

Understanding

Cancer of the Ovary

Caring for people with cancer

Understanding

Cancer of the Ovary

This booklet has been written to help you understand more about cancer of the ovary. It has been prepared and checked by cancer doctors, other relevant specialists, nurses and patients. The information in this booklet is an agreed view on this cancer, its diagnosis and treatment and the key aspects of living with it.

If you are a patient, your doctor or nurse may wish to go through the booklet with you and mark sections that are important for you. You can also make a note below of the contact names and information you may need.



Specialist nurse

Tel:

Family doctor (GP)

Tel:

Medical oncologist

Tel:

Surgeon

Tel:

Radiation oncologist

Tel:

Medical social worker

Tel:

Radiation therapist

Tel:

Emergency

Tel:

Treatments

Review dates

If you like, you can also add:

Your name

Address

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.

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Introduction

This booklet has been written to help you learn more about cancer of the ovary. This is also called ovarian cancer. It is divided into 4 parts:

- **About ovarian cancer** gives an introduction to cancer of the ovary, including symptoms and diagnosis.
- **Treatment and side-effects** looks at the different treatments used and possible side-effects.
- **Coping and emotions** discusses your feelings and the emotional effects of having cancer of the ovary.
- **Support resources** gives information on further sources of help and support. This includes helpful organisations, books, support groups and websites. You will also find an easy-to-read explanation of words and terms used throughout this booklet.

We hope the booklet answers some of your questions and encourages you to discuss them with your doctors and nurses. Talk to your doctor about your treatment and care, as the best choice for you will depend on your particular cancer and your individual circumstances.

>>> Reading this booklet

Remember you do not need to know everything about ovarian cancer straight away. Read a section about a particular item as it happens to you. Then when you want to know more, read another section.



If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call our Cancer Nurseline on Freephone 1800 200 700. It is open Monday to Thursday 9am–6pm and Friday 9am–5pm. You can also visit a Daffodil Centre. See page 61 for more about Daffodil Centres.



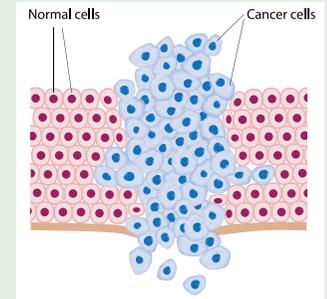
Cancer Nurseline Freephone 1800 200 700

Before diagnosis

>>> What is cancer?

Cancer is a word used to describe a group of diseases, not just one. There are more than 200 different types of cancer. Each is named after the organ or type of cell in which the cancer first grows. For example, prostate cancer, breast cancer or leukaemia. All cancers are a disease of the body's cells, which are the building blocks of your body. Normally, cells grow and divide in a controlled way and replace old cells to keep the body healthy. But with cancer, the abnormal cells grow without control. Groups of abnormal cells can form a growth or tumour.

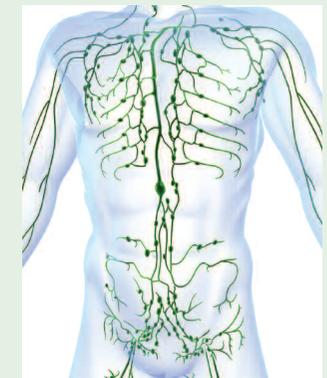
Tumours can be either benign or malignant. Benign tumours do not spread to other parts of your body but malignant tumours do. This happens when a cell or group of cells breaks away and is carried by your bloodstream or lymph vessels to other tissues and organs in your body. These cells can then grow into a new tumour. The new growth is called a metastasis or secondary tumour.



Cancer cells

What is the lymphatic system?

The lymphatic system is made up of groups of lymph nodes throughout the body. Lymph nodes are found mainly in the neck, armpit, groin and tummy. Lymph nodes are connected by a network of lymph vessels. These lymph vessels are tiny tubes, which usually lie just under the skin. The lymph vessels transport lymph fluid, which carries extra fluid and waste from body tissues. Sometimes cancer cells spread into lymph nodes or start in the lymph nodes themselves. If this happens the lymph nodes become swollen.



Lymphatic system



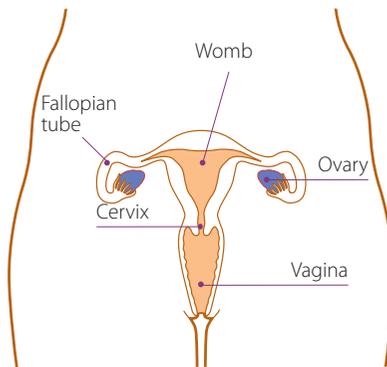
To sum up

- Cancer is a disease of the cells of your body.
- With cancer, the cells do not behave as normal. They keep on growing even when there is no need.
- If a tumour is malignant, cells can break away and be carried by your bloodstream or lymph vessels somewhere else. This is called a metastasis or secondary tumour.
- Lymph nodes can help to spread cancer cells.

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 the age when periods starts (puberty) to when they stop (menopause). During the menopause less hormones are made, so periods gradually stop.



The ovaries and female reproductive system

What is ovarian cancer?

When cancer occurs, the 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. When this happens the tumour may 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. There are several different types of ovarian cancer. Each type is classified according to the type of cell from which it starts. For more information, see page 10.

How common is ovarian cancer?

Ovarian cancer is the fourth most common cancer in women. Each year about 350 women are diagnosed with it in Ireland.



To sum up

- The ovaries are part of the female reproductive system.
- The normal cells in the ovary may change and grow to form a malignant tumour.
- The tumour can affect nearby tissues and organs.

What causes ovarian cancer?

The exact cause of ovarian cancer is not yet completely understood. But there are certain things called risk factors that can increase your chance of getting the disease. Even so, having a risk factor does not mean that you will get ovarian cancer. Some risk factors include:

- **Age:** Your risk increases with age. Ovarian cancer usually affects women who have been through the menopause.
- **Family history of cancer:** A faulty gene can lead to ovarian cancers in a very small number of women. Faulty genes that have been linked to ovarian cancer include BRCA1 and BRCA2. They are also known to be

linked to the development of breast cancer. If you have two or more close relatives (mother, sister or daughter) who have had ovarian cancer or breast cancer, you may be at a higher risk of the disease. Having relatives with ovarian cancer does not necessarily mean that you have a faulty inherited gene in the family. Tests can now check for faulty BRCA1 or BRCA2 genes. If you are concerned about a family history of ovarian or breast cancer, visit your family doctor (GP). Your doctor may decide to refer you to your local genetics service.

- **Reproductive history:** If you have no children or have your first child after the age of 35, your risk is higher. Breastfeeding may lower a woman's risk of developing ovarian cancer. Taking the oral contraceptive pill may also reduce a woman's risk of developing ovarian cancer. Research has shown that the longer you take the pill, the more your risk is thought to come down.
- **Hormone replacement therapy (HRT):** If you take the hormone oestrogen for 5 or more years, your risk of ovarian cancer may be higher. This risk decreases once you stop taking it.
- **Fertility treatments:** Some research has shown that there is an increased risk of ovarian cancer in women who have fertility treatment. But other studies have found that this is not the case. Fertility drugs are also linked to a higher risk of ovarian cancer.
- **Obesity:** Several studies have shown that there may be a link between ovarian cancer and obesity.

If you feel you may be at risk, visit your family doctor (GP) and talk about your concerns. You can also contact our Cancer Nurseline on 1800 200 700 for more information.

Can I be screened for ovarian cancer?

Testing for ovarian cancer when you have no symptoms is called screening. There is no national ovarian screening programme in Ireland at present. This is because so far no one test has been definitely proven to find ovarian cancer at an early stage. There is ongoing research to develop a screening test for ovarian cancer, but there hasn't been much success so far. The 2 tests used most often to screen for ovarian cancer are a transvaginal ultrasound and the CA125 blood test.

Transvaginal ultrasound: A small metal device called a probe is put into your vagina. A clear picture of your womb and ovaries can then be taken. This test can help find a mass (tumour) in the ovary, but it can't actually tell if a mass is cancer or not. When it is used for screening, most of the masses found are not cancer.

CA125 blood test: CA125 is a protein in the blood. In many women with ovarian cancer, levels of CA125 are high. However, common conditions other than ovarian cancer can also cause high levels of CA125 in the blood. Also, not everyone who has ovarian cancer will have a high CA125 level.

Cervical screening tests (smear tests) do not pick up signs of ovarian cancer.

What are the symptoms of ovarian cancer?

With ovarian cancer, you may or may not notice symptoms at first. This is because it can take a long time for symptoms to appear. When they do appear, they can be mild, vague or not go away (persist).

Symptoms can include:

- Bloating feeling
- Persistent swollen tummy
- Pain or dragging sensation in your lower tummy, back or legs
- Vague indigestion or nausea
- Loss of appetite or a feeling of fullness in your tummy
- Changes in your bowel or bladder habits, such as constipation or needing to pass urine urgently
- Feeling tired all the time
- Irregular periods or bleeding after menopause
- Back pain
- Pain during sex

Even though these symptoms can be caused by complaints other than cancer, do have them checked out by your GP. Remember ovarian cancer is not infectious and cannot be passed on to other people.

What are the types of ovarian cancer?

The most common type of ovarian cancer is epithelial. In this type the cancer is found in the surface layer that covers your ovary. There are several types of epithelial cancers with serous and endometrioid being the most common.

Less common types of epithelial ovarian cancer are mucinous, clear cell and undifferentiated.

There are other types of ovarian cancers such as germ cell tumours and stromal cell tumours. Both are rare. The germ cell type tends to affect younger women and starts in the ovary cells that produce eggs. Stromal cell tumours affect the tissues that support and keep your ovaries in place.

Borderline tumours: Borderline tumours have cells that are very like normal cells in your ovary. They usually grow slowly and have not spread into the normal tissue around your ovary. They are generally diagnosed at an early stage. Usually they are fully cured by surgery.

See page 14 for more about staging and grading of ovarian tumours.

How is ovarian cancer diagnosed?

Most people start by visiting their family doctor (GP). If your GP has concerns about you, he or she will refer you to a hospital to see a gynaecologist and have further tests. Or you might be seen by a gynaecological oncologist, who treats cancers of the female reproductive system. At the hospital you will be asked questions about your health before a physical exam is done. A blood test and a chest X-ray may be taken to check your general health.

The tests below are all used to diagnose ovarian cancer. If cancer is found, other tests will be done to show the stage of the cancer and check if it has spread to other parts of your body or not. This helps your doctors to plan the best treatment for you.

- Internal exam
- X-rays, such as a chest X-ray
- Special tests to look inside your abdomen
- Blood tests

Internal exam: Your doctor will place a gloved finger into your vagina while pushing down on your stomach with their other hand. He or she will examine your back passage (rectum) in the same way. These quick tests may be uncomfortable but are not painful. The doctor may also put an instrument called a speculum into your vagina to examine your cervix (the neck of the womb).

»»» Ovarian cancer can be diagnosed by an internal exam, special tests of your abdomen and special blood tests.

Special tests

You may need some of the following tests:

- Transvaginal ultrasound scan
- Ultrasound of abdomen
- Special blood tests
- CT scan
- MRI scan
- Image-guided biopsy:
- Laparoscopy
- Abdominal fluid aspiration
- Laparotomy

Transvaginal ultrasound scan: This test is carried out in the X-ray department of the hospital. A picture is built up of the inside of your body using sound waves. 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 taken. This test may be uncomfortable but is not painful.

Ultrasound of abdomen: Before this test you will need to drink plenty of clear fluids and not pass urine until afterwards. This means that your bladder is full, which helps to give a clearer picture. You lie on your back and gel will be spread over the area to be scanned. A probe that makes sound waves is used to take the scan. The sound waves are changed into a picture by a computer. This test does not hurt and only lasts about 10 minutes.

Special blood tests: A blood test called CA125 will be done. CA125 is a protein found in the blood that is sometimes released from ovarian

cancer cells. It is known as a tumour marker for ovarian cancer. Not all women with ovarian cancer will have high levels of CA125 in their blood. But if there is a high level of CA125 in your blood at time of diagnosis, 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 on treatment.

CT scan (CAT scan): This is a special type of X-ray that gives a detailed picture of the tissues inside your body.

The scan is painless. For some CT scans you may be asked to fast for 4 hours beforehand. For others a dye may be injected into your vein. This allows some areas of your body to be seen more clearly. This dye may make you feel warm

and flushed for a few minutes. For others you may be given a special drink which helps show up parts of your body on the scan. Preparation for a CT scan can vary but your doctor or nurse will tell you what to do. The test is usually done as an outpatient.

MRI scan: This is a special scan that uses magnetic energy to build up a picture of the tissues inside your body. It does not hurt but can be very noisy. So you will be given earplugs to wear during it. You will be placed inside a long tube which can upset some people with claustrophobia. You might have an injection before the scan to show up certain parts of your body. You cannot wear metal jewellery during the scan. If you have any medical device like a pacemaker or metal piece in your body, you may not be suitable for the test. Most people go home after the scan.

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



CT scan

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.

Laparoscopy: This test allows your doctor to look at your ovaries and nearby tissues. It can help doctors confirm the stage of the cancer and plan surgery or other treatments. 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. He or she then puts 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 a small 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 21 for more information.

Less common tests

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

Barium enema: This is an X-ray of your bowel. It allows your doctor to look at areas of your bowel that may be affected by the ovarian tumour.

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.

It will take about a week for all the test results to come back. This can be an anxious time for you. It may help to talk things over with a relative or close friend. You may also wish to call our Cancer Nurseline on 1800 200 700 and speak to one of our specially trained nurses.

Staging of ovarian cancer

Often, staging can only be confirmed after surgery. Some of the tests mentioned above can find out what stage your cancer is at. This means finding out the size of the tumour and checking to see if it has spread to other parts of your body. This can help your doctor to decide what the best course of treatment is for you.

There are a number of ways to stage ovarian cancer but the one most commonly used is the following:

Stage 1

Here the cancer affects only your ovaries.

- **Stage 1a** – The cancer is in one ovary only.
- **Stage 1b** – The cancer is in both ovaries.
- **Stage 1c** – There is fluid with cancer cells in your abdomen (ascites).

Stage 2

Here the cancer has spread outside your ovary but is still within your pelvis.

- **Stage 2a** – The cancer cells have spread to organs near your ovary, such as your vagina, womb or fallopian tubes.
- **Stage 2b** – The cancer has spread to other organs in your pelvis, such as your lower bowel or bladder.
- **Stage 2c** – The cancer has spread to other organs in your pelvis. Some fluid with cancer cells may be within your pelvis.

Stage 3

Here the cancer has spread outside your pelvis and into your abdominal cavity. It can affect the lining of your abdomen or lymph nodes there.

- **Stage 3a** – The cancer in your abdomen is tiny and can only be seen under a microscope.
- **Stage 3b** – The cancer in your abdomen can be seen but is smaller than 2cm across.
- **Stage 3c** – The cancer in your abdomen is larger than 2cm.

Stage 4

Here the cancer cells have spread to other parts of your body. This could be your lungs, liver or lymph nodes in your armpit or neck.

Recurrent ovarian cancer

This means that the cancer has come back (recurred) after you have completed treatment.

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

Grading of ovarian cancer

It is also possible to grade the cancer cells. This refers to their size and appearance under the microscope. They are checked to see how much they are like or unlike normal cells.

They are graded 1 to 3.

- **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.

Usually the higher the grade, the more quickly the cancer is likely to grow.



To sum up

- There are a number of tests to diagnose ovarian cancer.
- These tests include a transvaginal ultrasound, abdominal ultrasound, CT scan, MRI scan, laparoscopy, CA125 blood test.
- Sometimes an operation is the only way to diagnose ovarian cancer.
- Some tests will also show the stage of the cancer.
- Ovarian cancers can be staged as borderline tumours, stages 1 to 4, or recurrent cancer.
- Ovarian cancers can be graded 1 to 3: low grade, moderate grade or high grade.



Treatment and side-effects

How is ovarian cancer treated?

The type of treatment you receive will depend on:

- The size of your tumour
- If it has spread or not
- Your general state of health
- Your own preferences and lifestyle
- Stage and grade of the cancer

Cancer treatment

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.

Types of treatment

Treatments for ovarian cancer can include:

- Surgery
- Chemotherapy
- Radiotherapy

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 debulking. See page 21 for more details on surgery.

Chemotherapy: Chemotherapy is the use of drugs to kill or control the cancer cells. Sometimes two or three courses can be given before surgery, especially if the tumour is large and sticking to nearby tissues and organs. The drugs help to shrink it and make it easier to remove. See page 25 for more about chemotherapy.

Radiotherapy: This involves using high-energy X-rays to kill the cancer cells. It is used less often for ovarian cancer but might be given along with chemotherapy and surgery. See page 32 for more about radiotherapy.

>>> Your doctor will discuss your treatment options with you.

Deciding on treatment

At this time you may be anxious about what is going to happen next. Do not be afraid to ask for more information.

Multidisciplinary team meeting: A multidisciplinary team is a team of specialists involved in caring for your type of cancer. They will meet to discuss your test results and decide your treatment plan. For more information on the people who will be involved in your care, see page 20.

Treatment options: Your doctor and nurse will explain your treatment options to you. Sometimes, depending on the stage of your cancer, you may have fewer choices.

Do ask as many questions as you like, no matter how small or trivial you think they are. All questions are important. Sample questions are given at the back of the booklet.

Time to think: When faced with a life-threatening illness, it can be hard to decide what the right treatment is for you. It may feel as if everything is happening too fast. You may feel under pressure to make a decision. You might want more time to think things through.

Second opinion: You might also find it reassuring to have another medical opinion to help you decide about your treatment. Your doctor 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 wish to refuse 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 understand the benefits and risks.

Giving consent for treatment

Before you start any treatment, your doctor will explain the aims of the treatment to you. You should be asked to sign a consent form saying that you give permission for the treatment to take place. No medical treatment can be given without your consent. Before treatment, you should know:

- The type of treatment you are advised to have
- The benefits and risks of the treatment
- Any other treatments that may be available
- Any possible side-effects of the treatment

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 always ask for more time to decide about the treatment, if you are unsure when it is first explained to you.

>>> 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. Do not be afraid to ask your doctor about your own treatment.



Who will be involved in my care?

Some of the following may be involved in your care at the hospital.

Gynaecologist	A doctor who specialises in treating problems with the female reproductive organs and functions.
Gynaecological oncologist	This is a gynaecologist who specialises in cancer.
Medical oncologist	A doctor who specialises in treating cancer patients using chemotherapy and other drugs.
Radiation oncologist	A doctor who specialises in treating cancer patients using radiotherapy.
Gynaecology oncology nurse	A specially trained nurse who looks after patients who have ovarian cancer.
Liaison oncology nurse	A specially trained nurse who works in a cancer care unit. She or he can give information and reassurance to you and your family from diagnosis and throughout treatment.
Dietitian	An expert on food and nutrition. They are trained to give advice on diet during illness and use diet to help symptoms.
Occupational therapist (OT)	A therapist who specialises in helping people who are ill or disabled learn to manage their daily activities, e.g. self-care. They are mainly concerned with hand strength and the use of arms and hands.
Physiotherapist	A therapist who treats injury or illness with exercises and other physical treatments related to the illness.
Psychologist	A specialist who can talk to you and your family about emotional and personal matters and can help you 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.
Medical social worker	A person specially trained to help you and your family with all your social needs. They can give advice on benefits, entitlements and services available when you go home. They are also skilled in giving counselling and emotional support to children and families at times of change.

Surgery

Sometimes surgery is needed to make a diagnosis first. The main aim of surgery is to remove all of the tumour or as much as possible of it. Surgery may be done before or after chemotherapy. 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. Before any operation, make sure you discuss all the possible options with your surgeon.

Laparotomy

An operation that opens up your abdomen is called a laparotomy. During this operation the organs and tissues of your abdomen are carefully examined and biopsies (tissue samples) are taken. If the cancer is found in only one ovary at an early stage and you wish to have children in the future, it may be possible to remove the affected ovary and leave your other ovary and your womb in place.

In most cases, your surgeon will have to carry out a total 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 also remove the omentum and as much of the tumour as possible. This is known as debulking surgery. The omentum is a layer of fatty tissue that surrounds your stomach and other organs in your abdomen. Your surgeon may also take samples from other tissues, such as lymph glands, to see if the cancer has spread further.

It can sometimes be difficult for the surgeon to remove most or all of the cancer. 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 operation is called interval debulking surgery.

Colostomy

Sometimes if the tumour has spread to your bowel a small piece of bowel may be removed and the two 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 abdomen through a cut in your skin. This is called a colostomy.

This may be done in the short term or it may be permanent. If it is temporary, the bowel can be rejoined inside at a later stage. The opening onto the surface of your abdomen is known as a stoma. Instead of passing a bowel motion through your back passage, the motion passes through the stoma into a bag attached to your body.

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.

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 Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for more information.

Getting ready for surgery

Before surgery, you will attend the pre-operative assessment clinic. The purpose of this clinic is to make sure that you are ready and suitable for surgery. Extra tests may be done, including a chest X-ray, heart test (ECG) and more blood tests. You will also meet a member of the anaesthetic team to discuss pain control. You will be told what to expect before, during and after your surgery. A day or two before surgery some patients may be given special medication to empty the bowel. You may be told to take one light meal only. During this time you can drink lots of clear fluids such as water and fruit juice.

A physiotherapist or specialist nurse will show you how to do deep breathing and leg exercises. These exercises will help to prevent you getting a chest infection or blood clot after your operation. You will be given elastic stockings (TED stockings) or you may have calf

compressors. These are sleeves that are placed on your calves and attached to a pump to encourage blood flow and reduce the risk of blood clots forming in your legs. You may also have injections to prevent clots.

You will not be allowed to eat anything from the night before surgery. You may receive an injection to prevent a clot developing in your legs after surgery. Before theatre, you may receive medication to make you relaxed and sleepy.



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.

After surgery

When you wake up you will notice a number of tubes attached to your body. They may look alarming but are normal after an operation like this.

- A drip will be put into a vein in your arm. Through this you will be given fluids until you can drink again.
- A thin plastic tube may be placed in your nose and lead down into your stomach. By drawing up the fluid in your stomach through this tube, the nurses can keep your stomach empty. This will stop you from feeling sick.
- A small thin tube called a catheter may be put into your bladder and urine drained off into a drainage bag. This will save you having to get out of bed to go to the toilet.
- There may be drainage tubes from your wound to make sure it heals well.
- You may have a thin epidural catheter in your back to help with pain relief.

Pain: You will have some pain for the first few days. You might also feel sick. Your nurses can give you painkilling injections and

medication to prevent you feeling or getting sick if you need it. Always ask for help before the pain or sickness gets too bad. If the injections do not work let your nurse know as they can be changed.

You may also have an epidural in your back with an infusion of anaesthetic to stop you feeling pain in your stomach and pelvis. Or you may have patient-controlled analgesia. This is a small infusion pump where you safely control the amount of painkillers you get. You push a button and the pump sends the painkiller into your bloodstream through a vein.

Your pain will be monitored by your nurse and the pain team on a regular basis. It is important to tell the nurse if you are in pain so it can be well controlled. This makes it easier for you to move about and will speed up your recovery.

Eating and drinking: This type of operation slows down the movement of your bowel. As a result, 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 will be removed.

Bowel function: Some women will have difficulty passing wind or opening their bowels after the surgery. The nurses looking after you will be asking if you have passed wind on a regular basis. This helps them to know if the bowels are beginning to work properly again. Some women will need medication to help their bowels get back to normal and it can take a few days for this to happen. Things will also improve when you are up and moving about.

Getting up and about: A physiotherapist will visit you every day for the first few days to help you with your 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 your nurses 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. Soon you can go for walks on your own. Sitting down may be uncomfortable at first but should get better as your wound begins to heal. Most women are ready to go home 8 to 10 days after surgery.

Strenuous activity such as vacuum cleaning or lifting heavy bags of shopping should be avoided for at least 3 months. You will not be able to drive for at least 6 weeks after surgery. Your doctor will discuss this with you in more detail.

Going home: If you live alone or have problems getting around the house, talk to the medical social worker or nurse on your ward as soon as you are admitted to the hospital. This is so he or she can organise the community services that you may need after you leave hospital. On the day you go home you will be given a date to come back for a check-up in about 6 weeks' time.

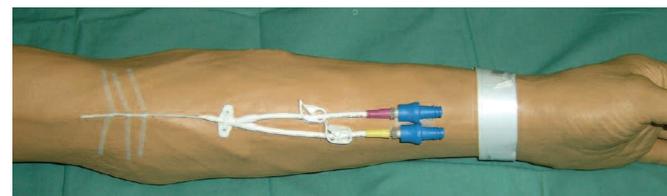
If you have a worry or symptom that is causing you concern before your check-up date, contact your doctor, cancer nurse specialist or hospital ward for advice.

Chemotherapy

Chemotherapy is a treatment using drugs that cure or control cancer. These drugs can be used on their own or with each other. This treatment may be given before or after surgery. The drugs used in chemotherapy travel through your bloodstream to almost every part of your body. They are often given in cycles such as once every 3 weeks with a rest period between treatments.

How is chemotherapy given?

Chemotherapy may be given directly into a vein as an injection or through an infusion or drip. It may also be given in tablet form. If your treatment is given by infusion into the vein, you may need to stay overnight in hospital. However, most treatments are given as a day patient.



A PICC line gives chemotherapy drugs into a vein in your arm

Chemotherapy can also be given directly into your tummy (abdomen) through a small tube. This is known as intraperitoneal chemotherapy. These drugs can destroy or control cancer in your abdomen and pelvis. Research has shown that intraperitoneal chemotherapy, when given with chemotherapy into a vein, can help to improve survival for a small number of women.

When is chemotherapy given?

Sometimes two or three courses of chemotherapy are given before surgery. This happens when the tumour is large and possibly sticking to other tissues and organs. The chemotherapy may shrink the tumour and make the operation easier and more effective. Once you have recovered from surgery you may need further chemotherapy

In some cases, it may not be possible to remove the entire tumour during surgery. Or there may be a risk that some cancer cells were left behind. This is more likely if the tumour has spread outside your ovary. The cancer may have released cells into your bloodstream or lymphatic system. These cells can sometimes cause secondary cancers called metastases in other parts of your body.

If the cancer has spread to your liver or beyond your abdomen and/or surgery is not possible for other reasons, chemotherapy is the main treatment used. Even if the cancer comes back after surgery or a course of chemotherapy, it can still be treated. Your doctor will consider your general health and where the cancer has spread. He or she will also take into account the kind of drugs you have had in the past.

>>> Even if the cancer comes back after surgery or a course of chemotherapy, it can still be treated.

Types of drugs 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. There are new drugs and different ways of treating ovarian cancer being developed all the time. For more information on research and clinical trials, see page 40.

>>> For more information on chemotherapy and ovarian cancer, call our Cancer Nurseline on Freephone 1800 200 700.

>>> Newer treatments

If your cancer does not respond to chemotherapy or comes back, there are newer treatments that may be available to you. For example, biological therapy. This kind of treatment uses your body's own immune system to fight cancer. There are different forms, such as targeted therapies. This includes the drug bevacizumab (Avastin®). You might receive a biological therapy as part of a clinical trial. For more about clinical trials see page 40.

Side-effects of treatment

The side-effects of chemotherapy vary from person to person and depend on the drugs used. These unwanted side-effects happen because chemotherapy can affect both cancer cells and normal cells too. In most cases the side-effects go away when the treatment ends or soon after. Your doctor or nurse can give you something to stop most side-effects or make them easier to cope with.

Side-effects may include:

- Infection
- Bruising
- Feeling very tired
- Feeling sick or getting sick
- Hair loss (alopecia)
- Sore mouth
- Numbness or pins and needles in your hands and feet
- Not wanting to eat
- Soreness or redness of palms or soles of feet

Infection: Chemotherapy can make you more likely to get infections. This happens because most chemotherapy drugs affect the bone

marrow, which makes the white blood cells that fight infection. If you do not have enough white blood cells, even minor infections such as a cold or sore throat could make you quite ill.

During treatment cycles you will have blood tests to make sure that you have enough white blood cells. If your white cell count is low, your doctor may ask you to watch out for signs of infection. These signs include feeling shivery and unwell or running a high temperature of 38°C (100.4°F) or higher. If this happens, tell your doctor straight away. He or she will tell you what to do. Some hospitals prefer you to ring them directly. Check this out with your doctor or nurse before you start treatment. If you have a high temperature, you will need to have a blood test taken. Sometimes antibiotics are needed to treat the infection.

>>> If you feel shivery and unwell or have a high temperature of 38°C (100.4°F) or higher, contact your hospital doctor straight away.

You will be more at risk of picking up infections while on treatment. Try to avoid close contact (such as hugging or kissing) with people who have colds or flu or other infections such as chickenpox, shingles or measles. Let your doctor know if you are in contact with these or any other infections. Wash your hands often during the day, especially before you eat and after going to the bathroom.

Bruising: You may notice that you bruise more easily or for no good reason. Platelets help to clot your blood if you hurt yourself and bleed. If there are not enough platelets in your blood (thrombocytopenia), you may bleed or bruise more easily than usual, even from a minor injury. Let your doctor or nurse know straight away if you are bruising easily or notice tiny red spots under your skin that can look like a rash (petechiae). He or she will tell you what to do.

Feeling very tired: You may feel very tired or fatigued. This may be due to less red blood cells (anaemia) in your bloodstream or as a general effect of chemotherapy. If you are anaemic you may have some shortness of breath, feel weak or dizzy or have no energy. Your doctor might order a blood transfusion or medication if your red cell count is very low.

General tiredness can last for some weeks after treatment has ended. If this happens take things easier and rest more if you can. Do less than you would normally do. Ask your family or friends to help you at work or at home. Do tell your doctor about the way you are feeling during your treatment as most side-effects can be eased with medication. See page 38 for more about fatigue.

A helpful booklet called *Coping with Fatigue* is available from the Irish Cancer Society. Call our Cancer Nurseline on 1800 200 700 for a free copy. You can also pick up a copy from a Daffodil Centre or download it at www.cancer.ie

>>> Tips & Hints – infection, bleeding, anaemia

- Contact the hospital immediately if you have a temperature of 38°C (100.4°F) or higher, shortness of breath or bleeding that cannot be stopped.
- Take plenty of rests and breaks if you are feeling tired or fatigued.
- Avoid crowds and close contact, such as hugging or kissing, with people who have colds, flu's and other infections, especially chickenpox, shingles or measles. Let your doctor know if you have been in contact with these infections.
- Wash your hands often during the day, especially before eating and after going to the toilet.
- Avoid unpasteurised milk, soft cheeses, undercooked meats and poultry, the skin of raw vegetables and of fresh fruit.
- Take care to avoid injury. Avoid contact sports. Use an electric razor when shaving, a soft toothbrush when cleaning your teeth, and thick rubber gloves when gardening.
- Do not take aspirin as it can increase your risk of bleeding.

Nausea and vomiting: Not everyone feels sick (nausea) or gets sick with chemotherapy. It depends on the drugs being given. If you do, it can happen before, during or after treatment. It may last for several hours. But your doctor or nurse will give you medication to stop you feeling sick. This may be in injection or tablet form. It is important that you take all medication while on treatment.

Hair loss (alopecia): The amount of hair loss you get will depend on the drugs you are given. This can vary from person to person. You may notice that your hair just thins out a little bit. If you do lose your hair, it will happen quite quickly. Try not to worry as your hair will grow again when treatment ends. You may feel upset at the thought of losing your hair. Talk to your nurse about your feelings. He or she will help you to find ways to cope with hair loss. You can get a wig or hairpiece when this happens or you may prefer to wear a hat, turban or scarf.

If you would like a hairpiece try to organise this before your hair falls out. Your medical social worker or nurse will be able to help you with this. If your hospital does not have a social worker, ask if they have the name of a wig fitter you could go to see. Your local hairdresser may also be able to help. In some cases it is possible to get financial assistance towards the cost of a wig. Ask your medical social worker or nurse for more information about this. For some patients the amount of hair loss is small and a wig may not be needed.

Contact our Cancer Nurseline on 1800 200 700 for more advice or a copy of the factsheet on *Hair Loss and Cancer Treatment*. You can also pick up a copy from a Daffodil Centre or download it at www.cancer.ie

Sore mouth: Some drugs used to treat ovarian cancer may cause a sore mouth. They can also cause little ulcers to appear on your tongue, gums and inside the cheeks of your mouth. Try to keep your teeth, gums and mouth very clean, as this will reduce the risk of getting a mouth infection. Clean your teeth after every meal using a soft toothbrush. If you have dentures remove them if your gums are sore. There are also special mouthwashes and gels that you can use. Your nurse will show you how to use these properly.

Numbness or pins and needles in the hands and feet: Some chemotherapy drugs can cause tingling or burning sensations in your hands and feet. You may also have trouble picking up small objects or buttoning up a shirt or cardigan. This is called peripheral neuropathy. This side-effect is almost always temporary and goes

away after treatment stops. It is best treated by preventing further damage to your nerves and reporting symptoms early. Sometimes painkillers are prescribed to relieve any pain. For more about this side-effect, call our Cancer Nurseline on 1800 200 700. Ask for a copy of the factsheet on peripheral neuropathy. You can also pick up a copy from a Daffodil Centre or download it at www.cancer.ie

Not wanting to eat: Do eat as much as you can while on chemotherapy to keep up your strength. It helps to eat smaller amounts more often. If you do not feel like eating during treatment, you could try replacing some meals with special high-calorie drinks. Talk to the hospital dietitian who can give you advice. A helpful booklet on what to eat is called *Diet and Cancer* and is available from the Irish Cancer Society. Call our Cancer Nurseline on 1800 200 700 for a free copy. You can also pick up a copy from a Daffodil Centre or download it at www.cancer.ie

Sore and red palms of hands and soles of feet: You may develop sore and red palms in your hands and soles of your feet. Sometimes this is known as palmar plantar or hand-foot syndrome. It can begin after two or three cycles of treatment but is temporary. You may be prescribed vitamin B6 (pyridoxine) to help to reduce it. It is best to keep your hands and feet cool and avoid any tight-fitting clothes like socks, shoes and gloves.

Other side-effects: If you have a different side-effect or symptom from those listed above that concerns you, tell your doctor or nurse straight away. He or she will tell you what to do. A helpful booklet called *Understanding Chemotherapy* is available from the Irish Cancer Society. Call our Cancer Nurseline on 1800 200 700 for a free copy. You can also pick up a copy from a Daffodil Centre or download it at www.cancer.ie



To sum up

- Chemotherapy is a treatment using drugs to cure or control cancer.
- The drugs can be given directly into a vein as an injection or in a drip, or may be given in tablet form or directly into your abdomen (intraperitoneal).
- Chemotherapy can be given before surgery, after surgery, or even if the cancer comes back after having been treated with chemotherapy already.
- Side-effects to chemotherapy vary between people and depend on the drugs used.
- Side-effects may include infection, bruising, nausea and vomiting, hair loss (alopecia), sore mouth, numbness or pins and needles in your hands and feet, feeling very tired and not wanting to eat.

Radiotherapy

This is a treatment where high-energy X-rays are aimed at a cancer to cure or shrink it. Usually the X-rays come from a machine called a linear accelerator. This is known as external radiotherapy.

Radiotherapy may be used along with chemotherapy and surgery to treat your cancer. The treatment may be as short as one session or continue for several weeks, depending on the stage of ovarian cancer.

Radiation can be given to your whole abdomen. But it is more usually given to your pelvic area to control or relieve any symptoms you may have. This could include any pain, discomfort or bleeding if the cancer comes back after having been treated.

Planning your treatment

Before radiotherapy your doctors and other specialists plan how to give it to you. They work out how to give you the right amount of radiotherapy with the least damage to normal cells. On your first visit to the radiotherapy department, you may be asked to lie under a machine called a simulator that takes X-rays of the area to be treated. Treatment planning is an important part of radiotherapy and it may take a few visits before your treatment can go ahead.

Your skin in the area to be treated will be marked. This may be with ink or a permanent tattoo. This is so the rays can be aimed at the same area each day. The ink marks are temporary and should not be washed off until treatment is over. Before starting radiotherapy, you will be told how to look after your skin during and after treatment.

Getting your radiotherapy

Radiotherapy treatment is quite straightforward. You will be asked to come for treatment every day during the week with a rest at weekends. Your treatment can go on for several weeks. Each treatment session only lasts a few minutes. It will not cause you any pain during treatment but you will be asked to lie still. How much treatment you need will depend on the type and size of the tumour. Your doctors will discuss this with you.

Each time you come for treatment you will go into a radiotherapy room. The radiation therapist will ask you to lie or sit in a certain position under the machine. To make sure less radiation reaches your small bowel and so reduce any side-effects, a special piece of equipment called a belly board will be fitted to you.



A linear accelerator

When you are ready your radiation therapist will leave the room. The machine will then be turned on and your treatment given. Even though you are on your own in the room, your radiation therapist can see you all the time through a closed circuit camera. You can talk through an intercom to the staff if you wish.

External radiotherapy does not make you radioactive. It is perfectly safe for you to mix with family and friends.

>>> External radiotherapy does not make you radioactive. It is perfectly safe for you to mix with family and friends.

Will I have any side-effects?

Radiotherapy is given directly to the area where the cancer is found. As a result, the side-effects that occur are related to the part of your body being treated. How severe these side-effects are will vary from person to person and depend on the amount of treatment received.

When the pelvic area is being treated, the most common side-effects are:

- Diarrhoea
- Skin changes
- Wanting to pass urine more often
- Tiredness
- Nausea

The belly board device helps to prevent or improve side-effects such as diarrhoea and feeling sick. The above side-effects usually last for 4 to 6 weeks after treatment.

Diarrhoea: Passing watery bowel motions more than twice a day is known as diarrhoea. You may also have some cramping or abdominal pain. Tell your doctor, as he or she can give you medication to prevent it. If you have diarrhoea it is important to drink plenty of clear fluids to replace the fluid you are losing. Let your doctor know if the diarrhoea last for longer than 24 hours.

Tiredness: This can build up over the course of your treatment. It may be due to the treatment itself or perhaps you have to travel long distances for treatment. Rest as much as you can and cut down on the things you normally do while on treatment. A helpful booklet called *Coping with Fatigue* is available from the Irish Cancer Society. Call our Cancer Nurseline on 1800 200 700 for a free copy. You can also pick up a copy from a Daffodil Centre or download it at www.cancer.ie

Skin changes: During radiotherapy your skin in the treated area may become red and sore. It may even look like sunburn. A special cream can be used to treat this problem. Only use creams recommended by your nurses and radiation therapists. If you need to wash the area, use warm water and pat it dry with a soft towel. Do not rub the skin while washing and drying. Avoid perfumed creams or powders too. Check with your radiation therapist or nurse before putting anything on your skin.

Nausea: Your doctor can give you medication to help prevent you feeling sick. Take these 1 hour before treatment. It can also help to eat small amounts often. Do drink plenty of clear fluids such as water or fruit juice.

Passing urine more often: During radiotherapy for ovarian cancer the bladder may become irritated. This may result in you passing urine more often. Sometimes a trace of blood may be in the urine. If this occurs, discuss it with your doctor.

Other side-effects: These or any other effects you develop will be watched very carefully during the radiation treatments. Information will be given on how to prevent side-effects and medication will be prescribed if needed.

All these side-effects should go away when treatment is over, but do let your doctor know if they continue. A helpful booklet called *Understanding Radiotherapy* is available from the Irish Cancer Society. Call our Cancer Nurseline on 1800 200 700 for a free copy. You can also pick up a copy from a Daffodil Centre or download it at www.cancer.ie

Long-term effects of radiotherapy

There can also be long-term side-effects of radiotherapy. They will depend on which part of your body is treated, so you might not experience all of them. These long-term side-effects can take months or even years to develop. They may include some of the following:

- Bowel symptoms like diarrhoea, urgency, frequent bowel motions or leakage
- Urinary symptoms like frequency, urgency or a burning sensation
- Tiredness (fatigue)
- Early menopause
- Infertility – if your ovaries are within the treatment area
- Your vagina may become narrower, making sex difficult and uncomfortable

For more information on the long-term side-effects of radiotherapy, contact our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.



To sum up

- Radiotherapy is a treatment using high-energy X-rays or radiation.
- The X-rays are aimed at the cancer to cure or shrink it.
- There is a lot of preparation before the actual treatment is given.
- Radiotherapy is painless and only takes a few minutes.
- The treatment may be as short as one session or continue for several weeks.
- Side-effects to radiotherapy depend on the area being treated. They include diarrhoea, tiredness, skin changes, feeling sick, and wanting to pass urine more often.

Will treatment affect my sex life and fertility?

After a hysterectomy, women often ask if the surgery will affect their sex life. To allow your wound to heal properly it is best to wait at least 6 weeks before having sex again. Many women have no problem resuming intimacy and sex after this time. Others may need more time to come to terms with what has happened.

If you have a supportive partner, you may find that talking about your feelings may ease your anxiety. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner. Do not feel guilty or embarrassed to talk to your doctor or nurse about what is troubling you. He or she may refer you for specialist counselling if you feel that would be helpful. For example, to a psychosexual counsellor.

Sometimes there may be a physical reason why you lose the desire for sex. For younger women who are still having periods, the removal of the ovaries will bring on an early menopause. See page 37 for more details. There may also be a change of body image, especially if you have a colostomy.

Remember that cancer cannot be passed on to a partner during sex. It is quite safe for you to resume sex with your partner.

How will my fertility be affected?

After a hysterectomy, younger women often find it hard to accept that they can no longer have children. Indeed infertility may cause feelings of anger or loss of identity. But it is natural to feel this way at this time.

It is important to talk openly to your partner or a friend about these feelings. If you are finding it hard to deal with infertility it may also be helpful to talk to your nurse or doctor. If you cannot deal with any strong emotions you might have, your doctor may arrange for you to speak to a trained counsellor or a specialist. Do seek professional help if infertility is likely to trouble you.

Early menopause

The result of removing the ovaries in younger women is that they will experience an early menopause. This may involve having hot flushes, dry skin, dryness of your vagina, reduced sexual desire (libido), night sweats, mood swings and osteoporosis. Talk to your nurse or doctor about drugs to help with hot flushes.

Dryness of the vagina that makes sex uncomfortable can be eased by using vaginal lubricants. These can be bought in your local pharmacy.



Hints & Tips – coping with early menopause

- Dress in layers, so you can cool off easily if you do have a hot flush.
- Avoid caffeine and alcohol.
- During sex use a vaginal lubricant that is based on water or mineral oil.
- If sex continues to be painful, discuss alternative treatments.

How can I cope with fatigue?

Fatigue is a common symptom of cancer and described as an overwhelming tiredness. Often it is not relieved by rest. You also may find it hard to concentrate or make decisions. The reason for your fatigue can sometimes be hard to identify. It may be caused by anxiety over a cancer diagnosis or the added stress caused by treatment. Whatever the reason, there are things you can do to help.

For many patients, treatment may help by relieving symptoms such as pain and nausea, allowing you to get back to your normal routine. Ask your doctor before you start treatment what side-effects you can expect.

If you are feeling very worried, you may find it hard to sleep at night. Do tell your doctor or nurse, who may be able to help. Also, try talking to your family or close friends about your concerns. If you find this difficult, ask to see a counsellor. He or she will help you to find ways to cope.

If your illness allows you to do physical exercise, get some regularly. For example, a 30-minute walk 3 days a week might be a realistic goal and will boost your morale when you achieve it. Get others to help you around the house, with travelling to hospital, at work, with the children or with shopping. Use the extra free time to do something that you especially enjoy.

A helpful booklet called *Coping with Fatigue* is available from the Irish Cancer Society. Call our Cancer Nurseline on 1800 200 700 for a free copy. You can also pick up a copy from a Daffodil Centre or download it at www.cancer.ie

Cancer Nurseline Freephone 1800 200 700



Tips & Hints – fatigue

- Build rest periods into your day. If you are going somewhere special, have a rest before you go out.
- Save your energy for doing the things you most enjoy.
- Ask for help at work or with cooking, housework or childcare.
- Keep your energy for eating. Eat little and often and use ready-made meals or snacks.
- Wear clothes that are easy to put on and take off.
- If you find it hard to sleep, make sure your bedroom is quiet and not too hot or cold.
- Do some gentle exercise each day. Ask your doctor or nurse for advice.
- Go to bed each night at the same time. Each morning get up at same time and do not lie in.
- Use relaxation techniques to get to sleep. For example, gentle exercise, relaxation tapes.
- Avoid stimulants before bedtime, such as alcohol, coffee, tea, coke or chocolate.

What follow-up do I need?

No matter what type of cancer treatment you get, you will still need to come back for regular check-ups once it is over. This is called follow-up. At first these visits to your doctor will be quite often. Follow-ups may include seeing your doctor and having some tests such as blood tests and scans. At first you will see your gynaecologist or medical oncologist every three months. These visits will usually continue for 5 years but will grow less frequent over time. After this, you will continue to have check-ups with your GP.

If you are between check-ups and have a symptom or problem that is worrying you, let your doctor know. Make an appointment to see him or her as soon as possible.



Research – what is a clinical trial?



Research into better ways of treating ovarian cancer goes on all the time. By using new drugs or new combinations of drugs and treatments that are already in use, doctors can find new and better ways of treating cancer. If a drug or treatment looks as if it might be useful in treating cancer, it is given to patients in research studies called clinical trials. These aim to find a safe dose, see what side-effects may occur and see which cancers can be treated.

If early studies suggest that a new drug may be both safe and effective, further trials are carried out. These aim to:

- Find out if the treatment is better than ones already in use.
- Find out if there are more benefits when the new treatment is given together with current ones.
- Compare the new treatment with current best standard treatments.

Taking part in clinical trials

Your doctor may ask you to try a new way of treating your cancer as part of a trial. Not everyone is suitable to take part in a clinical trial. Some trials want a particular type of person. For example, someone with advanced cancer or someone who has had a particular type of treatment in the past.

Your doctor may refer you to another hospital if he or she feels a clinical trial there may help you. Before a drug or treatment is used on patients, it goes through many phases of research to make sure it is safe to use. You will be carefully monitored during and after the study.

You cannot be included in a clinical trial without your permission. You can only give this consent if the trial has been fully explained to you, so that you understand what it is about. This is called informed consent. You will also need time to think about the trial and discuss it with your family or friends. If you decide not to take part, you will still be given the best proven treatment available. If you change your mind at any time you can stop taking part in the trial and will go back to having the standard treatment. As part of research into the causes of cancer, your doctors may ask your permission to store some samples of your cancer cells or blood.

For more information, call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or see our website: www.cancer.ie

Cancer and complementary therapies

Complementary treatments for cancer are treatments that can be given alongside standard (conventional) medical treatment. For example, yoga or massage. Some people find them very helpful during their illness. The way cancer is treated often depends on the culture of the country you live in. In Ireland conventional cancer treatments are based on scientific research, which allows the response to treatment, side-effects and the general effect of treatment to be predicted.

You may hear about the following types of treatments or therapies.

Conventional therapies

Conventional therapies are treatments which doctors use most often to treat people with cancer. These include surgery, radiotherapy, chemotherapy, biological therapies and hormone treatments. They are tried and trusted methods where there is a long history of use. Many of the treatments have been tested in clinical trials.

Complementary therapies

Complementary therapies are treatments that are sometimes given **together with** conventional treatment. They include therapies such as:

- Meditation
- Relaxation
- Visualisation
- Gentle massage
- Aromatherapy
- Reflexology
- Music, art and dance therapy
- Nutrition therapy
- Shiatsu
- Yoga
- Acupuncture
- Hypnotherapy

Many people find complementary therapies helpful in a number of ways. You may feel more positive about yourself and your illness. You may be better able to cope with the physical side-effects of cancer and the distressing emotions that it can often bring. Some complementary therapies also focus on the spiritual dimension of a person to aid healing.

Alternative therapies

Alternative therapies are generally treatments that are used **instead of** conventional treatments. These therapies include diet therapy, megavitamin therapy and herbalism. Alternative therapies have not been scientifically proven. Some alternative therapies may even harm your health. For example, some diet therapies restrict the types of food you can eat. This can mean you don't get the calories or nutrients that you need. Always talk to your doctor if you are considering an alternative to conventional treatment.



If you decide to have complementary or alternative treatments...



Before you decide to change your treatment or add any methods of your own, be sure to talk to your doctor or nurse. Some methods can be safely used along with standard medical treatment. But others can interfere with standard treatment or cause serious side-effects. For that reason, it is important to talk openly with your GP or cancer specialist if you are thinking of having treatment with either a complementary or alternative practitioner. Don't be afraid that your doctor will be offended by your wish for other treatments. In fact, he or she may be able to recommend therapies that could be safe and useful for you.

Be cautious in selecting a practitioner. Don't be misled by promises of cures. At present in Ireland, this area is not fully regulated. Ensure that the practitioners you plan to visit are properly qualified and have a good reputation. Check to see if they belong to a professional body or not. If you are unsure but would like to know what other patients have found helpful, contact your doctor or a patient support group. Also, it is important to make sure that the practitioner is charging a fair price for your treatment.

More information is available in a free booklet from the Irish Cancer Society called *Understanding Cancer and Complementary Therapies. A Guide for Cancer Patients*. If you would like a copy or more advice, call our Cancer Nurseline on 1800 200 700.

Coping and emotions

How can I cope with my feelings?

There are many reactions when told you have cancer. Reactions can differ from person to person. There is no right or wrong way to feel. There is also no set time to have one particular emotion or not. Some reactions may occur at the time of diagnosis, while others might appear or reappear later during your treatment. Or indeed it may not be until you recover from your illness that your emotions hit hard.

Common reactions include:

- Shock and disbelief
- Fear and uncertainty
- Loss of control
- Sorrow and sadness
- Denial
- Anger
- Resentment
- Blame and guilt
- Withdrawal and isolation

Sometimes a cancer diagnosis can bring greater distress and cause anxiety and depression. A helpful booklet called *Understanding the Emotional Effects of Cancer* is available from the Irish Cancer Society. Call our Cancer Nurseline on 1800 200 700 for a free copy.

Shock and disbelief

*It can't be me.
Has there been a mistake?
Cancer happens to other
people, not me.*

Shock is often the first reaction to a cancer diagnosis. In fact, you may feel numb and the situation may seem unreal. Many people think cancer will never happen to them and are totally shocked when it does. Even if your doctor and nurse discuss your cancer with you, the news may not sink in for a while. You may find yourself confused, asking the same questions over and over again. Or else you may accept the news calmly and say nothing because you cannot really believe what is happening to you.

Fear and uncertainty

*I'm going to die.
Will it be painful?
Will I become a
different person?*

There is no doubt that cancer is a scary word. Not surprisingly, you may have many fears when first told of your diagnosis. Often the first thing people think about is dying. They think the worst. But nowadays many cancers can be cured or controlled with modern treatments. Another great fear about cancer is pain. The fear of pain can sometimes overwhelm everything else. However, some cancers cause no physical pain at all or else can be controlled with good painkillers. You may also have fears that your experience of cancer will change who you are and that people will reject or avoid you. For example, after some cancer treatments your body image may be different, and it will take some time for you and for others to adjust to your new look.

You may also have practical worries and fears about the effect of your illness on your family, your finances, your job, and your lifestyle.

It is natural for you to be afraid or concerned about the future too. You may wonder if you will be cured or if your cancer will recur. Living with this uncertainty can make you feel anxious and fearful. You may not wish to make any plans or decisions. Do discuss your concerns with your doctor, nurse or medical social worker, as they can advise and help you. If living with uncertainty overwhelms you, it may help to talk to someone in a support group.

Loss of control

*I can't cope with this.
I'll never get through it.*

After a cancer diagnosis, it is common for people to feel their life is beyond their control. All your plans may be put on hold. You may even lose some independence and freedom. Because you don't know enough about your illness at first, you may rely totally on the advice of your doctors and nurses. You may not feel confident making any decisions about your treatment. When you experience a loss of control it can lead to feelings of helplessness. You may also feel that you will be unable to cope with your treatment or that you will 'fall to pieces' or 'go crazy'.

You may even lose hope. It takes a while to know what is within your control and what is beyond it. Finding out as much as possible about your illness can help you regain some control. Taking an active part in making decisions about your treatment can help you feel more in control of your illness too.

Sorrow and sadness

*I used to be so healthy.
I had so many plans.
I've let my family down.*

It is natural to feel sad when told you have cancer. You may feel sad for a variety of reasons: for the loss of your good health, for the plans that are put on hold, for the people you feel you've let down, and for any changes to your body due to treatment. Depending on your type of cancer, your fertility or body image may be affected by treatment. In this case the sadness or sorrow can come from feeling as if a part of you has died. These feelings may not be there all the time and may come and go, but will gradually fade.

Denial

*I'm fine, really.
I don't have cancer.*

Sometimes after being told their diagnosis, people deny they have cancer. While this may seem unusual, it is a valid way of coping. As a result, you may not wish to mention or discuss your illness. Or else you may talk as if your illness is nothing serious. Denial may last for a short or long time, depending on how long it takes for you to adjust to your illness. Tell your family and close friends that you would prefer not to talk about your illness, at least for the time being. Your doctors and nurses will also understand if you don't want to hear any information about your cancer until you're ready.

Anger

*Why me?
I always took care of my
health.
Why did this happen now?*

It is normal too to be very upset when told you have cancer. Many aspects of your illness can result in anger and distress. Anger can often hide other feelings such as fear, sadness or frustration. You may feel angry towards the doctors and nurses who are caring for you. Or if you have a

religious belief, you may feel angry with God for allowing cancer to occur. You may vent your anger on those closest to you. Indeed being unable to protect the ones you love may frustrate you a lot. Your family and friends may not always be aware that your anger is really at your illness and not at them. It may be helpful to talk to them when you are calm, rather than feeling guilty or trying to bottle up your angry thoughts. Anger can sometimes affect your ability to think clearly. So if it persists and you are finding it hard to talk to your family, tell your nurse or doctor.

Resentment

How can you talk – you don't have to deal with cancer.

How come I'm not getting better?

It is natural that you might be resentful and unhappy because you have cancer, while other people are well. During the course of your illness similar feelings of resentment may occur for many reasons. You may resent that another patient receiving the same treatment as you has responded quicker than you have. You may

resent having to change your lifestyle in some way. Sometimes relatives, especially adolescents, can resent the changes that your illness makes to their lives. It is best to admit that these feelings of resentment exist and to express them. Bottling up resentment helps no one. Instead everyone ends up feeling angry and guilty.

»»» Don't bottle up your feelings – express them.

Blame and guilt

I should have been more careful.

If only I had a more positive attitude, I wouldn't have got sick.

When diagnosed with a serious illness such as cancer, it is natural to want to know what caused it. Sometimes people blame themselves or others for their illness. As cancer experts rarely know exactly what has caused cancer, there is no good in blaming yourself. Other times, people feel guilty because they delayed going to the doctor with their symptoms, fearing

the worst. No matter what the reason, don't torture yourself at this time.

Don't feel guilty if you can't keep a positive attitude, especially when you feel unwell. Low periods are to be expected. There is no evidence that your attitude will affect your health or cancer. Regret and guilt serve no useful purpose. Instead focus on what you can change or do to make you feel more in control of your illness.

Withdrawal and isolation

I just need to be on my own.

There is no doubt that a cancer diagnosis is stressful. It can leave you feeling confused and overwhelmed with so much information to take in. At times during your illness you may want to be left alone and withdraw from people. It is normal for you to want to be alone to sort out your thoughts and feelings. You will want to take stock of things and work out how best you can cope. However, it is not a good idea to spend long hours on your own every day. Sometimes depression can make you avoid family and friends and stop you wanting to talk. If you isolate yourself, it can be hard for your family and friends, as they will want to share this difficult time with you. They may worry about you needlessly. Let your family and friends know that you will talk to them once you are ready.

If you would like more information on how to talk about your cancer, there is a useful booklet available called *Who Can Ever Understand? – Talking about Your Cancer*. If you would like a copy, call our Cancer Nurseline on 1800 200 700.

Learning to cope

After any treatment for cancer it can take some time to come to terms with your emotions. Coping with the physical effects of treatment can also add to the burden of dealing with cancer.

While it is true that some treatments can have some unpleasant side-effects, many people are able to live a normal life during treatment. You will need to take some time off for your treatment as well as time afterwards to recover. Just do as much as you feel like and take plenty of rest. It is not a sign of failure to ask for help or to feel unable to cope on your own. Once other people understand how you are feeling, they too can give you more support.

>>> Positive emotions

A cancer experience can also bring positive emotions. You may experience great love, affection and closeness by those around you, not only family and friends but also neighbours and the healthcare team. With that can come a sense of gratitude too. The experience of cancer can also bring personal growth and knowledge – it can make you realise where your strength lies and what is important in life for you. You may also get the chance to do and enjoy different things that you would never have done otherwise.

How can my family and friends help?

Your family and friends can support you through your cancer journey in different ways. Some family members and friends can offer a listening ear and give you advice if needed. Some may gather up-to-date information on cancer to know what you can expect and what you are going through. Others may prefer to help you in a practical way with travelling to and from the hospital, with childcare, cooking, shopping or housework. It may take time to know which way suits you and your family or friend best.

>>> How to talk to someone with cancer



When someone close to you has cancer it can be hard to know what to do. Their welfare may be a priority for you, but still you might be unsure when to visit or what to talk about. You may be afraid of upsetting them or saying the wrong thing. So it may seem best to pretend that everything is okay and carry on as normal. Sadly, by not talking to your friend or loved one, it can make them feel even more lonely and isolated. Try not to withdraw because you're afraid of their illness or what might happen in the future. Although some people do die from cancer, many do not. Be honest with own your feelings too.

Often those with cancer do not wish to burden their family and friends with their worries and concerns. Gentle encouragement can sometimes help. But don't rush into talking about their illness – knowing that you are always ready to listen and give help may reassure them. You may think you are not doing much by just listening. In fact, it is one of the best ways to help.

Be patient

Sometimes your friend or relative may get cross or irritable for what may seem to be no good reason. These feelings are completely normal. Be as patient and understanding as you can. Give them the space and time to adjust to the changes in their life. Above all, let them know that you are there, if they want to talk or need help. In time, life will begin to be normal again.

Lost for Words: How to Talk to Someone with Cancer is a useful booklet written for relatives and friends of people with cancer. Call our Cancer Nurseline on 1800 200 700 for a free copy. You can also pick up a copy from a Daffodil Centre or download it from www.cancer.ie

How can I talk to my children?

A cancer diagnosis can affect an entire family. It can bring changes that may be either great or small. Even so, it is best to keep family life as normal as possible. Continue with school and other activities, with birthdays and celebrations or work commitments. It may take a while but families can learn to adjust to big changes in their lives.

Every family deals with cancer in its own way. You may feel that you do not want your illness to upset family life, or feel guilty that you cannot do activities with your children or that you're letting them down. These are all natural feelings to have at this time.

Be honest

The main thing to remember is that being honest with your family really helps. Keeping your illness a secret may not be the best thing for your children. It can put added pressures on your family and lead to confusion. Children are very sensitive to stress and tension and if you try to protect them by saying nothing, they may feel isolated. In fact, they may have greater fears if told nothing.

It is best that you or your partner tell your children about your cancer diagnosis. If this is not possible, then someone else close to your children should break the news.

How much you tell children will depend on their age and level of maturity. Very young children do not understand illness and need a simple reason why their parent or friend is sick and has to go to hospital regularly. A story about good cells and bad cells usually works well. Most children over 10 years of age can take in fairly full explanations of why you are sick. Adolescents can understand far more.

It is best to prepare children for what to expect from the side-effects of treatments before they happen and to answer their questions simply and honestly. For example, if you get hair loss due to treatment. It is also important not to force your children to talk about your illness. If they rebel or turn quiet, it may be their way of showing their feelings.

Coping with children's emotions

During your illness, your children may experience a range of emotions from fear, guilt and anger to neglect, loneliness, isolation and embarrassment. They need to be reassured that your illness is not their fault. Whether they show it or not, children may feel that they somehow are to blame. Also, by having an open honest approach, it may bring you a sense of relief too. Your family may also find new depths of love and inner strength that will boost your life together.

If you need some extra help in dealing with children, talk to your nurse or medical social worker. A useful booklet called *Talking to Children about Cancer. A Guide for a Parent with Cancer* gives practical advice for talking to children about cancer. If you would like a copy, call our Cancer Nurseline on 1800 200 700.

What else can I do?

Everyone experiences cancer in a different way. And how each person copes with cancer varies too. There is no right or wrong way to cope, only your way. During your illness there are many things that you can learn, not only about cancer itself but also about you as a person. Here is a list of things to help make you feel more involved and more in control of your illness. They can help to boost your self-esteem and well-being, making it easier to deal with cancer.

- **Communicate with your family and close friends:** Do not keep your worries or symptoms secret from the people closest to you. This includes physical or emotional problems. Ask the person closest to you to come with you when visiting the doctor and when treatments will be discussed.
- **Live one day at a time:** 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.
- **Live well:** Try to eat as well as you can. Eat little and often including lots of different types of foods with plenty of fresh fruit

and vegetables. Do some regular exercise that you enjoy. Take it easy at first, building up the amount you do, as you feel stronger.

- **Expect change in your life:** Even though you may want to stick to your old routines, sometimes this may not be possible. It may take a while to adjust to your new routine but keep an open mind. Change may bring new opportunities and blessings.
- **Keep an open mind:** Don't feel you have to be positive all the time. Expect ups and downs during your cancer journey. There will be times when you feel low but don't feel guilty about it, as it will pass.
- **Seek information:** Be sure to ask your doctor as many questions as you can and get involved in decisions about your treatment. Always ask for information that is personal to you. Ask what side-effects you can expect so you can prepare yourself for them. Build up as much information about your cancer and treatment as possible. Follow your doctor's instructions carefully. Take your medication. If you forget and are not sure what to do, ask your doctor. Keep a notebook of all your dates for blood tests, X-rays, scans, treatments, symptoms, side-effects, medications, and your general health. Keep a record of any emotions you are feeling too, especially strong ones. Call 1800 200 700 for a free copy of *Journey Journal* to help you keep track of your cancer treatment.
- **Find what works for you:** It can help to use whatever way of coping that has helped you solve problems in the past. Some people are comfortable taking about their illness, others are not. You may prefer relaxation, meditation, walking, listening to music, or other approaches helpful. Do whatever suits you. But if it's not working, be open to finding a new way to cope.
- **Build a support network:** Be realistic about what you can manage by yourself. No man is an island, so seek help from those who want to support you. Talk to your family, friends, nurses or doctors. Meet with other patients in support groups and self-help groups as they can understand what you are going through. If the group does not suit you and is not helping, leave it.

- **Seek professional help:** If you have any low moods or strong emotions talk to your close friends and family – or someone who is a good listener. If they are still getting the better of you, discuss them with your nurse and doctor. They may recommend you talk to a trained counsellor or other specialist.
- **Spiritual care:** When faced with a cancer diagnosis and treatment, you may start thinking about the meaning of life and the afterlife. For some people spiritual and religious beliefs can bring comfort and hope. Prayer or meditation can help you to focus on what has value and meaning in your life. Even if you do not consider yourself a religious or spiritual person, it is still possible to take comfort and support from these practices. Some complementary therapies that have a spiritual dimension may also help you to focus on being positive and hopeful.
- **Express yourself:** Keep a diary or journal if you need to express yourself without holding back. It can help you to make sense of your cancer journey and can bring great healing and relief. Other forms of creative expression, such as music and art, may help too.

A useful booklet called *Understanding the Emotional Effects of Cancer* has been written for people with cancer and is available from the Irish Cancer Society. Call our Cancer Nurseline on 1800 200 700 if you would like a free copy. You can also pick up a copy from a Daffodil Centre or download it at www.cancer.ie

»»» Don't feel you have to be positive all the time. Expect ups and downs during your cancer journey.



Support resources

Who else can help?

There are many people ready to help you and your family throughout treatment and afterwards.

- Cancer nurse specialists
- Medical social worker
- Psycho-oncology services
- Family doctor (GP)
- Community health services
- Support groups
- Irish Cancer Society nurses

Cancer nurse specialists: Some of the major cancer treatment hospitals have oncology liaison nurses and/or cancer nurse coordinators. These specially trained nurses can support you and your family from the time of diagnosis and throughout treatment. The nurses work along with other members of your medical team to meet your needs.

Medical social worker: The medical social worker in your hospital can help in many ways. He or she can give support and counselling to you and your family and give advice on practical and financial support and services available when you go home.

Psycho-oncology services: In some larger hospitals there are special units that provide psycho-oncology services. This means that you can receive psychological care and support during your diagnosis, treatment and recovery by a team of experts. Usually the team consists of psychiatrists, clinical psychologists and nurses working closely together.

GP (family doctor): You may feel comfortable talking to your family doctor (GP) about your cancer too. He or she can discuss any of your queries and offer advice and support.

Community health services: There are various community health services available from your local health centre. These centres have public health nurses (who can visit you at home), welfare officers and

home-help organisers. If you live far from your hospital, your community welfare officer can also help with practical issues such as financial problems or exceptional needs. More information on the services is available either from the medical social worker in your hospital before you go home or at your local health centre.

Support groups: Joining a support group can put you in touch with people who have been in a similar situation. They can give you practical advice about living with cancer. Cancer support groups and centres are found in most counties in Ireland and can offer a wide range of services. Some are listed at the back of this booklet. You can also download the Irish Cancer Society's Directory of Cancer Support Services from www.cancer.ie.

Irish Cancer Society nurses: Our cancer nurses will be happy to talk about any concerns you or your family may have, at any stage of your illness. This can range from treatment information to practical advice about financial matters. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to talk to a cancer nurse in confidence. They can also give you information about any of the services outlined above or support services in your area. You can also email the nurses at cancernurseline@irishcancer.ie

>>> Remember that there are many people ready to help you.

Health cover

Health cover falls into two categories – cover for medical card holders and cover for all other categories. Details of the following are given here:

- Hospital cover
- Outpatient cover
- Medical card
- GP visit card
- Drug Payments Scheme (DPS)
- Private healthcare cover
- Benefits and allowances

At the end of this section there are also some useful telephone numbers and addresses for further help.

Hospital cover

At present, everyone is entitled to hospital inpatient services in a public ward in a public hospital. There is a €75 a night charge up to a limit of €750 in 1 year. These charges do not apply to medical card holders. Higher rates apply for semi-private or private care.

Outpatient cover

If you go to the accident and emergency department of a public hospital without being referred there by a GP, you will be charged €100. There is no charge if you have a medical card or are admitted to hospital because of attending the accident and emergency department first.

The €100 charge applies to the first visit in relation to an illness or accident. If you have to return for further visits to an outpatient clinic in relation to the same illness or accident, you should not have to pay the charge again.

Medical card

A medical card usually allows you, your spouse and any child under 16 to free GP services, prescribed drugs and medicines, inpatient public hospital services as well as outpatient services and medical appliances. You will have to pay a prescription charge of €2.50 per item up to a limit of €25 per family per month.

To qualify for a medical card depends on a means test regardless of age. If you are over 70 and your weekly income is €500 or less (€900 for couples), you can still apply for a card. Financial guidelines are set out each year and are available from your local Health Service Executive (HSE) office. If your means are above but close to the guidelines, you should apply for a card anyway as a card may be granted in some situations. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card.

If you wish to apply for a medical card, you can download an application form and apply online (www.medicalcard.ie) or at your local health centre. LoCall 1890 252 919.

GP visit card

If you do not qualify for a full medical card, you may be eligible for a GP visit card. This card covers visits to your doctor only and you will have to pay for drugs, outpatient/inpatient charges and medical appliances yourself. It is means tested but will take into account your after-tax income and certain expenses like childcare, rent/mortgage and travel to work. Check with the medical social worker at the hospital or your HSE office to see if you are eligible. If you wish to apply for a GP visit card, you can download an application form and apply online (www.medicalcard.ie) or at your local health centre. LoCall 1890 252 919.

Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families, including spouses and dependent children, pay a limit of €144 each month to cover the cost of prescribed drugs, medicines and appliances. You can apply for cover under the scheme by contacting your local HSE office or your local pharmacy.

Private healthcare cover

Private health insurance is used to pay for private care in hospital or from various specialists in hospitals or in their practices. In Ireland, this is available through the VHI, Laya Healthcare, AVIVA Health, GloHealth, and other schemes. They provide cover for day care/inpatient treatment and hospital outpatient treatment. Before attending hospital, it is best to check the level of cover provided by your insurance company, both for inpatient and outpatient services.

If you have private insurance, you may not always be able to have your tests done as quickly as you would like. Your health insurer has to approve some tests in advance. For example, MRI and PET scans. In some cases, it may take 24–48 hours to get approval from your health insurer.

Benefits and allowances

You or a family member may qualify for a number of benefits and allowances. For example: Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, Carer's Leave.

More information on these is available in a booklet called *Managing the Financial Impact of Cancer: A Guide for Patients and Their Families*. For a free copy, contact our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download it from www.cancer.ie



Application forms for the benefits are available from social welfare offices or the Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or LoCall 1890 927 770. You can also download the forms from websites such as www.welfare.ie or www.citizensinformation.ie

Appliances

If you have a medical card most appliances such as wigs and prostheses are free of charge or subsidised. The subsidy will depend on the HSE area. For further information, contact your local HSE office.

Travel to hospital

You may be faced with many expenses including travelling to and from hospital. If your travel costs are very expensive, discuss it with your medical social worker at the hospital. Limited help may also be available from your community welfare officer. Some HSE areas provide transport services to hospitals for outpatient appointments and day centres, usually for patients with medical cards.

See pages 61 and 62 for information on the Travel2Care fund and the Volunteer Driving Service provided by the Irish Cancer Society. Some local communities may also provide volunteer transport services.

Further information

Depending on your circumstances at the time of your illness, there are many other benefits and entitlements that may be relevant to you. Always have your PPS number to hand when you are enquiring about entitlements and benefits. The most direct way to check your eligibility is to contact:

- Your community welfare officer in your local health centre
- The medical social worker in the hospital you are attending

For social welfare queries, contact:

Dept of Social Protection – Information Service

Oisín House Leaflet line: 1890 202 325
212–213 Pearse Street Email: info@welfare.ie
Dublin 2 Website: www.welfare.ie
Tel: 1850 662 244

For queries about local health and social services, contact the HSE.
HSE infoline: 1850 24 1850 **Email:** info@hse.ie **Website:** www.hse.ie

Information is also available from your local Citizens Information Centre. A list of these centres is available from:

Citizens Information Tel: 0761 07 4000

Email: information@citizensinformation.ie

Website: www.citizensinformation.ie

**If you have financial worries...**

A diagnosis of cancer can sometimes bring the added burden of financial worries. You may find that you have a lot more expenses, like medication, travel, food, heating, laundry, clothing and childcare costs. If you are not able to work or you are unemployed, this may cause even more stress. It may be hard for you to deal with cancer if you are worried about providing for your family and keeping a roof over your head.

There is help available if you find it hard to cope with all these expenses. Contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some assistance towards travel costs and other expenses because of your illness. See page 61 for more details. You can also call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre and the cancer nurse will suggest ways to help you manage.

If you feel you are getting into debt or are in debt, there is help available. Contact the Money Advice and Budgeting Service on the MABS Helpline on 0761 07 2000. This service can help you work through any financial issues you have. They can assess your situation, work out your budget, help you deal with your debts and manage your payments. The service is free and confidential. See page 63 for contact details.

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:

- Cancer Nurseline Freephone 1800 200 700
- Daffodil Centres
- Survivor Support
- Support in your area
- Patient travel and financial support
- Night nursing
- Publications and website information

- Our **Cancer Nurseline Freephone 1800 200 700**. Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information. The Cancer Nurseline is open Monday to Thursday 9am–6pm and Friday 9am–5pm. You can also email us on cancernurseline@irishcancer.ie or visit our Online Community at www.cancer.ie
- Our **Daffodil Centres**. Visit our Daffodil Centres, located in thirteen hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer.
- Our **Survivor Support**. Speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.
- **Support in your area**. We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support including counselling.
- **Patient travel and financial support**. We provide practical and financial support for patients in need, undergoing cancer treatments. There are three services available through the Society:
 - **Travel2Care** is a fund, made available by the NCCP, for patients who are having difficulty getting to and from their treatments while attending one of the national centres of excellence.

- Through our **Financial Support** programme, limited, once off financial support is available to patients identified as being in need, who are undergoing cancer treatments nationally.
- **Irish Cancer Society Volunteer Driving Service** is mainly for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments.

To access any of these services please contact your hospital healthcare professional.

- **Irish Cancer Society Night Nursing.** We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is the only service of its kind in the Republic, providing palliative nursing care at night to cancer patients.
- **Our publications and website information.** We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer and financial concerns. Visit our website www.cancer.ie or call our Cancer Nurseline for a free copy of our publications.



If you would like more information on any of the above services, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

Cancer Nurseline Freephone 1800 200 700

Useful organisations

Irish Cancer Society

43/45 Northumberland Road
Dublin 4
Tel: 01 231 0500
Cancer Nurseline: 1800 200 700
Email: cancernurseline@irishcancer.ie
Website: www.cancer.ie

The Carers Association

Market Square
Tullamore
Co Offaly
Freefone: 1800 240 724
Email: info@carersireland.com

Citizens Information

Tel: 0761 07 4000
Email: information@citizensinformation.ie
Website: www.citizensinformation.ie

Get Ireland Active: Promoting Physical Activity in Ireland

Website: www.getirelandactive.ie

Health Promotion HSE

Website: www.healthpromotion.ie

All Ireland Co-operative Oncology Research Group

Website: www.icorg.ie

Irish Nutrition & Dietetic Institute

Ashgrove House
Kill Avenue
Dún Laoghaire
Co Dublin
Tel: 01 280 4839
Email: info@indi.ie
Website: www.indi.ie

Irish Oncology and Haematology Social Workers Group

Website: <http://socialworkandcancer.com>

Money Advice and Budgeting Service (MABS)

Commercial House
Westend Commercial Village
Blanchardstown
Dublin 15
Tel: 01 812 9350
Helpline 0761 07 2000
Email: helpline@mabs.ie
Website: www.mabs.ie

Rotunda IVF

Rotunda Hospital
Parnell Square
Dublin 1
Tel: 01 807 2732
Email: info@rotundaivf.ie
Website: www.rotundaivf.ie

Health insurers

AVIVA Health

PO Box 764
Togher
Cork
Tel: 1850 717 717
Email: info@avivahealth.ie
Website: www.avivahealth.ie

GloHealth

PO Box 12218
Dublin 18
Tel: 1890 781 781
Email: findoutmore@glohealth.ie
Website: www.glohealth.ie

Laya Healthcare

Eastgate Road
Eastgate Business Park
Little Island
Co Cork
Tel: 021 202 2000
LoCall: 1890 700 890
Email: info@layahealthcare.ie
Website: www.layahealthcare.ie

Voluntary Health Insurance (VHI)

IDA Business Park
Purcellsinch
Dublin Road
Kilkenny
CallSave: 1850 44 44 44
Email: info@vhi.ie
Website: www.vhi.ie

National support services**Survivor Support**

Irish Cancer Society
43/45 Northumberland Road
Dublin 4
Cancer Nurseline:
1800 200 700
Email: support@irishcancer.ie
Website: www.cancer.ie

ARC Cancer Support Centres Dublin
[See page 65]**Brain Tumour Support Group**

Medical Social Work Department
St Luke's Hospital
Highfield Road
Rathgar
Dublin 6
Tel: 01 406 5295

Canteen Ireland

[Teenage cancer support]
Carmichael Centre
North Brunswick Street
Dublin 7
Tel: 01 872 2012
Email: info@canteen.ie
Website: www.canteen.ie

Cancer Support Sanctuary LARCC
[See page 65]**Connaught support services****Athenry Cancer Care**

Social Service Centre
New Line
Athenry
Co Galway
Tel: 091 845 228 / 087 412 8080
Email: athenrycancercares@gmail.com
Website: www.athenrycancercares.com

Ballinasloe Cancer Support Centre

Main Street
Ballinasloe
Co Galway
Tel: 090 964 3431
Email: ballinasloecancer@yahoo.co.uk

Cara Iorrais Cancer Support Centre

2 Church Street
Belmullet
Co Mayo
Tel: 097 20590 / 087 391 8573
Email: caraiorrais@gmail.com

Gort Cancer Support Group

Garrabeg
Gort
Co Galway
Tel: 091 648 606 / 086 172 4500
Email: info@gortcancersupport.ie
Website: www.gortcancersupport.ie

Hand in Hand

[Children's Cancer Support Centre]
Main Street
Oranmore
Co Galway
Tel: 091 799 759
Email: info@handinhand.ie
Website: www.handinhand.ie

Mayo Cancer Support Association

Rock Rose House
32 St Patrick's Avenue
Castlebar
Co Mayo
Tel: 094 903 8407
Email: info@mayocancer.ie
Website: www.mayocancer.ie

Roscommon Cancer Support Centre

Vita House Family Centre
Abbey Street
Roscommon
Tel: 090 662 5898
Email: info@vitahouse.org

Sligo Cancer Support Centre

44 Wine Street
Sligo
Tel: 071 917 0399
Email: scsc@eircom.net
Website: www.sligocancersupportcentre.ie

Tuam Cancer Care Centre

Cricknet Court
Dunmore Road
Tuam
Co Galway
Tel: 093 285 22
Email: support@tuamcancercares.ie
Website: www.tuamcancercares.ie

Leinster support services**ARC Cancer Support Centre**

ARC House, 65 Eccles Street
Dublin 7
Tel: 01 830 7333
Email: info@arccancersupport.ie
Website: www.arccancersupport.ie

ARC Cancer Support Centre

ARC House, 559 South Circular Road
Dublin 8
Tel: 01 707 8880
Email: info@arccancersupport.ie
Website: www.arccancersupport.ie

Arklow Cancer Support Group

25 Kings Hill
Arklow
Co Wicklow
Tel: 0402 23590 / 085 110 0066
Email: info@arklowcancersupport.com
Website: www.arklowcancersupport.com

Balbriggan Cancer Support Group

Unit 23, Balbriggan Business Park
Harry Reynold's Road
Balbriggan
Co Dublin
Tel: 087 353 2872 / 086 164 2234

Cancer Support Sanctuary LARCC

Coole Road
Multyfarnham
Mullingar
Co Westmeath
Tel: 044 937 1971
CallSave: 1850 719 719
Email: info@cancersupport.ie
Website: www.cancersupport.ie

Cara Cancer Support Centre

7 Williamson's Place
Dundalk
Co Louth
Tel: 042 937 4905
Mobile: 087 395 5335
Email: info@ccscdundalk.ie
Website: ccscdundalk.ie

Cois Nore Cancer Support Centre

8 Walkin Street
Kilkenny
Tel: 056 775 2222
Email: coisnorekilkenny@gmail.com
Website: www.kilkennycancersupport.ie

Cuisle Cancer Support Centre

Block Road
Portlaoise
Co Laois
Tel: 057 868 1492
Email: cuislecentre@eircom.net
Website: www.cuislecentre.com

Dóchas: Offaly Cancer Support Group

Teach Dóchas
Offaly Street
Tullamore
Co Offaly
Tel: 057 932 8268
Email: info@dochasoffaly.ie
Website: www.dochasoffaly.ie

Dublin West Cancer Support Group

Generic Social Work Department
Oak Unit
Cherry Orchard Hospital
Ballyfermot
Dublin 10
Tel: 01 620 6273
Email: martina.mcGovern2@hse.ie/
noreen.obrien4@hse.ie

Éist Carlow Cancer Support Centre

The Waterfront
Mill Lane
Carlow
Tel: 059 913 9684
Mobile: 085 144 0510
Email: info@eistcarlowcancersupport.ie
Website: www.eistcarlowcancersupport.ie

Gary Kelly Cancer Support Centre

George's Street
Drogheda
Co Louth
Tel: 041 980 5100
Email: info@gkcancersupport.com
Website: www.gkcancersupport.com

Greystones Cancer Support

La Touche Place
Greystones
Co Wicklow
Tel: 01 287 1601
Email: info@greystonescancersupport.com
Website: www.greystonescancersupport.com

Hope Cancer Support Centre

22 Weafer Street
Enniscorthy
Co Wexford
Tel: 053 923 8555
Email: info@hopesupportcentre.ie
Website: www.hopesupportcentre.ie

Midlands Myeloma Support Group

Teach Dóchas
Offaly Street
Tullamore
Co Offaly
Tel: 057 932 8268
Email: info@dochasoffaly.ie

Purple House – Cancer Support

Aubrey Court
Parnell Road
Bray
Co Wicklow
Tel: 01 286 6966
Email: info@purplehouse.ie
Website: www.purplehouse.ie

Tallaght Cancer Support Group

Trustus House
1–2 Main Street
Tallaght
Dublin 24
Tel: 086 400 2736
Email: ctallaght@yahoo.ie
Website: tallaghtcancersupport.com

Wicklow Cancer Support Centre

Rear of Butler's Medical Hall
Abbey Street
Wicklow
Tel: 0404 326 96
Email: wicklowcancersupport@gmail.com

Munster support services**Cancer Information & Support Centre**

University Hospital Limerick
Dooradoyle
Co Limerick
Tel: 061 485 163
Website: www.midwesterncancercentre.ie

CARE Cancer Support Centre

14 Wellington Street
Clonmel
Co Tipperary
Tel: 052 618 2667
Email: caresupport@eircom.net
Website: www.cancercare.ie

Cork ARC Cancer Support House

Cliffdale
5 O'Donovan Rossa Road
Cork
Tel: 021 427 6688
Email: info@corkcancersupport.ie
Website: www.corkcancersupport.ie

Kerry Cancer Support Group

Acorn Centre
124 Tralee Townhouse Apartments
Maine Street
Tralee
Co Kerry
Tel: 066 719 5560 / 087 230 8734
Email: kerrycancersupportgroup@eircom.net
Website: www.kerrycancersupport.com

Recovery Haven

5 Haig's Terrace
Tralee
Co Kerry
Tel: 066 719 2122
Email: recoveryhaven@gmail.com
Website: www.recoveryhavenkerry.com

Solas Centre

South Eastern Cancer Foundation
Williamstown
Waterford
Tel: 051 304 604
Email: info@solascentre.ie
Website: www.solascentre.ie

Suaimhneas Cancer Support Centre

2 Clonaslee
Gortland Roe
Nenagh
Co Tipperary
Tel: 067 37403
Email: suaimhneascancersupport@eircom.net

Suir Haven Cancer Support Centre

Clongour Road
Thurles
Co Tipperary
Tel: 0504 21197
Email: suirhaven@gmail.com

Ulster support services**Coiste Scaoil Saor Ó Ailse**

C/O Ionad Naomh Padraig
Upper Dore
Bunbeg
Letterkenny
Co Donegal
Tel: 074 953 2949
Email: ionadnp@eircom.net
Website: www.scaoilsaor.ie

Crocus: Monaghan Cancer Support Centre

The Wellness Centre
19 The Grange
Plantation Walk
Monaghan
Tel: 087 368 0965 / 047 62565
Email: crocus.2011@yahoo.com

Cuan Cancer Social Support and Wellness Group

2nd Floor, Cootehill Credit Union
22–24 Market Street
Cootehill
Co Cavan
Tel: 086 455 6632

Other support services**Aoibheann's Pink Tie**

[Supporting children with cancer]
Unit 22
Docklands Innovation Centre
128–130 East Wall Road
Dublin 3
Tel: 01 240 1300
Email: aoibheannspinktie2@gmail.com
Website: www.aoibheannspinktie.ie

The Bella Rose Foundation

Merry Maid House
West Park Campus
Garter's Lane
Citywest
Dublin 24
Tel: 087 320 3201
Email: thebellarosefoundation@gmail.com
Website: www.bellarose.ie

Cancer Care West

72 Seamus Quirke Road
Galway
Tel: 091 545 000
Email: info@cancercarewest.ie
Website: www.cancercarewest.ie

Cúnamh: Bons Secours Cancer Support Group

Bon Secours Hospital
College Road
Cork
Tel: 021 480 1676
Website: www.cunamh.ie

Dundalk Cancer Support Group

Philipstown
Hackballscross
Dundalk
Co Louth
Tel: 086 107 4257

East Galway & Midlands Cancer Support

Cluain Mhuire
Brackernagh
Ballinasloe
Co Galway
Tel: 090 964 2088 / 087 984 0304
Email: info@egmcancersupport.com
Website:
www.eastgalwaycancersupport.com

The Forge Cancer Support Service

The Forge Family Resource Centre
Pettigo
Co Donegal
Tel: 071 986 1924
Email: theforgefrc@eircom.net

Killybegs Cancer Support Group

Kille
Kilcar
Co Donegal
Tel: 074 973 1292
Email: riverbankdunne@eircom.net

Newbridge Cancer Support Group

Tel: 083 360 9898
Email:
newbridgecancerhealinghelp@gmail.com

Rathdrum Cancer Support Group

St Anne's
Lower Street
Rathdrum
Co Wicklow
Tel: 087 925 3915
Email: rathcan@gmail.com

Sláinte an Chláir: Clare Cancer Support

Tír Mhuire
Kilnamona
Ennis
Co Clare
Tel: 1850 211 630
Email: admin@clarecancersupport.com
Website: www.clarecancersupport.com

Solace: Donegal Cancer Support Centre

St Joseph's Avenue
Donegal Town
Tel: 074 974 0837
Email: solacedonegal@eircom.net

Useful contacts outside Republic of Ireland**Action Cancer**

Action Cancer House
1 Marlborough Park
Belfast BT9 6XS
Tel: 028 9080 3344
Email: info@actioncancer.org
Website: www.actioncancer.org

American Cancer Society (US)

Website: www.cancer.org

Cancer Focus Northern Ireland

40-44 Eglantine Avenue
Belfast BT9 6DX
Tel: 048 9066 3281
Email: hello@cancerfocusni.org
Website: www.cancerfocusni.org

Cancer Buddies Network

Website: www.cancerbuddiesnetwork.org

Cancer Research UK

Tel: 0044 20 7242 0200
Website: www.cancerhelp.org.uk

Healthtalkonline (UK)

Website: www.healthtalk.org

Macmillan Cancer Support (UK)

Tel: 0044 20 7840 7840
Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk

Macmillan Support & Information Centre

Belfast City Hospital Trust
77-81 Lisburn Road
Belfast BT9 7AB
Tel: 028 9069 9202
Email: cancerinfo@belfasttrust.hscni.net
Website: www.cancerni.net

National Cancer Institute (US)

Website: www.nci.nih.gov

For other support services in your area, call 1800 200 700.

Helpful books**Free booklets from the Irish Cancer Society:**

- *Understanding Chemotherapy*
- *Understanding Radiotherapy*
- *Understanding Cancer and Complementary Therapies*
- *Diet and Cancer*
- *Coping with Fatigue*
- *Understanding the Emotional Effects of Cancer*
- *Lost for Words: How to Talk to Someone with Cancer*
- *Who Can Ever Understand? Taking About Your Cancer*
- *Talking to Children about Cancer: A Guide for Parents*
- *A Time to Care: Caring for Someone Seriously Ill at Home*
- *Managing the Financial Impact of Cancer: A Guide for Patients and Their Families.*
- *Journey Journal: Keeping Track of Your Cancer Treatment*

**Cancer at Your Fingertips**

Val Speechley & Maxine Rosenfeld
Class Publishing, 2001
ISBN 1859590365

Challenging Cancer: Fighting Back,

Taking Control, Finding Options
Maurice Slevin & Nira Kfir
Class Publishing, 2002
ISBN 1859590683

Taking Control of Cancer

Beverly van der Molen
Class Publishing, 2003
ISBN 1859590918

Explaining cancer to children**The Secret C: Straight Talking About Cancer**

Julie A Stokes
Winston's Wish, 2000
ISBN 0953912302

Why Mum? A Small Child with a Big Problem

Catherine Thornton
Veritas, 2005
ISBN 1853908916
Call 1800 200 700 for a copy.

Email: cancernurseline@irishcancer.ie

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?

Acknowledgements

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Anne-Marie Dunne, Information Officer

Michelle Griffin, Clinical Nurse Specialist

Elaine Purcell, Medical Social Worker

Would you like more information?

We hope this booklet has been of help to you. If you feel you would like more information or someone to talk to, please call the National Cancer Helpline 1800 200 700.

Would you like to be a patient reviewer?



If you have any suggestions as to how this booklet could be improved, we would be delighted to hear from you. The views of patients, relatives, carers and friends are all welcome. Your comments would help us greatly in the preparation of future information booklets.

If you wish to email your comments, have an idea for a new booklet or would like to review any of our booklets, please contact us at reviewers@irishcancer.ie. If you prefer to phone or write to us, see contact details below.

Would you like to help us?

The Irish Cancer Society relies entirely on voluntary contributions from the public to fund its programmes of patient care, education and research. If you would like to support our work in any way – perhaps by making a donation or by organising a local fundraising event – please contact at CallSave 1850 60 60 60 or email fundraising@irishcancer.ie

Irish Cancer Society, 43/45 Northumberland Road, Dublin 4

Tel: 01 231 0500 **Email:** info@irishcancer.ie **Website:** www.cancer.ie

Irish Cancer Society

43/45 Northumberland Road, Dublin 4

T: 01 231 0500

E: info@irishcancer.ie

W: www.cancer.ie

Cancer Nurseline Freephone 1800 200 700

Open Monday to Thursday 9am to 6pm

Friday 9am to 5pm

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