot flushes may also make you feel less like having sex. See page 79 for more on managing menopausal symptoms

If you have a colostomy, it can affect the way you feel about your body. You may feel self-conscious about your body with your partner or if you're starting a new relationship.

There's more about managing the sexual side-effects of treatment on our website, www.cancer.ie

Always let your medical team know if you're having problems. They can give you advice and refer you to another specialist, if necessary.

Contraception

If you did not have a hysterectomy and are fertile, you should use a reliable method of contraception during and for some time after treatment. Some chemotherapy and other cancer drugs may harm a developing baby, so it's important to avoid pregnancy during and for a time after treatment.

Many specialists recommend that you wait for up to 2 years after treatment before trying to start a family or having more children. This time gives your body a chance to recover from the effects of the cancer and its treatment.

Ask your doctor's advice about contraception and family planning.



Asking for advice

If you have any questions about how treatment may affect your sex life, you can ask your doctor or nurse. Your doctor and nurse are well used to talking about these matters, so there's no need to feel embarrassed. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with a cancer nurse in confidence. Or email the nurses at supportline@irishcancer.ie

How will treatment affect my fertility?

Some treatments can also affect your fertility, either temporarily or permanently.

Discuss any worries you have about infertility with your doctor before treatment starts. He or she can tell you if there are any options open to you. For example, it may be possible to freeze your eggs before treatment begins. Your doctor can refer you to a specialist fertility clinic for advice, counselling and support if this is an option for you.

Dealing with infertility can bring feelings of sadness, anger and loss of identity. It can help to talk through your concerns with someone who is a good listener or with a professional counsellor. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre for information and support from a cancer nurse.



Coping with early menopause

If you haven't yet gone through the menopause, having your ovaries removed will cause an early menopause. Symptoms can include hot flushes, night sweats, disturbed sleep, headaches, joint pain, osteoporosis, dry skin, dryness of your vagina, reduced sexual desire (libido), mood swings, difficulty concentrating or remembering things, anxiety or low mood.

Tell your nurse or doctor if you're troubled by menopausal symptoms. There are also some tips below that may help. You can read more about the sexual side-effects of treatment on page 75.

Managing menopausal symptoms

Menopausal symptoms can have a big impact on your day-to-day life, especially when you are trying to deal with a cancer diagnosis. Fortunately, there are lots of treatments to help with most menopausal symptoms, and ways to help you cope better. For example:

- **Prescription medications** like hormone replacement therapy (HRT)
- **Complementary therapies** such as acupuncture and aromatherapy. Check with your doctor that complementary therapies are safe for you
- **Relaxation techniques** like meditation and yoga
- **Dietary or herbal supplements** such as evening primrose oil and ginseng
- **Emotional support** from counsellors and support groups

Always talk to your doctor before trying complementary therapies or if you are thinking of taking any supplements, to check they are safe for you.

Hints and tips: Coping with hot flushes

- Avoid warm areas and use an electric fan to lower your skin temperature.
- Avoid spicy foods, caffeine, alcohol, sugar and hot drinks.
- Avoid hot baths or showers, as they may trigger a hot flush.
- Wear cotton or wicking-fabric clothing. Cotton absorbs moisture and wicking fabrics take moisture away from the body to keep you dry and comfortable.
- Have layers of clothing and bedding so that you can remove or add layers as your body temperature changes.
- Keep a cool gel pack under your pillow at night.
- Use sprays or moist wipes to help lower your skin temperature.
- Drink cold drinks.
- Taking regular exercise and being a healthy weight may reduce symptoms.
- Don't smoke.
- Ask your doctor about medication that may help.

Going through the menopause and perhaps facing infertility at an early age can be isolating. You may feel that you cannot share your experiences with your friends, or that they won't understand what you are going through. Talk to your doctor or nurse about your feelings. Or call our cancer nurses on 1800 200 700 for confidential advice and support.

Cancer and complementary therapies

Complementary therapies are treatments and activities that you can have along with your standard medical treatment to try and feel better. For example, massage, counselling and aromatherapy.

Complementary therapies can't treat or cure cancer, but some people say that complementary therapies help them to feel more relaxed and better able to cope with their cancer and the side-effects of treatment.

It's very important to talk to your doctor if you're thinking of using complementary therapies. Tell them also if you're using or considering using over-the-counter or herbal medications. Some can interfere with your treatment or be harmful to you, even if you have used them safely before your cancer diagnosis.

Integrative care

Integrative care means combining (integrating) your standard cancer treatment with complementary therapies to try to feel as well as possible and to cope better with your cancer.



What's the difference between complementary and alternative therapies?

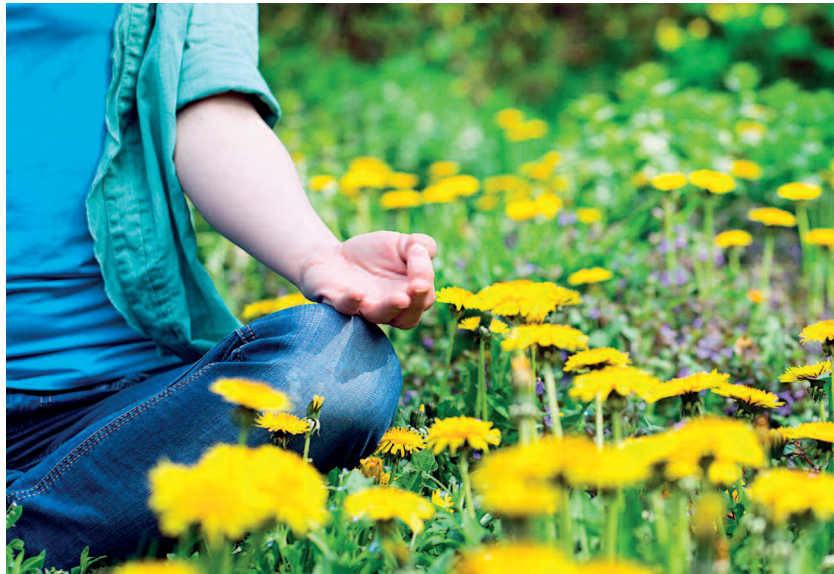
Complementary therapies are used **together with** standard medical treatment.

Alternative therapies are used **instead of** standard medical care.

Modern medical treatments are very effective at curing cancer and keeping it under control. An unproven alternative could harm your health, or you might miss out on a treatment that could really help you.

More information

To find out more about complementary therapies, you can talk to one of our cancer nurses - call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also ask for a free copy of our booklet *Understanding cancer and complementary therapies*, or download it from our website www.cancer.ie



After treatment

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What follow-up will I need?

After your cancer treatment has ended you will still need regular check-ups. This is called follow-up. For some patients, follow-up may involve consultations over the phone; others may need to go to the hospital for clinical assessment. There may be a combination of phone consultations and outpatient visits. Your gynae-oncology team will discuss your follow-up procedure with you. How often and the type of follow-up will depend on the type and stage of your cancer. The follow-up is often shared between the teams that have treated your cancer. This may include the surgical team and / or the medical oncologist.



The purpose of follow-up is to:

- Help with any side-effects that you may have
- Check for signs of new side-effects that may develop after you have finished treatment
- Check for signs of the cancer coming back (recurrence)

Tell your doctor or nurse how you have been since your last appointment. Remember to tell them about any new symptoms, aches or pains you have, or if you are finding it hard to cope.

It can help to write down what you want to say before you see the doctor, so you don't forget what you wanted to say.

You will be told about the symptoms you should be alert to, so you can report them to your doctor or specialist nurse.

The 'alert symptoms' are:

- Vaginal bleeding or discharge
- Pain or discomfort in tummy or pelvis
- Pain or discomfort in back or legs
- Swelling in tummy or legs
- Unexplained weight loss
- Unexplained lethargy or tiredness
- Loss of appetite
- New or persistent cough or shortness of breath

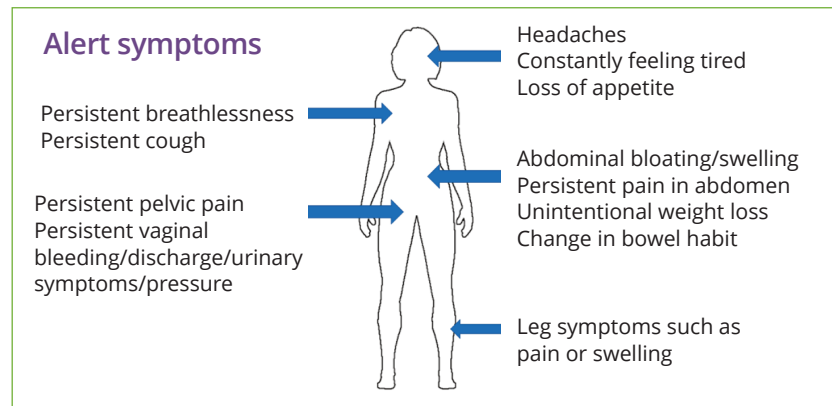


Image courtesy of MMUH Gynae-oncology team, 2020

If you are between check-ups and have a symptom or problem that is worrying you, call your specialist nurse for advice or to arrange an earlier outpatient appointment if necessary.

If you become suddenly unwell and can't contact your specialist nurse or hospital team, go to your GP or the emergency department at the hospital.

What if the cancer comes back?

If cancer comes back, it can often be treated again (see page 69). Your cancer doctor will advise you on what your treatment options are.

Life after treatment

It can take some time to adjust to life after cancer treatment. It isn't unusual to feel quite low and lost after your treatment has ended, especially during the first few months.

Feelings you may have include:

- **Fear of cancer coming back** and worrying about every small symptom
- **Loneliness** without the company and support of your medical team and fellow patients
- **Stress** at having to deal with things that may have been on hold during your treatment, such as your finances, going back to work and family issues
- **Isolation or guilt** if your family and friends expect you to get back to normal before you are ready
- **Anxiety and self-doubt** about sexual and romantic relationships
- **Anger** at what has happened and the effect on you and your loved ones
- **Depression or sadness**

There is more about how to cope with these feelings and adjusting to life after cancer on our website www.cancer.ie You can also call our Support Line or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 96 for other ways to get emotional support.

After-treatment workshops

You might like to join our *Life and Cancer – Enhancing Survivorship (LACES)* programme when you have completed treatment or have started maintenance therapy. This workshop covers topics such as diet, exercise, wellbeing, finance and self-management and gives information on support and services to help you. Call our Support Line or visit a Daffodil Centre for details.

Living a healthy lifestyle

Having a healthy lifestyle is important as it can help you to:

- Feel better
- Heal and recover faster
- Cope better with side-effects
- Keep up your energy and strength
- Reduce your risk of other illnesses

A healthy lifestyle includes:

- Exercising
- Eating well
- Not smoking
- Protecting yourself from the sun
- Avoiding alcohol

It's also important to have any vaccines recommended for you. For example, flu and pneumonia. Some vaccinations may not be suitable if you've had cancer treatment, so check with your doctor which you should have and make sure you get them.

If you want more information or advice, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also go to our website www.cancer.ie for tips and publications on healthy living.

Planning ahead

Planning ahead is useful for everyone, whether they have an illness or not. Many people find it puts their mind at rest to have medical plans in place and sort out legal and practical matters, even though they still hope to live for a long time

Planning ahead might include:

- **Thinking about how you feel about different types of medical treatment**, including if you want to stop treatment at any stage or carry on for as long as possible.
- **Writing an advance care directive**. This is where you can write down your wishes about your medical care. Doctors can use this if you are not well enough to say what you want.
- **Picking someone to make medical decisions for you** if you are not well enough.
- **Making a will**.
- **Sorting financial affairs**.
- **Talking about what you want to your family, friends, carers and healthcare providers**. Talking to your loved ones about your wishes and concerns can be very difficult for everyone. If you need information or support, call our Support Line on 1800 200 700 or drop into a Daffodil Centre.

Who can help me plan?

Think Ahead is a planning booklet with easy-to-read forms to fill in to record your personal, medical, financial and legal information and preferences. It's available from the Irish Hospice Foundation at www.hospicefoundation.ie





Coping and emotions

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How can I cope with my feelings?



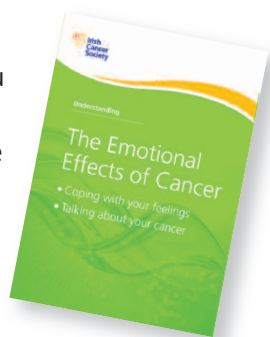
Some people say that trying to cope with their thoughts and feelings is the hardest part of having cancer.

You may find it hard to come to terms with your diagnosis, you may blame yourself, resent other people who are healthy or feel very anxious or depressed.

Feelings like sadness, fear, grief, hopelessness, anxiety and anger can happen at different times, sometimes months or years after treatment.

A cancer diagnosis can be hard on you - mentally and emotionally. Give yourself time and space to deal with your emotions, and get help if you need it.

A helpful booklet that discusses in detail how you may be feeling is called ***Understanding the Emotional Effects of Cancer***. Call our Support Line on 1800 200 700 or visit a Daffodil Centre for a free copy.



Anxiety and depression

If you feel that anxiety or low moods are getting the better of you or you're finding it hard to cope, it's important to get help. Try to talk with someone you know who is a good listener, join a support group or tell your GP. Medical social workers can also offer support to you and your family.

Your doctor may also suggest medication to help with anxiety or depression. Often a short course of antidepressants or anti-anxiety medication can work well. Professional counselling can also be very helpful.

It's not a sign of failure to ask for help or to feel unable to cope on your own.

'Counselling has helped me with every part of my life. I feel I have a future now.'

Counselling

If you're feeling very distressed or finding it hard to cope, a trained counsellor who is not involved in your situation can help you to express your feelings, worries and fears and make sense of them. Counselling can also give you emotional support, help you to make decisions and learn ways to cope better.

Free one-to-one counselling is available through some local cancer support centres. To find out more about counselling call our Support Line on Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at supportline@irishcancer.ie

A list of counsellors funded by the Irish Cancer Society is available at www.cancer.ie



Ways to get emotional support



Find out about cancer support services in your area: Most provide a range of helpful services like counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 118 for more about cancer support services.

Join a support or educational group: You might find it reassuring to talk to other people who are facing similar challenges. Many cancer support centres have activities and groups where you can meet other people affected by cancer.

'Talking about cancer made it less awful and helped ease my fears. I learned to cope and understand myself better.'

Ask about psycho-oncology services at the hospital: Hospital psycho-oncology services give cancer patients emotional and psychological support to help them cope. Your healthcare team can refer you to psycho-oncology services if they're available at your hospital.

Peer Support: Peer Support is the Irish Cancer Society's one-to-one support programme. You can be put in contact with a trained volunteer who has dealt with a cancer diagnosis. Volunteers give support, practical information and reassurance. Call 1800 200 700 for more information or visit a Daffodil Centre.

Get online support: Special websites called online communities let you write questions, share stories, and give and receive advice and support. Visit www.cancer.ie/community to join the Irish Cancer Society online community.

Talk things through: It can be a great weight off your mind to share your feelings and worries. You could talk to a friend or family member if you feel comfortable doing so. You could also speak to the medical social worker at the hospital or to one of our cancer nurses.

Seek spiritual support: For some people spiritual and religious beliefs can bring comfort and hope. Practices such as prayer or meditation may help you to focus on what has value and meaning in your life.

If you need more information or help with finding support, call our Support Line on 1800 200 700 or drop into a Daffodil Centre.



Positive feelings



In time, some people say they can find positive things in their cancer experience. They say that cancer brought them closer to the people around them or made them appreciate what's important in life. Or it opened up new experiences and relationships.

Getting support, such as counselling, may help you to come to terms with your diagnosis and feel more positive.

You and your family

Every family deals with cancer in its own way. You may feel that you don't want your illness to upset family life, feel guilty that you can't join in as much as before, or that you're letting down your partner or children. You may also worry about the emotional impact your illness will have on your loved ones. Our booklet *Understanding the Emotional Effects of Cancer* can help you to find ways to talk about your cancer and to ask for the help and support you need.

Further information and support

If you or your family members need more support or advice, speak to the medical social worker at the hospital or get in touch with one of our cancer nurses. Call us on 1800 200 700 or visit a Daffodil Centre. The nurses can also support you if you have children and aren't sure what to say to them. You could also read our booklet *Talking to Children about Cancer*, which has practical advice about how to talk to children of different ages.



Changing relationships

You may feel that people are treating you differently. Some people may withdraw and not contact you as much because they are afraid of doing or saying the wrong thing. Others may not understand that you feel too unwell to go out. Try to talk openly to your friends and family if there are any misunderstandings or problems. Tell them how you feel. If you find it hard, ask another family member or friend to talk to them.

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Supporting someone with cancer



Finding out someone you love has cancer and trying to care for them can be difficult. You might be unsure about how best to support the person with cancer, practically or emotionally. You might also be struggling with your own feelings and responsibilities.

Here are some things that can help to make life a little easier:

Learn about cancer

Try to go to hospital visits and also read any information from the hospital so you can understand your loved one's illness and treatment, how it might affect them, physically and emotionally, and how you can best support them. Visit our website www.cancer.ie or call our Support Line for free copies of our cancer information booklets.

Share worries

If you are feeling anxious or overwhelmed, share your worries with someone else. Call our Support Line on 1800 200 700 or drop into a Daffodil Centre if you want to chat to a cancer nurse in confidence.

Be kind to yourself

Your health and happiness matter too. Make some time for yourself, stay in touch with your friends and don't be afraid to let other people help out with the caring.

Try counselling

You might find it helpful to talk to a counsellor. Free one-to-one counselling is available to friends and family members through some local cancer support centres. Talk to your GP or see page 95.

Find out about support for carers

Find out about groups and organisations especially for carers of people with cancer. Many local cancer support centres have services for carers too.

How to talk to someone with cancer



When someone close to you has cancer, it can be hard to know what to say. You may find it difficult to talk about their cancer. Or you may be afraid of saying the wrong thing. Often what people with cancer want most is someone to listen to them.

If you want advice on how to support a friend or loved one with cancer, call our Support Line on 1800 200 700. Ask for a copy of our booklet *Caring for someone with cancer*. The booklet gives advice on talking to someone with cancer. It also has tips to help you to feel more confident about supporting your friend or relative. You can pick up a copy of the booklet at any Daffodil Centre, or download it at www.cancer.ie

Support for you



Our cancer nurses are there to support you. Call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie for confidential support, advice and information.

Our booklet, *Caring for Someone with Cancer* has lots of information on:

- Getting organised
- Managing and giving medications
- Giving personal care
- Practical and money matters
- Relationships with other people
- Looking after yourself
- Life after caring

Free copies are available from our Daffodil Centres or the Support Line, or download it from our website www.cancer.ie



Support Line Freephone 1800 200 700



Support resources

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Money matters

- If you have cancer you may not be able to work for a time. You may also have extra expenses.
 - You may have to pay for some of your cancer treatment.
 - You might be entitled to certain social welfare payments.
 - There are services to help you if you're finding it hard to manage.

A diagnosis of cancer often means that you will have extra expenses, such as car parking during hospital visits, medication, travel, heating and childcare costs. If you can't work or you are unemployed, this may cause even more stress. It may be harder for you to deal with cancer if you are worried about money.

Practical and financial advice from the Irish Cancer Society



We provide individualised financial and practical advice for people living with cancer. This includes:

- **Understanding your welfare entitlements**
- **Advice on accessing extra childcare**
- **Telling your boss about your diagnosis**
- **Public supports**
- **Community supports**
- **Legal entitlements**

We can also act as advocates for patients and their families, for example when discussing your diagnosis with your employer or your financial provider.

Call our Support Line on 1800 200 700 or visit a Daffodil Centre to access any of these supports.

Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Visits to hospital
- Medicines
- Medical aids and equipment (appliances), like wigs

How much you pay towards your medical expenses depends on whether or not you qualify for a medical card and what type of health insurance you have, if any.

If you have a medical card, you will probably have very little to pay for hospital and GP (family doctor) care or your medication. If you are over 70, you can get a free GP-visit card.

Medical cards are usually for people on low incomes, but sometimes a card can be given even if your income is above the limit. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card.

An emergency medical card may be issued if you are terminally ill and in palliative care, irrespective of your income.

If you don't have a medical card you will have to pay some of the cost of your care and medication.

If you have health insurance, the insurance company will pay some of the costs, but the amount will depend on your insurance plan. It's important to contact your insurance company before starting tests or treatment to check you're covered.

Email: supportline@irishcancer.ie

Benefits and allowances

There are benefits that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, Carer's Leave.

If you want more information on benefits and allowances, contact:

- **The medical social worker** in the hospital you are attending
- **Citizens Information** – Tel: 0818 074 000
- **Department of Employment Affairs and Social Protection** – Tel: 0818 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

Always have your PPS number to hand when you are asking about entitlements and benefits. It's also a good idea to keep a copy of completed forms, so take a photo or photocopy them before posting.



If you have money problems

If you are getting into debt or you are in debt, the Money Advice and Budgeting Service (MABS) can help you. MABS can look at your situation, work out your budget, help you to deal with your debts and manage your payments. The service is free and confidential. Call the MABS Helpline 0818 07 2000 for information.

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 115 for more details of our Volunteer Driver Service and the Travel2Care fund.

You can also call our Support Line 1800 200 700 or visit a Daffodil Centre and the nurse will suggest ways to help you manage.

Money and finances

Go to www.cancer.ie and see our **Managing money** page for information on:

- **Medical costs and help available**
- **Benefits and allowances that you or your family may qualify for**
- **Travel services**
- **Ways to cope with the cost of cancer**

Our Benefits Hub on our website has lots of information on government supports for people who are unwell and their carers. It also has advice on how to apply.

Support Line Freephone 1800 200 700

Irish Cancer Society services

Our Cancer Support Department provides a range of cancer support services for people with cancer, at home and in hospital, including:

- **Support Line**
- **Daffodil Centres**
- **Telephone interpreting service**
- **Peer Support**
- **Psychological support services**
- **Patient travel and financial grants**
- **Night nursing**
- **Publications and website information**
- **Support in your area**
- **Practical support and financial solution services (see page 107)**

Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our cancer nurses for confidential advice, support and information for anyone affected by cancer. Our Support Line is open Monday to Friday, 9am–5pm.

The Support Line service also offers video calls for those who want a face-to-face chat with one of our cancer nurses. From the comfort of your own home, you can meet a cancer nurse online and receive confidential advice, support and information on any aspect of cancer.



Our cancer nurses are available Monday to Friday to take video calls on Microsoft Teams platform. To avail of the service, please go to <https://www.cancer.ie/Support-Line-Video-Form>

You can also email us any time on supportline@irishcancer.ie; or visit our Online Community at www.cancer.ie.

Daffodil Centres

Daffodil Centres in 13 hospitals nationwide are staffed by cancer nurses and trained volunteers. They provide face-to-face advice, support and information to anyone affected by cancer. The service is free and confidential.



This is a walk-in service. For opening hours and contact details for each of the Daffodil Centres, go to www.cancer.ie and search 'Daffodil Centres'. You can also email daffodilcentreinfo@irishcancer.ie

Who can use the Daffodil Centres?

Daffodil Centres are open to everyone – you don't need an appointment. Just call in if you want to talk or need information on any aspect of cancer including:

- Cancer treatments and side-effects
- Chemotherapy group education sessions
- Emotional support
- Practical entitlements and services
- Living with and beyond cancer
- End-of-life services
- Lifestyle and cancer prevention
- Local cancer support groups and centres

Telephone Interpreting Service

Speak to our Support Line and Daffodil Centre nurses in your own language through our telephone interpreting service.

Call Freephone 1800 200 700 or visit a cancer nurse in a Daffodil Centre and we will connect you to an interpreter.

Peer Support Programme

Peer Support is a free and confidential telephone service connecting people with similar cancer experiences. Peer Support volunteers are fully trained to provide emotional and practical cancer support in a safe, responsible and kind way.

To be referred to a Peer Support volunteer, call Freephone 1800 200 700 or contact your nearest Daffodil Centre.



Email: supportline@irishcancer.ie

Psychological Support Services

The Society funds professional one-to-one counselling. The services we provide are:

- **Remote counselling nationwide**, by telephone or video call.
- **In-person counselling sessions** in cancer support centres around the country.

Counselling is available for patients, family members and close friends.

For more information, call Freephone 1800 200 700, or contact your nearest Daffodil Centre.

Support in your area

We work with local cancer support centres and the National Cancer Control Programme to ensure cancer patients and their families have access to high-quality, confidential support in a location that's convenient to them.

For more information about what's available near you, contact your nearest Daffodil Centre, or call our Support Line on Freephone 1800 200 700.



Patient travel and financial grants

We provide patient travel and financial grants for patients in need who are in cancer treatment.

- The Irish Cancer Society **Volunteer Driver Service** is available mainly to patients undergoing chemotherapy treatments in our partner hospitals who are having difficulty getting to and from their local appointments.
- We have recently opened a pilot service for radiotherapy patients attending University Hospital Cork and the Bons, Cork for treatment.
- **Travel2Care** is a fund for patients who are having difficulty getting to and from their diagnostic test appointments or cancer treatments. Patients can apply for this fund if they are travelling over 50 kilometres one way to a national designated cancer centre or satellite. Travel2Care is made available by the National Cancer Control Programme.

To access any of these supports, please contact your hospital healthcare professional, call Freephone 1800 200 700, or contact your nearest Daffodil Centre.



Irish Cancer Society Night Nursing

We provide end-of-life care for cancer patients in their own homes. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is a unique service in Ireland, providing palliative nursing care at night between 11pm and 7am to cancer patients.

The health professional who is looking after your loved one can



request a night nurse for you, so talk to your palliative care team member, GP or public health nurse about this.

Support Line Freephone 1800 200 700

Publications and website information

We provide information on a range of topics, including cancer types, treatments and side-effects and coping with cancer. Visit our website www.cancer.ie to see our full range of information and download copies. You can also Freephone our Support Line or call into your nearest Daffodil Centre for a free copy of any of our publications.



To find out more about the Irish Cancer Society's services and programmes:

- **Visit us** at www.cancer.ie
- **Call** our Support Line on Freephone 1800 200 700
- **Email** our Support Line at supportline@irishcancer.ie
- **Contact** your nearest Daffodil Centre
- **Follow us** on Facebook
- **Follow us** on Twitter
- **Follow us** on Instagram

Local cancer support services

The Irish Cancer Society works with cancer support services all over Ireland. They have a range of services for cancer patients, their partners, families and carers, during and after treatment, many of which are free. For example:

- **Professional counselling** – The Irish Cancer Society funds free one-to-one counselling through many local support services
- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- **Special exercise programmes**
- **Stress management and relaxation techniques**, such as mindfulness and meditation
- **Complementary therapies** like massage, reflexology and acupuncture
- **Specialist services** such as prosthesis or wig fitting and lymphoedema services, such as education, exercise, self-management and manual lymph drainage
- **Mind and body sessions**, for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics

Cancer support services usually have a drop-in service where you can call in for a cup of tea and find out what's available.

You can call our Support Line on Freephone 1800 200 700 to find your nearest cancer support centre. Or go to www.cancer.ie and search 'Find support'.



What does that word mean?

Abdomen The part of your body that lies between your chest and hips

Adjuvant treatment Treatment given soon after surgery when a diagnosis of cancer is made

Alopecia Loss of hair or baldness. No hair where you normally have hair

Benign Not cancer. A tumour that does not spread

Biopsy Removing a small amount of tissue from your body to find out if cancer cells are present

Cells The building blocks that make up your body. They are tiny and can only be seen under a microscope

Chemotherapy Treatment using drugs that cure or control cancer

Fatigue Ongoing tiredness often not relieved by rest

Grading Tests that look at the appearance of cancer cells under the microscope

Malignant Cancer. A tumour that spreads

Medical oncologist A doctor who specialises in treating cancer patients using chemotherapy and other drugs

Metastasis The spread of cancer from one part of your body to other tissues and organs

Nausea Feeling sick or wanting to be sick

Oncology The study of cancer

Radiotherapy The treatment of cancer using high-energy X-rays

Radiation oncologist A doctor who specialises in treating cancer patients using radiotherapy

Staging A series of tests that measure the size and extent of cancer

Questions to ask your doctor

Here is a list of questions that you might like to ask. Never be shy about asking questions. It is always better to ask than to worry.

What tests do I need?

What type of ovarian cancer do I have? Where exactly is it?

Will you know what treatment I need after you have the test results?

How long will it take to do all the tests?

What type of treatment do I need? Why is this one better for me?

How successful is this treatment for my cancer?

Are there other treatment options?

What side-effects or after-effects will I get?

How long will my treatment take?

Do I have to stay in hospital for my treatment?

Is there anything I can do to help myself during treatment?

Should I eat special foods?

Notes/questions

Acknowledgments

This booklet has been produced by the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible. We would particularly like to acknowledge the contribution of the many consultants, nurses and other healthcare professionals who so kindly gave up their time and expertise to contribute to previous editions of this booklet.

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The following sources were used in the publication of this booklet:

- *National Cancer Strategy 2017-2026*, National Cancer Control Programme
- *Cancer in Ireland 1994-2017 with estimates for 2017-2019*: Annual report of the National Cancer Registry (2018)
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- *The Chemotherapy Source Book*, M Perry, Lippincott Williams and Wilkins, 5th Ed (2012).

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Join the Irish Cancer Society team

If you want to make a difference to people affected by cancer, join our team!

Support people affected by cancer

Reaching out directly to people with cancer is one of the most rewarding ways to help:

- Help people needing lifts to hospital by becoming a volunteer driver
- Give one-on-one support to someone newly diagnosed with cancer as part of our Peer Support programme
- Give information and support to people concerned about or affected by cancer at one of our hospital-based Daffodil Centres

Share your experiences

Use your voice to bring reassurance to cancer patients and their families, help people to connect with our services or inspire them to get involved as a volunteer:

- Share your cancer story
- Tell people about our services
- Describe what it's like to organise or take part in a fundraising event

Raise money

All our services are funded by the public's generosity:

- Donate direct
- Take part in one of our fundraising events or challenges
- Organise your own event

Contact our Support Line on Freephone 1800 200 700 if you want to get involved!

Did you like this booklet?

We would love to hear your comments or suggestions.

Please email reviewers@irishcancer.ie

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