

Understanding

Uterine (womb) cancer

Caring for people with cancer

Understanding

Uterine (womb) cancer

This booklet has information on:

- Treatment for uterine cancer
- Side-effects and how to manage them
- Coping with the emotional side of cancer
- Financial and practical matters

Useful numbers

Specialist nurse

Family doctor (GP)

Gynaecologist

Surgeon

Medical oncologist

Radiation oncologist

Radiation therapist

Medical social worker

Emergency

Hospital records number (MRN)



Contents

About uterine cancer	7
Preparing for your hospital appointments	13
Diagnosis and further tests	19
Treatment overview	33
Treatments	49
Managing side-effects and symptoms	75
After treatment	87
Coping and emotions	95
Supporting someone with cancer	103
Support resources	109
What does that word mean?	123
Questions to ask your doctor	125

Fast facts

Can my cancer be treated? Page 33

There are many treatments available for uterine cancer. Your doctor will discuss with you what treatments will be of most benefit to you.

Will I be OK? Page 31

What is likely to happen to you (your prognosis) is hard to predict. It depends on a lot of things and everyone's prognosis is different. Your doctor will advise you on what is likely to happen in your situation.

What kind of treatments might I have? Page 49

Surgery: An operation to remove the cancer.

Radiotherapy: Uses high-energy rays to kill cancer cells. It can be given internally and/or externally.

Chemotherapy: A type of drug therapy intended to slow down and control the growth of cancer.

Radiotherapy and chemotherapy: Sometimes called chemoradiation. Chemotherapy can make the radiotherapy more effective.

Targeted therapies / immunotherapy: Drugs that work with your body to help fight cancer.

Are there side-effects from treatment? Page 75

Your doctor and the team caring for you will talk to you about possible side-effects. Read about each of the treatments to learn more about their side-effects. There are treatments to help with most side-effects, so tell your doctor. Don't suffer in silence!

Clinical trials Page 73

Clinical trials are research studies that try to find new or better ways of treating cancer or reducing side-effects. Ask your consultant if there are any trials suitable for you. You can also see a list of current cancer trials at www.cancertrials.ie

We're here for you Page 115

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

Ways to get in touch

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

See page 115 for more about our services.

Reading this booklet



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

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

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

About our information

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

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

In this booklet, we use the term 'woman / women' but we understand that not everyone who has a uterus identifies as a woman. Whatever your sex or gender identity, we are here for you. For confidential advice, information and support, contact our Support Line on Freephone 1800 200 700.



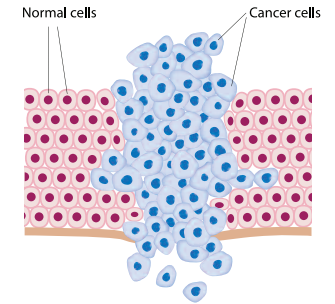
Support Line Freephone 1800 200 700

About uterine cancer

What is cancer?	9
What is the lymphatic system?	9
What is the uterus (womb)?	10
What is uterine cancer?	11
What is endometrial cancer?	11
What caused my cancer?	11
What are the types of uterine cancer?	12
How common is uterine cancer?	12

What is cancer?

- **Cancer is a disease of the body's cells**
Cancer cells are abnormal cells that grow without control. They can form a lump (tumour).

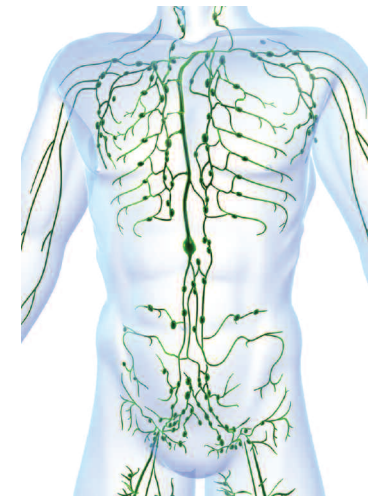


- **Cancers are named after the organ or cell where the cancer starts**
Uterine cancer starts in the uterus.
Endometrial cancer – the most common type of uterine cancer – starts in the lining of the uterus (endometrium).

- **Cancers sometimes spread**
If a tumour is cancerous (malignant), a cell or group of cells can be carried by your blood or lymph fluid to another part of your body, where it can form a new tumour. This is called metastasis. Sometimes cancer cells spread into nearby lymph nodes.

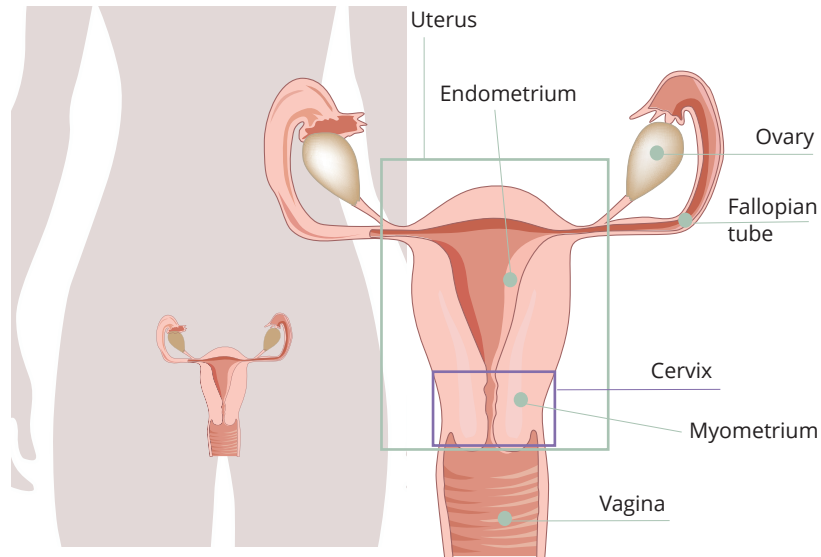
What is the lymphatic system?

- The lymphatic system is part of our immune system. It protects us from infection and disease and removes extra fluid and waste from the body's tissues.
- It is made up of lymph nodes connected by tiny tubes called lymph vessels.
- Lymph nodes are found mainly in the neck, armpit, groin and tummy.
- If cancer cells spread into lymph nodes or cancer starts in the lymph nodes, they can become swollen.



What is the uterus (womb)?

The uterus is the part of your body that holds a baby if you are pregnant. The uterus is a muscular, pear-shaped organ found in your lower abdomen, between your bladder and back passage (rectum). It is part of the female reproductive system, together with the ovaries, the fallopian tubes, the cervix and the vagina.



The lining of your uterus is called the endometrium. Every month this lining thickens, grows and then falls away from the uterus as a monthly period. During pregnancy, your uterus protects the growing baby.

There are also layers of muscle in the uterus called the myometrium. The lower part of the uterus is the cervix, which is also known as 'the neck of the uterus'. Although the cervix is part of the uterus, cancer of the cervix is diagnosed and treated differently to cancer of the uterus. If you have been diagnosed with cervical cancer, call our Support Line on 1800 200 700 for a copy of our booklet *Understanding cervical cancer*. It is also on our website www.cancer.ie

What is uterine cancer?

Cancer of the uterus occurs when the cells in the uterus change and grow in an abnormal way. A group of these cancer cells can form a tumour.

What is endometrial cancer?

Most cancers in the uterus start in the lining of the uterus (endometrium). This type of cancer is called endometrial cancer. See page 12 for more about the different types of uterine cancer.

What caused my cancer?

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

Family history of Lynch syndrome

Lynch syndrome is a rare genetic condition that runs in some families. People with Lynch syndrome have a higher risk of getting certain types of cancer, including uterine and bowel cancer. If any of your family is concerned about having Lynch syndrome, they should talk to their GP, who can advise them if they might benefit from screening.

Email: supportline@irishcancer.ie

What are the types of uterine cancer?

There are two main types of womb cancer: endometrial cancer and sarcoma of the womb.

Endometrial cancer

Nearly all uterine cancers (95%) affect the endometrium – the lining of the uterus. They are called endometrial cancers. The most common type of endometrial cancer is adenocarcinoma. Less common types of endometrial cancers include:

- Clear cell carcinoma
- Serous carcinoma
- Carcinosarcoma

Uterine sarcoma

This cancer affects the muscle layers of the uterus rather than the lining. The most common type is leiomyosarcoma. It is much less common than endometrial cancer.

Your doctor or specialist nurse will explain the type of uterine cancer that you have. The different types of uterine cancer can behave differently.

Since most uterine cancers are endometrial, the information in this booklet is mainly aimed at women with endometrial cancer.

How common is uterine cancer?

About 460 women are diagnosed with uterine cancer every year in Ireland. Most cases occur in women aged 50 to 64.

Support Line Freephone 1800 200 700

Preparing for your hospital appointments

Before your appointment	15
What to take to your appointment	16
Before leaving the appointment	17
After the appointment	17
Cancelling your appointment	17

Preparing for your hospital appointments

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



Before your appointment

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

What to take to your appointment

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

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

Email: supportline@irishcancer.ie

Before leaving the appointment

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

After the appointment

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

Note

If you have to cancel your appointment...

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

Support Line Freephone 1800 200 700



Diagnosis and further tests

Being diagnosed with uterine cancer	21
Telling people about your diagnosis	22
What tests will I have?	23
Staging and grading uterine cancer	27
Asking about your prognosis	31

Being diagnosed with uterine cancer

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

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

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

- **Ask to speak to the cancer (oncology) liaison nurse or the medical social worker at the hospital.** They can help you and your family to cope with your feelings and advise you about practical matters.
- **Talk to one of our cancer nurses in confidence** – visit a Daffodil Centre or call our Support Line on 1800 200 700. You can email the nurses at supportline@irishcancer.ie
- **Speak to an Irish Cancer Society Peer Support volunteer** who has had a cancer diagnosis and really knows what you are going through. Our nurses can put you in touch with a volunteer.
- **Talk to other people affected by cancer.** Join our online community at www.cancer.ie/community
- **Go to your local cancer support centre.** For more information, see page 122.

'However you feel,
you are not alone.'

Telling people about your diagnosis



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

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



What tests will I have?

- Tests you may have after diagnosis include an MRI, chest X-ray and CT scan. Sometimes the medical team will request a more detailed scan, called a PET CT scan.
- The tests will tell your medical team more about your cancer and help them to decide on the best treatment for you.

The following tests give doctors more information about your cancer. Some tests may also be used to see how well you are responding to treatment.

Blood tests

Blood tests can help to check your general health. They will be done regularly during your treatment to help your medical team monitor how your body is coping with treatment.

Chest X-ray

This is taken to check your general health.

Hysteroscopy

A thin, flexible tube with a light at the end (a hysteroscope) is passed through your vagina and into your uterus. This allows your doctor to look inside your uterus and take tissue samples or a biopsy. You may be given a local anaesthetic for this test.

Biopsy

Your doctor can take small amounts of tissue samples from your uterus during the hysteroscopy. These are called biopsies. Biopsies are sent to a laboratory and looked at under a microscope to find out if cancer cells are present.

CT scan (CAT scan)

This special X-ray gives a detailed picture of the tissues inside your body. You may be asked to fast (not eat) before the test. You may be given a special drink and an injection of an X-ray contrast agent, which helps show up parts of your body on the scan. Preparations for a CT scan can vary. Your doctor or nurse will tell you what to do. The test is usually done as an outpatient. During the scan you will lie on a table which passes through a large doughnut-shaped machine. The scan is painless and takes between 10 and 30 minutes. You'll probably be able to go home as soon as the scan is over.

MRI scan

MRI is a scan that uses magnetic energy and radio waves to create a picture of the tissues inside your body. MRI scans can produce images from different angles all around the body. You will need to complete a form before the test to ensure that it is safe for you to have an MRI scan.

If you have any medical device in your body, like a pacemaker or pin, you may not be suitable for the test. During the scan, you cannot wear metal jewellery.

During the test you will lie inside a tunnel-like machine for about 30-60 minutes. It is important that you keep as still as possible during the scan.

Some people are afraid they will feel claustrophobic inside the tunnel. Tell the radiation therapist if you're feeling anxious.

An MRI can also be noisy, but you will be given earplugs to help block out the sound. You might get an injection before the scan to show up certain parts of your body.

Usually you can go home soon after the scan.



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

PET CT scan

A PET CT scan gives a detailed picture of the tissues inside the body. It can also show if the cancer has spread to other tissues and organs. A low dose of radiotracer (radioactive sugar) is injected into your arm. An hour or so later you will have a scan. The scan uses the radiotracer to highlight cancer cells in your body. During the scan, you will lie on a table which moves through a scanning ring. The scan can last up to an hour. Before the scan, you may have to fast (not eat) and drink only plain unflavoured water for a few hours.

You may have to travel to a specialist centre to have this scan, as not every hospital has these scanners. Not every patient with uterine cancer will need a PET CT scan. You can discuss this with your doctor.

You will be slightly radioactive after the PET scan, so you will be advised not to have close contact with pregnant women, babies or young children for a few hours after the scan.

Drink plenty of fluids and empty your bladder regularly after the scan; this can help flush the radiotracer from your body.

Transvaginal ultrasound

A small metal device called a probe is gently put into your vagina. It uses sound waves to build up a picture of the tissues in your uterus. This test is not painful but may be a little uncomfortable.

Dilatation and curettage (D&C)

Here the doctor gently opens your cervix and entrance to the uterus and takes samples of tissue from the inner lining of your uterus. This is done with an instrument shaped like a spoon called a curette. The samples are then sent to the laboratory to be examined. This test is done under general anaesthetic.

Waiting for test results



It usually takes up to 2 weeks for all the test results to come back. Naturally, this can be an anxious time for you. It may help to talk things over with the specialist nurse or with a relative or close friend. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

Once all the tests have been completed, the multidisciplinary team will meet to decide on how to manage your cancer.



Staging and grading uterine cancer

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

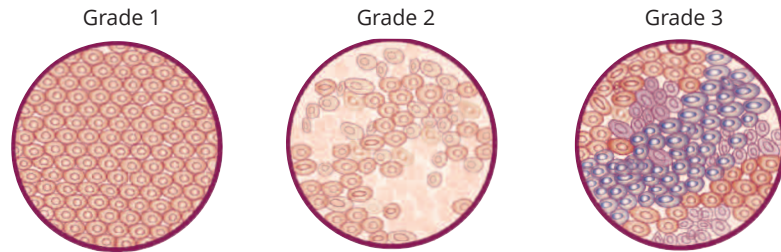
The tests you have after diagnosis help the doctor to give your cancer a stage and a grade.

- **Staging** describes where the cancer is in your body
- **Grading** describes the cancer cells – what they look like under the microscope and how they might grow

Knowing the stage and grade helps your doctor to decide the best treatment for you.



What are the grades of uterine cancer?



Low-grade uterine cancer

The cancer cells look only slightly abnormal, much like normal uterine cells. The cancer is usually slow growing and less likely to spread than high-grade uterine cancer.

High-grade uterine cancer

The cancer cells look fairly or very abnormal and are more likely to grow quickly.

How is uterine cancer staged?

There are two different staging systems for uterine cancer:

- TNM staging system
- FIGO staging system

TNM staging

Tumour (T): The size and depth of the tumour.

Nodes (N): This refers to whether the cancer has spread into the lymph nodes. N0 refers to no lymph nodes affected, N1, N2, N3 refer to the number of lymph nodes affected and where they are located.

Metastasis (M): M1 means the cancer has spread to other parts of your body and M0 means it hasn't.

Your doctor often uses this TNM information to give your cancer a number stage – from 1 to 4. A higher number, such as stage 4, means a more advanced cancer. Some stages are further divided into stage A and B.

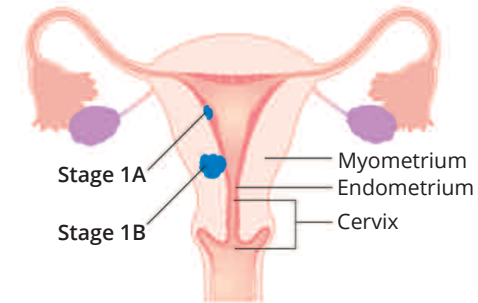
In general, the lower the number, the less the cancer has spread.

What are the stages of uterine cancer?

There are four stages of uterine cancer – 1 to 4. They tell how far the cancer has spread through the womb lining and muscle layers. Staging also describes if the cancer is still in the pelvic area or has spread to other distant organs (metastasis).

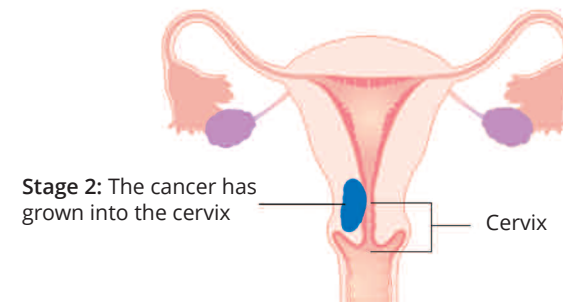
Stage 1A: The cancer cells are in the lining of the uterus (endometrium) and less than halfway into the muscle layer (myometrium).

Stage 1B: The cancer cells have grown more than halfway into the muscle layer.



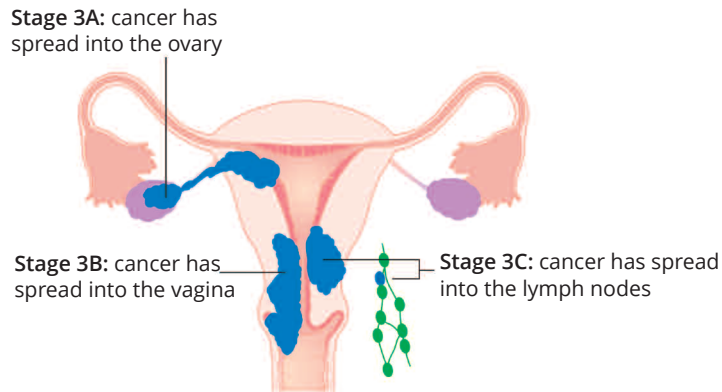
Stage 2

The cancer cells have spread to the connective tissue of the cervix (the neck of the uterus).



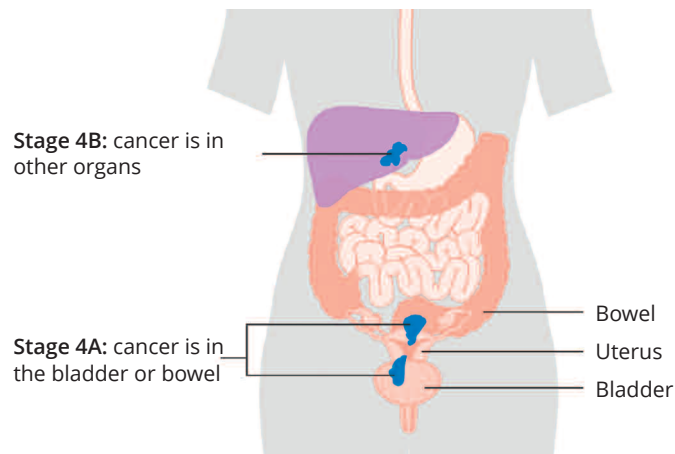
Stage 3

The cancer cells have spread outside the uterus but are still in the pelvis.



Stage 4

The cancer has spread to other body organs and tissues.



Pictures courtesy of Cancer Research UK/Wikimedia Commons

FIGO staging

The FIGO staging system is similar. The different stages are given a number I (1) to IV (4). Each number stage is sub-divided using letters a, b and c. For example, stage Ia, stage IIc, etc. Again, the higher the letter and number within each stage, the more advanced the disease.

Staging and grading are helpful for your medical team to decide the best treatment for you. However, you don't need to understand the staging and grading system in depth.

Asking about your prognosis

Your prognosis includes information about how your cancer is likely to progress, including average survival times or life expectancy.

It's not easy for doctors to answer a question about life expectancy. Everyone is different, so what happens to you might be quite different from what the doctor expects.



Should I ask about my prognosis?

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

If you decide you want information on your prognosis:

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

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

Support Line Freephone 1800 200 700

Treatment overview

How is uterine cancer treated?	35
Deciding on treatment	38
Who will be involved in my care?	39
Giving consent for treatment	42
Waiting for treatment to start	43
How can I help myself?	44

How is uterine cancer treated?

- Surgery is the main treatment for uterine cancer.
- A team of healthcare professionals will be looking after you (multidisciplinary team).

The type of treatment you have will depend on:

- The size and stage of your cancer
- The type of cancer
- Your general health
- Your age and fertility



Types of treatments

Surgery

Surgery is the most common way to treat uterine cancer. The aim of the surgery is to remove all the tumour. Your doctor will discuss if surgery is suitable for you. It will depend on the type and size of the cancer and if it has spread.

The most common type of surgery is the removal of the uterus, the ovaries and the fallopian tubes. This is called a total hysterectomy with bilateral salpingo-oophorectomy. The surgery is usually done using the keyhole (laparoscopic) technique. Sometimes the lymph nodes are also removed or tested. See page 51 for more about surgery.

Some people will not need further treatment after surgery if surgery removes the cancer. But other people might need further treatment. For example, radiotherapy and / or chemotherapy.

Radiotherapy

Radiotherapy is the use of high-energy rays to kill the cancer cells. It can be given after surgery. It may also be given if the cancer has spread to the area around the uterus. External radiotherapy is where the radiation comes from machines called linear accelerators, which aim rays directly at your tumour.

Internal radiotherapy (brachytherapy) is when the radiation source is placed inside your body – in this case into your vagina – for a very short time to kill the cancer cells. See page 61 for more about radiotherapy.



Chemotherapy

Chemotherapy is the use of drugs to kill or control the growth of the cancer cells. It can be given after surgery (adjuvant therapy) in the treatment of uterine cancer. It can also be used alone or with radiotherapy. See page 66 for more information.

Hormone therapy

The two female sex hormones, progesterone and oestrogen, can affect how cancer cells grow in the lining of your uterus. Hormone treatment may be given to help reduce the tumour and control some of your symptoms. See page 71 for more.

The main hormone treatment is progesterone, which is usually given in tablet or injection form. Side-effects are usually mild – weight gain, fluid retention or feeling sick – but let your doctor know if you have any side-effects that are troubling you.

Targeted therapies / Immunotherapies

Targeted therapies and immunotherapy can help your body to fight cancer, slow its growth or control side-effects from other cancer treatments. Your medical oncologist will tell you if there any therapies available that will be of benefit to you. See page 72 for more information.

Specialist cancer centres

Uterine cancer is treated in specialist gynaecological centres in Ireland. The staff at these centres have a lot of experience in managing patients with uterine cancer. As a result, you may be transferred to another hospital from the one where you received your diagnosis, depending on your diagnosis and your suggested treatment plan.

Email: supportline@irishcancer.ie

Deciding on treatment

Multidisciplinary team

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

Understanding your treatment

Your doctor and nurse will explain your treatment options. You could use the fill-in page at the back of this booklet to write down your questions. Ask as many questions as you like. If you forget something or need more explanations, ask your specialist nurse or talk to one of our cancer nurses – call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Time to think

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

Second opinion

You might also find it reassuring to have another medical opinion to help you decide about your treatment. Your treating doctor or GP can refer you to another specialist for a second opinion if you feel this would be helpful. Getting a second opinion will not affect the care you will receive.

Accepting treatment

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

Who will be involved in my care?

Some of the following health professionals may be involved in your care. Usually a team of specialists (multidisciplinary team) will decide your treatment.

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



Gynaecological oncology surgeon A doctor who specialises in the surgical treatment of cancers of the female reproductive system.

Pathologist A doctor who specialises in looking at cells under a microscope and diagnosing the cell type.

Radiologist A doctor who specialises in interpreting X-rays and scans such as ultrasound, CT, MRI and PET.

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.

Radiation therapist A healthcare professional who delivers the radiotherapy and gives advice to cancer patients about their radiation treatment.

Advanced nurse practitioner A specialist nurse who has extra experience and skills in looking after patients in a specialty area such as cancers of the female reproductive system.

Gynaecological oncology clinical nurse specialist A specially trained nurse who cares for patients who have uterine cancer and other cancers of the female reproductive system.

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

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

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

GP (family doctor) While your medical team will be your main point of contact, your GP is still very much a part of your care and can be a great support to you.

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

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

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

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

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

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

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

Individual treatment

You may notice that other people with a uterine cancer are not getting the same treatment as you. Their tumour may not be the same type or the same grade as yours. Everyone's treatment needs will be different. Do not be afraid to ask your doctor about your treatment.

Email: supportline@irishcancer.ie

Giving consent for treatment

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

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

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



Waiting for treatment to start

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

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

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



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

How can I help myself?

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

Eat well

Eating as well as possible can help you during your treatment. It can help you to:

- Keep up your energy and strength
- Keep your weight stable and avoid muscle loss
- Tolerate your treatment better so you can finish your course of treatment
- Cope better with side-effects of treatment
- Reduce your risk of infection and other complications
- Recover faster



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

Keep active

If you are able, it can really help to stay active before, during and after your treatment. Keeping up or increasing your activity levels can help to:

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

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

Quit smoking

If you are coping with a cancer diagnosis, you may find it stressful to quit smoking. However, research tells us that:

- Non-smokers are likely to have fewer or less severe side-effects during cancer treatment. For example, chest infections
- Smoking can reduce how well chemotherapy or radiotherapy work
- Not smoking can help you to heal better after surgery
- Quitting reduces your chance of further illness



If you would like advice or support on quitting, call the HSE Quit Team on CallSave 1800 201 203, visit www.QUIT.ie or Freetext QUIT to 50100. Ask your nurse or medical social worker about quitting – some hospitals have a stop-smoking service, with advisors who can help and support you.

You will have a better quality of life if you give up smoking.

Other ways to help yourself

Get information about your cancer and treatment

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

This is GO

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

Involve your family and close friends

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

Use your support network

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

Try relaxation and stress management techniques

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

Accept change in your life

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



Be aware that there will be ups and downs

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

Try to cope day by day

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



Types of treatment

Surgery	51
Radiotherapy	61
Chemotherapy	66
Hormone therapy	71
Targeted therapies	72
Immunotherapy	72
Clinical trials	73
Treatment for cancer that has spread	74

Surgery

- Surgery means removing a tumour.
- A hysterectomy is the most common surgery for uterine cancer.

Hysterectomy

The aim of surgery is to remove the cancer. A hysterectomy is the most common surgery carried out for uterine cancer. A total hysterectomy is where the surgeon removes the uterus and cervix. You may also have both ovaries and the fallopian tubes removed. This is known as a bilateral salpingo-oophorectomy.



Image courtesy of Cancer Research UK / Wikimedia Commons

In some cases, in younger women, there may be a possibility of conserving the ovaries and not removing them during surgery. Your doctor will tell you if this is a possibility.

Lymphadenectomy

You may also have lymph nodes removed or tested to see if there are any cancer cells present.

More commonly, the 'sentinel' lymph nodes are removed. These are the first nodes that the uterus drains into on each side of the pelvis. The sentinel lymph nodes are identified using a special dye injected into the cervix (neck of the uterus) at the start of the operation. Once these are identified they are then removed. Generally, if these nodes are negative for cancer, the other pelvic lymph nodes are negative for cancer.

If the sentinel lymph nodes cannot be identified there may be a need to remove a greater number of lymph nodes in the pelvis. Your doctor will discuss this with you before the operation.

How is surgery done?

The surgery will be performed under general anaesthetic – and can be done in different ways:

Laparoscopy (keyhole surgery)

A laparoscopy or keyhole surgery is done by making small openings (usually 4) in your abdomen or tummy wall. The surgeon will use a laparoscope, which is a thin tube with a light and camera, to help remove the uterus and other organs through the vagina. Sometimes the procedure is robotic assisted. This means a 'robot' type of device helps guide the surgeon during the operation.



Open surgery

Open surgery is where the surgeon removes the uterus and other organs through a cut in the abdomen or tummy wall. Sometimes this cut is made along the pubic line. This type of surgery is also called a laparotomy or abdominal hysterectomy.

Your surgeon will discuss your options and what they think is most appropriate for you. They will also explain the risks and benefits of each. The type of hysterectomy you have will depend on factors such as the size of the tumour, your age, your build and the size of your uterus.

Getting ready for surgery

Your surgical team and specialist nurse will tell you about your surgery. It is natural to feel very anxious about having surgery.

Talk to your doctor or nurse if you are feeling anxious. If there is anything that you do not understand, ask again. Your doctor or nurse will be happy to answer your questions. They will tell you what you can expect after the operation and help you find ways to cope. You can also call our Support Line on 1800 200 700.

Surgical removal of your uterus will mean you are no longer able to get pregnant. This can be difficult to deal with. Talk to your doctor about any fertility concerns you have before treatment starts. They can tell you if there are any options open to you at this time. They can refer you to a specialist fertility centre for advice, counselling and support.

Tests before surgery

Before surgery, patients are usually given an appointment for a pre-operative assessment clinic. You may have some tests to make sure you are strong enough for surgery. These may include blood tests and an ECG heart test. Sometimes an ECHO (heart ultrasound) and pulmonary function (lung/breathing) tests will be needed, depending on your age and general health.

You will also meet the anaesthetic doctor (anaesthetist). These doctors are responsible for putting you asleep for the surgery. If you are a smoker, giving up before your operation will improve the quality of your breathing and reduce the risk of a chest infection after surgery. See page 45 for more on giving up smoking.

Before surgery

You will not be allowed to eat or drink for a few hours before surgery. You may get an anti-clotting injection like heparin and elastic stockings may be put on your legs to prevent blood clots. You will receive anaesthesia before surgery. Anaesthesia is a medical term for different types of medicine that people get before and during surgery and other procedures. These medicines are given to make sure you do not feel pain during the procedure. In some cases, like when you are 'put to sleep' for surgery, the anaesthesia medicine also prevents you from remembering it afterwards.

After surgery

You will wake up in the recovery room before returning to the ward. Occasionally, some patients may require an overnight stay in the high dependency unit (HDU), where the staff will keep you under close observation.

Drips, drains and tubes

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

- You will have a drip in a vein in your arm. You will be given fluids through this until you can drink again.
- You will have an oxygen mask over your face.
- A thin tube called a catheter may be put into your bladder to drain any urine. It is usually removed after 24 hours.

Pain

Following keyhole surgery, you may experience 'wind' type pain or cramps. This is because air is put into the tummy or pelvis during the operation. This pain may radiate to your shoulder and may be quite severe. This is normal. A combination of pain-relieving medication, peppermint water and moving about may help.

With open surgery, you will most likely have some pain – and sometimes feel sick – for the first few days. Your nurse can give you medicine to control the pain and prevent you feeling or getting sick,

if you need it. You may have an epidural tube in your back to relieve pain after the surgery. If you have a patient-controlled analgesia pump (PCA), your nurse will show you how to use it. Always ask for help if you have any pain or feel sick. You will be given a prescription for pain relief when you're discharged from hospital.



Eating and drinking

After keyhole surgery, you will be able to take sips of water or even a light meal later that day. Your drip will be stopped when you are taking enough fluid by mouth. After open surgery it may take a little longer to start normal eating and drinking.

Bladder and bowel function

The bladder can be slow to empty after a hysterectomy. Your surgeon may leave a tube (catheter) in place to drain your bladder for 12-24 hours after keyhole surgery. It may be left in for longer following open surgery.

Following surgery, you may get constipated and you may need to take a laxative for a few weeks or months. See page 60 for more on bladder and bowel side-effects.

Getting up and about

For the first few hours after surgery, while you are in bed, you will be encouraged to move your legs and do deep breathing exercises at least once an hour.

Following keyhole surgery, you will be able to move about that evening or the following morning. With open surgery, you will be slower to move around but the nurses will help and encourage you to get up and about. You may be seen by a physiotherapist to help with exercises.



Recovery period

This will depend on whether you have keyhole surgery or open surgery. After keyhole surgery, you may be ready to go home after 1-2 days. With open surgery, you may be in hospital for 4-5 days. You should avoid strenuous activity (including heavy housework) and driving for 3 weeks following keyhole surgery and 6 weeks following open surgery. Following both types of surgery, you will be encouraged to walk regularly, increasing the time spent walking every day. Your nurse or physiotherapist will discuss this with you in more detail.

It is normal, following both types of surgery, to experience vaginal bleeding or discharge intermittently for about 6-8 weeks. This happens because there are internal stitches at the top of the vagina, which dissolve over a period of a few weeks. After leaving hospital, if you experience heavy vaginal clotting or bleeding or offensive vaginal discharge you should contact your medical team or specialist nurse for advice.

It is normal to experience tiredness as your body recovers from the surgery. You may need to have regular rest periods.

Exercise

It is important to continue with exercises as advised by the physiotherapist or specialist nurse. They will be happy to give specific advice on your individual needs. You should avoid aerobic exercise such as jogging or swimming until healing has taken place.

The physiotherapist or specialist nurse may recommend pelvic floor exercises, as well as leg exercises to reduce your risk of developing swelling (lymphoedema) in your legs in the future. Women who have pelvic lymph nodes removed as part of their surgery are at risk of developing lymphoedema. See page 58 for more on lymphoedema.

Sexual activity

Following surgery, it is advisable not to start having sexual intercourse again for at least 6 weeks, to allow your body to heal.

Following a diagnosis of uterine cancer you may not feel physically or emotionally ready to start having sex for a while. See page 81 for more on how a cancer diagnosis and treatment can impact on your sex life.

Email: supportline@irishcancer.ie

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 hospital. That way, they 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 for a 6-week check-up. If you have a worry or symptom that is causing you concern before your check-up date, contact your doctor, cancer nurse specialist or hospital ward for advice.

Possible side-effects of surgery

Risk of clotting (DVT)

Surgery in your pelvis puts you at risk of clotting in the deep veins of your legs and body. This is called deep venous thrombosis (DVT). You may be given an injection to prevent this. Usually you will have injections for 4 weeks after your surgery, so you or a member of your family will be shown how to give the injection. It is very easy and is given with a very fine needle just under the skin. Keep the injection well away from the surgical wounds. You may also wear special elastic stockings while you are on bed rest. Getting up and about and exercising your legs is most important in preventing DVT.

Infection

You will be at higher risk of infection, such as a urinary tract infection, after the surgery. Antibiotics will be given during your surgery. You may also be prescribed antibiotics after surgery. For the first few weeks, you will have a brown discharge from your vagina. If it gets heavier, foul smelling or if you have bleeding, contact your specialist nurse or doctor for advice.

Lymphoedema

Lymphoedema or swelling in one or both of your legs may happen in the long term if your lymph glands are removed during surgery. When the glands are removed, they can no longer drain away excess fluid in your body, so there may be a build-up of fluid in your legs.

Ask your physiotherapist for more information about lymphoedema or call our Support Line on 1800 200 700. You can also find out more about lymphoedema on our website www.cancer.ie

Infertility

If you have a hysterectomy, you will no longer be able to get pregnant. This can be difficult to deal with and you may need extra support to help you cope.

It can help to talk through your feelings with someone who is a good listener or with a professional counsellor (see page 98). You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre for information and support from a cancer nurse. See more on coping with infertility on page 85.

Early menopause

If your ovaries are removed during surgery, you will get menopausal symptoms. These may include hot flashes, night sweats, dry skin, vaginal dryness, decreased sex drive (low libido), low mood, poor concentration and difficulty in sleeping.

Your doctor may talk to you about medication to lessen the effects of the menopause. Not all women are suitable for hormone replacement therapy following a diagnosis of uterine cancer. See page 79 for more on coping with early menopause.



Bladder and bowel side-effects

With any pelvic surgery there is a risk of damage to the bladder, your ureters (tubes that carry urine) or bowel. If this does happen during surgery your surgeon is usually able to repair it there and then, but in some cases you may need to go back for further surgery.

Bowels may be sluggish immediately after your surgery. Constipation is very common and can take a few days to improve. You may need to take a laxative. Your doctor or nurse will discuss medication to help.



Pathology report



During your surgery, samples of tissue will be taken. The samples will be tested by a doctor, called a pathologist, to give more information about the cancer. The pathology report will show how effective the treatment has been and help your doctors to decide if you need further treatment. Your doctor will talk to you about your test results and future plans for monitoring / treating you at your first follow-up appointment (see page 89 for more on follow-up).

Radiotherapy

- Radiotherapy uses high-energy rays to kill cancer cells.
- You normally have treatment every weekday for a number of weeks – or you may have a much shorter course of radiotherapy.
- Side-effects affect the area being treated.

Radiotherapy is a treatment that uses high-energy rays to kill cancer cells. The aim of radiotherapy is to destroy the cancer cells with as little damage as possible to normal cells. Radiotherapy for uterine cancer may be given:

- Before surgery to shrink the cancer, making it easier to remove. This is called neo-adjuvant treatment.
- After surgery to destroy small amounts of the cancer that may be left. This is called adjuvant treatment.
- With chemotherapy to make the treatment work better. This is called chemoradiation.
- As a palliative treatment if surgery is not possible. Radiotherapy can help to manage symptoms such as bleeding or pain.

Radiotherapy can be given in two ways:

External beam radiotherapy: The radiation comes from machines which aim rays directly at your tumour or the tumour site. The machines are called linear accelerators.

Internal radiotherapy (brachytherapy): The radiation source is placed inside your body – usually inside your vagina – in special applicators on or near your tumour.

You may have either external or internal radiotherapy, or both.

External radiotherapy

Planning your treatment

Radiotherapy must be carefully planned so that the highest dose is given to the tumour area and as little as possible to the nearby cells. You will have a CT scan to pinpoint the area to be treated (this is also called CT planning). The treatment field or area will then be marked carefully on your skin, usually using tiny tattoo dots. The dose of radiation will be decided and tightly controlled for your treatment.

Getting your treatment

During treatment you will first be positioned carefully on a treatment table. Then the machine will move around you so that you receive the precise treatment at different angles. The treatment normally takes several minutes and is painless. Most people receive radiotherapy as outpatients, travelling to the radiotherapy unit each day. For some internal radiotherapy treatments, you may have to stay in hospital for a few days.

How much external radiotherapy do I need?

The course can be several treatments over a number of days or weeks (6-8 weeks) or between 1 and 10 doses for treatment to relieve your symptoms.

External radiotherapy does not make you radioactive. It's completely safe for you to mix with family and friends, including pregnant women and children.

Radiotherapy is given in special cancer treatment centres, so you may have to attend a different hospital from where you had surgery or chemotherapy.

For more information on radiotherapy or a copy of our booklet *Understanding Radiotherapy*, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Possible side-effects of external radiotherapy

Any side-effects tend to affect the area of the body being treated. When the uterus is being treated, the most common side-effects include:

Short term

- Bladder and back passage irritation
- Changes to your bowel habits (constipation or diarrhoea)
- Skin irritation and rashes
- Tiredness (fatigue)
- Loss of hair in genital area
- Nausea and sickness

Longer term

- Blood in your urine or bowel motions
- Narrowing of the vagina
- Infertility
- Lymphoedema (leg swelling)

How severe these side-effects are will vary from person to person, depending on the amount of treatment you receive.

Most side-effects develop during or shortly after your treatment and get better within a few weeks. Late side-effects may develop some time after treatment. Some side-effects are long term or may even be permanent. If you feel unwell or have any other side-effects or symptoms – during or at any time after treatment – tell your doctor, nurse or radiation therapist. For more information on the side-effects of radiotherapy or for a copy of our booklet *Understanding Radiotherapy*, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Internal radiotherapy

With internal radiotherapy (also known as brachytherapy), the radiation source is placed inside your body on or near your tumour. The radiation source is sealed and referred to as an implant.

This treatment gives a high dose of radiation to a small area to kill cancer cells in an area at the top of the vagina called the vaginal vault. A small radioactive source goes into your vagina through a hollow tube (applicator).

Before brachytherapy treatment

The applicator is inserted into the vagina so it will sit against the vaginal vault. This procedure will not be painful but may be a little uncomfortable. You will not need an anaesthetic for this procedure. The treatment will take about an hour. Most of the time is spent on planning the treatment to make sure the right area is being targeted. The treatment itself only takes a couple of minutes to deliver. Once the treatment is completed, the applicator is removed and you can go home.



You may need to come back again for further treatments. Your consultant will decide how many you will need. It is usually between 2 and 4.

Possible side-effects of internal radiotherapy

Short term

- Vaginal and back passage irritation
- Changes to your bowel habits (constipation or diarrhoea)
- Skin irritation and rashes in the area
- Tiredness (fatigue)
- Feeling sick
- Problems passing urine
- Vaginal discharge
- Abdominal (tummy) cramps

These side-effects usually last for 2-4 weeks after treatment.

Longer term

- Early menopause
- Narrowing of the vagina
- Difficulty having sex
- Infertility
- Bladder or bowel problems

These can happen months or even years after treatment. See page 75 for more on managing side-effects of treatment.



Chemotherapy

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

Chemotherapy is a treatment that uses drugs to kill cancer cells. The doctor who specialises in chemotherapy is called a medical oncologist. Chemotherapy is not usually used to treat stage 1 and 2 endometrial cancers.

Chemotherapy drugs may be given:

- Before surgery or radiotherapy to shrink the cancer and reduce the risk of it coming back. This is called neo-adjuvant treatment.
- At the same time as radiotherapy to make the treatment work better (chemoradiotherapy).
- After surgery to reduce the risk of the cancer coming back. This is called adjuvant treatment.
- As a treatment on its own.

How often will I have chemotherapy?

Chemotherapy is given in cycles with a rest period between treatments. For example, you might have a few days of treatment every week for 3 weeks and then a week off. This rest period allows your body time to recover from the side-effects of treatment. The number of treatments and cycles can vary, depending on your cancer type and how well it is responding to treatment.

How is chemotherapy given?

Chemotherapy may be given directly into a vein as an injection and/or through an intravenous infusion (by drip or pump).

It may also be given in tablet form. You may have a central venous access device fitted. This is a thin tube (line) which goes directly into a vein and stays in place until your treatment is over. This saves you having repeated injections. There are different types of central venous access devices, such as ports and PICC lines. Usually, your treatment will be given in the chemotherapy day unit.



What kinds of drugs are used?

There are several chemotherapy drugs used to treat uterine cancer. Your doctor or nurse will discuss your treatment with you. Chemotherapy drugs can be used on their own or in combination with each other.

Understanding your drug treatment



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

If you know the name of your drug, you can visit the Health Products Regulatory Authority's website at www.hpra.ie for information about the drug and possible side-effects.

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

What are the side-effects of chemotherapy?

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

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

Fatigue

Fatigue is where you feel tired and weak and rest does not seem to help. For more information see page 77.



Nausea and vomiting

Chemotherapy can cause nausea (feeling sick) and vomiting (being sick). Always take any anti-sickness medication you are given, even if you don't feel sick, as it can stop the sickness from happening in the first place.

Increased risk of infection

Chemotherapy drugs can make you more likely to get infections by suppressing your immune system. You will be asked to always watch out for signs of infection. These signs include feeling shivery and unwell, having a high or low temperature, having a cough or pain passing urine.

Avoiding infections

If you have a high temperature, or feel unwell (even with a normal temperature), it is very important to call the hospital straight away – never delay. Check with your hospital about the temperature advice to follow.

Anaemia

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

Bleeding and bruising

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

Mouth and throat problems

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

Hair loss (alopecia)

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

Constipation and diarrhoea

Chemotherapy can cause constipation (not having a bowel movement often enough) and diarrhoea (frequent loose or watery bowel movements). Your doctor can give you medication to help with these side-effects, if necessary.

Skin and nail changes

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



Peripheral neuropathy

Some drugs can affect your nerve endings. It's important to tell your doctor if you have numbness, or a tingling or burning sensation in your hands and feet. This is known as peripheral neuropathy.

Changes in kidney or liver function

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

Other side-effects

Other side-effects include headaches, a loss of appetite and an itchy rash or dry skin. For more about fertility see page 85. If you have any other side-effect or symptom that concerns you, tell your doctor or nurse straight away. They will give you advice. For more information on the side-effects of chemotherapy or for a copy of the booklet *Understanding chemotherapy and other cancer drugs*, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also look at our website www.cancer.ie for tips on coping with different side-effects.

Hormone therapy

The two female sex hormones, progesterone and oestrogen, can affect how cancer cells grow in the lining of your uterus. Hormone treatment may be given to help reduce the tumour and control some of your symptoms.

Normally hormone therapy involves tablets or injections of the hormone progesterone.

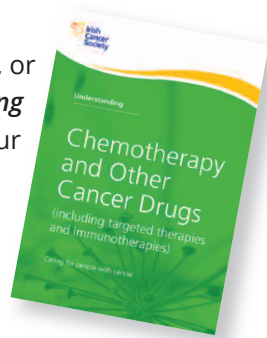
Some women who are unsuitable for surgery may have a contraceptive (Mirena) coil inserted. This releases progesterone which affects the lining of the uterus and helps shrink or control the cancer.

Side-effects are usually mild – weight gain, fluid retention or feeling sick – but let your doctor know if you have any side-effects that are troubling you.

Targeted therapies

Targeted therapies are drugs that target certain parts of cancer cells that make them different from other cells. In other words, they take advantage of differences between normal cells and cancer cells. New targeted therapies are being developed all the time and existing therapies are being used in new ways. You may also be given a targeted therapy as part of a clinical trial (see page 73).

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



Immunotherapy

Immunotherapy drugs help the body's natural defences or immune system to fight cancer cells.

Our immune system can often be the most effective weapon to clear cancer cells from our body. But sometimes cancer cells find a way of hiding from the immune system. This allows a tumour to develop or spread.

Immunotherapy treatment helps your immune system to work better to destroy cancer cells. The side-effects of immunotherapy depend on the drugs being used and vary from person to person. Because immunotherapy acts on the immune system, it can cause inflammation in any part of your body.

Your doctor and nurse will explain your treatment to you in more detail and tell you about any likely side-effects.

Support Line Freephone 1800 200 700

Clinical trials

Clinical trials are research studies that try to find new or better ways of treating or diagnosing tumours or reducing side-effects. They can also help improve a person's quality of life when living with a diagnosis.

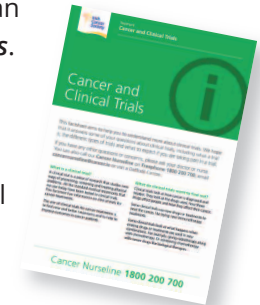
Patients with tumours are sometimes asked to take part in a clinical trial. This means that instead of the standard treatment you get a new trial drug. Or you may be given existing treatments used in different ways. For example, you may be given a different dose of a drug or you may be given two treatments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

Because the drugs are still in trial, you'll be very closely monitored and may have extra tests and appointments.

Trials often investigate very specific features of a particular type of tumour or treatment, so you may not be suitable for a trial. Your doctor can advise you about this.

More information

It's best to talk to your doctor if you're interested in taking part in a clinical trial. For more information, you can read our factsheet ***Cancer and Clinical Trials***. It's available to read or download on our website, www.cancer.ie. You can also get a free copy by calling our Support Line on 1800 200 700 or by dropping into a Daffodil Centre. You can see a list of current cancer trials at www.cancertrials.ie



Email: supportline@irishcancer.ie

Treatment for cancer that has spread (metastatic cancer)

If the cancer spreads to another part of your body, it is called metastatic or secondary cancer. The cancer may be in more than one part of your body when it is first diagnosed. If it has spread it can still be treated. Treatment is usually to try to control the cancer rather than to cure it. There are a range of treatment options for most advanced cancers and new treatments are being developed all the time.

Often metastatic cancer is treated with chemotherapy, immunotherapy or targeted therapies. There may also be treatments that you can have as part of a clinical trial (see page 73).

Thanks to recent advances in research and treatments, many people are living longer with metastatic cancer and with a better quality of life.

You can also have treatment to help with any symptoms. You may be referred to the palliative care team who are experts in managing the symptoms of metastatic cancer.

Palliative care

Palliative care helps you to manage your symptoms and improve your quality of life. Palliative care includes end-of-life care, but your doctor may also recommend palliative care to relieve symptoms earlier in your illness. The palliative care team can include specially trained doctors, nurses, social workers, physiotherapists, occupational therapists, complementary therapists, chaplains and counsellors.

Palliative care can be arranged by your family doctor (GP), public health nurse or by the hospital. Palliative care is a free service for all patients with advanced cancer.

Managing side-effects and symptoms

How can I cope with fatigue?	77
Coping with early menopause	79
Will treatment affect my sex life?	81
Will treatment affect my fertility?	85
Cancer and complementary therapies	86

How can I cope with fatigue?

Fatigue means feeling extremely tired. Fatigue is very common with cancer. Usually, fatigue starts to improve once treatment is over, but it can carry on for some people. Tell your doctor or nurse if fatigue is affecting you so that they can help you.



Fatigue when you have cancer can be caused by many things, including:

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

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

Hints and tips: Fatigue

- **Ask your doctor about exercising.** Being active can help with fatigue. Your doctor may also be able to recommend an exercise programme for you.
- **Plan your days:** Get to know when your energy levels tend to be better. You may have to decide which tasks are important to finish and do them over the course of the day or when you have most energy.
- **Ask for help at work or at home** with any jobs that you find tiring.
- **Try to eat a well-balanced diet.** Eat little and often if your appetite is poor. Our booklet *Diet and Cancer* has tips to help.
- **Try to avoid stress.** Talk to friends and family about any worries you have and take time to enjoy yourself. Counselling may help too (see page 98).
- **If you are not sleeping well, have a good bedtime routine and try relaxation techniques.** Avoid stimulants like caffeine and alcohol in the evening and try not to use electronic devices for an hour before bedtime.
- **Short naps (less than an hour) and rest periods can be helpful,** as long as they don't stop you from sleeping at night.
- **Try complementary therapies** like meditation, acupuncture or massage, if your doctor says they're safe for you.

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

Coping with early menopause

You may experience menopausal symptoms if you have a hysterectomy and removal of your ovaries. You may also have an early menopause following radiotherapy or chemotherapy.

The main menopausal symptoms are:

- Hot flushes/night sweats
- Dry skin and dryness of your vagina
- Lower sex drive
- Mood changes
- General aches and pains
- Poor concentration
- Trouble sleeping (insomnia)

Dealing with menopausal symptoms

Menopausal symptoms can have a big impact on your day-to-day life, especially when you are trying to deal with a cancer diagnosis.

Most of the symptoms can be prevented or reversed by replacing the hormones that your ovaries previously made. Your doctor may prescribe hormone replacement therapy (HRT) following treatment for uterine cancer. However, you may not be suitable for HRT if, for example, you have a family history of breast or ovarian cancer.

If you are not suitable for HRT, you may be at risk of developing osteoporosis (thinning of the bone). In this case, your doctor will give you advice on how to prevent it. This may include taking a calcium and vitamin D supplement.

HRT can be given in different ways. For example, in tablet form or through an implant device put under your skin, or by a slow-release patch worn on your arm or leg. Talk to your nurse if you are having problems with symptoms of menopause.

Other things that may help

- Complementary therapies such as reflexology, massage, meditation and aromatherapy can help relieve menopausal symptoms for some people. Always discuss complementary therapies with your cancer specialist or GP before starting
- Relaxation techniques such as meditation and yoga
- Emotional support from counsellors and support groups

Hints and tips: Coping with hot flashes

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

Will treatment affect my sex life?

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



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

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

There is no set time for you to be ready to have sex again. It varies from person to person. Your doctor will advise if you can have sex while on radiotherapy. But you may find it will be some weeks before you will feel well enough to have sex again after surgery.

Some people fear that cancer can be passed on to a partner during sex. There is no truth to this.

Physical side-effects

Uterine cancer treatments can cause side-effects like vaginal dryness, a narrower or shorter vagina, pain during sex and low sexual desire (low libido). These problems usually improve with time and there are things you can do to help improve these side-effects. If any side-effects are troubling you, talk to your nurse specialist or doctor.



Vaginal dryness

After pelvic radiotherapy your vagina may be drier than before. This can make having sex uncomfortable.

Coping with vaginal dryness

- Vaginal moisturisers can be used regularly to help with vaginal dryness.
- If you experience discomfort during sex, water-based lubricants may help.
- Ask your pharmacist, doctor or nurse about which products are suitable.
- Hormonal creams can also help with vaginal dryness. Your doctor, nurse specialist or pharmacist can give you advice about this.

Shortening/narrowing of the vagina

Your vagina may become shorter or narrower if scar tissue forms after pelvic radiotherapy. This generally happens over a period of time. Also, the walls of the vagina can become less stretchy and drier than before treatment. These changes may make it uncomfortable to have sex. It can make internal examinations more uncomfortable. Internal examinations are an important part of your follow-up care after treatment. Vaginal dilation may prevent the vagina becoming shorter or narrower by preventing scar tissue developing in the vagina. Regular gentle sex can help too. Dilation means 'stretching and opening'.

Your nurse specialist may recommend that you use vaginal dilators to try to prevent these vaginal changes from happening. Dilators are tampon-shaped plastic tubes of different sizes that you use with a lubricant. Or you could use a vibrator. Vibrators tend to be more flexible and come in a larger variety of shapes and sizes.

Your specialist nurse will advise you on how helpful a dilator or vibrator may be in your situation and explain how to use them. You may feel embarrassed or uncomfortable about using them. Talk to your specialist nurse or medical team – they will understand your concerns and will always respect your feelings.

Pain

You may feel tender or sore for a few weeks after surgery or radiotherapy. You may want to avoid sex during this time to allow the area to heal fully and avoid any further damage.

Asking for advice

If you have any questions about how treatment may affect your sex life, you can ask your doctor or nurse specialist. Your doctor and nurse are well used to talking about these matters, so try not to feel embarrassed. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with a cancer nurse in confidence. Or email the nurses at supportline@irishcancer.ie

Hints and tips: Sex after uterine cancer treatment

- **Always speak with your specialist nurse about any concerns you may have about your sex life.** Try not to feel embarrassed. The nurse will be happy to talk to you and give you advice.
- **Lubricants can be used during sex** to make it more comfortable and pleasurable.
- **Vaginal dilation means gently stretching and opening the vagina.** This can help to prevent the vagina becoming shorter and narrower.
- **Dilation can be done by regular use of a dilator, vibrator or regular gentle sex.**
- **It may be useful to become more aware of your vaginal muscles and learn how to relax your muscles** when you are having sexual intercourse.
- **If having sex is uncomfortable, try different positions.** Lying on your side or having your partner underneath you may be easier.

Will treatment affect my fertility?

Your fertility will be affected if you have a hysterectomy or radiotherapy. You will not be able to become pregnant after these treatments. Discuss any worries you have about infertility with your doctor before treatment starts. They can tell you about the options open to you at this time.

Dealing with infertility can be as hard as dealing with a cancer diagnosis for some women. Feelings of anger, grief, sadness and loss of identity are common 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 help to talk to your nurse or doctor. Do not be afraid to ask for help in dealing with this matter. Your doctor may arrange for you to speak to a trained counsellor or an oncology fertility specialist.

You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre for information and support from a cancer nurse.



Cancer and complementary therapies

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

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

It's very important to talk to your doctor if you're thinking of using complementary therapies. Some can interfere with your treatment or be harmful to you, even if you have used them safely before your diagnosis.

Integrative care

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

What's the difference between complementary and alternative therapies?

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

Alternative therapies are used **instead of** standard medical care. Modern medical treatments are very effective. An unproven alternative could harm your health, or you might miss out on a treatment that could really help you.

More information

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

After treatment

What follow-up will I need?	89
Life after treatment	91
Living a healthy lifestyle	92
Planning ahead	93

What follow-up will I need?

After your cancer treatment has ended, you will still need to go back to the hospital for regular check-ups. This is called follow-up. Your gynae-oncology team will discuss your follow-up with you. How often and the type of follow-up will depend on the type and stage of your uterine cancer.



The follow-up is often shared between the teams that have treated your cancer. This may be the surgical team as well as the radiation oncologist and/or medical oncologist.

The purpose of follow-up is to:

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

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

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

For some patients, follow-up may involve consultations over the phone; for others, they may need to go to the hospital for clinical assessment. Follow-up tests can include blood tests and imaging tests such as X-rays or CT scans.

There may be a combination of phone consultations and outpatient visits. You will be told about the symptoms you should be alert to, so you can report them to your doctor or specialist nurse.

The 'alert symptoms' are:

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

If you're between check-ups and have a symptom or problem that's worrying you, call your specialist nurse for advice or to arrange an earlier outpatient appointment, if necessary. Go to your GP if you're unwell and you can't contact the hospital team, or attend the hospital's emergency department if necessary.



Life after treatment

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

Feelings you may have include:

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

There is more about how to cope with these feelings and adjusting to life after treatment on our website www.cancer.ie

You can also call our Support Line or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 99 for other ways to get emotional support.

After-treatment workshops

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

Living a healthy lifestyle

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

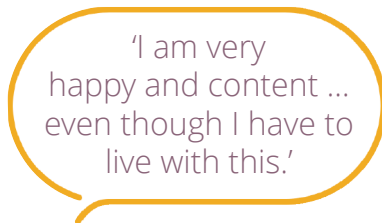
- Feel better
- Heal and recover faster
- Keep up your energy and strength
- Cope better with the side-effects of treatment
- Reduce your risk of further illness

A healthy lifestyle includes:

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

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

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



What if the cancer comes back?

If cancer does come back, it can often be treated again. Your cancer doctor will advise you on your treatment options.

Planning ahead

Many people find it puts their mind at rest to have medical plans in place and sort out legal and practical matters, even though they still hope to live for a long time. Planning ahead enables people to concentrate on their illness and its treatment knowing that their wishes and desires are clearly documented should a need arise.

Planning ahead might include:

- **Thinking about how you feel about different types of medical treatment**, including if you want to stop treatment at any stage or carry on for as long as possible.
- **Writing an advance care directive**. This is where you can write down your wishes about your medical care. Doctors can use this if you are not well enough to say what you want.
- **Picking someone to make medical decisions for you** if you are not well enough.
- **Making a will**.
- **Talking about what you want** to your family, friends, carers and healthcare providers.
- **Sorting financial affairs**.

Who can help me plan?

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





Coping and emotions

How can I cope with my feelings?	97
Ways to get emotional support	99
You and your family	101

How can I cope with my feelings?



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

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

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

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

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

Anxiety and depression

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

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

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

Counselling

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

The Irish Cancer Society funds one-to-one counselling through many local cancer support centres. To find out more about counselling call our Support Line on Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at supportline@irishcancer.ie

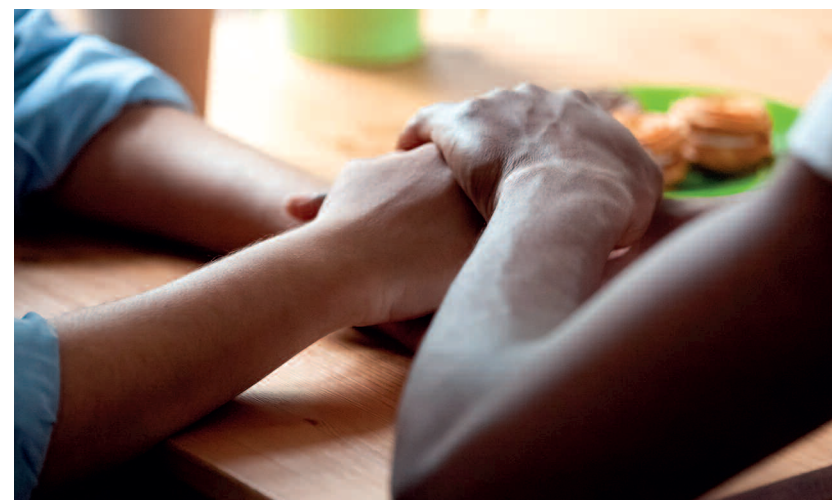
A list of counsellors funded by the Irish Cancer Society is available at www.cancer.ie

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

Positive feelings

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

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



Ways to get emotional support

Find out about support services in your area: Most provide a range of helpful services like counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 122 for more about cancer support services.

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

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

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

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

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



You and your family

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

If you or your family members need more support or advice, speak to the medical social worker at the hospital or get in touch with one of our cancer nurses. Call us on 1800 200 700 or visit a Daffodil Centre.

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

Talking to children and teenagers

Saying nothing

You may feel it's best not to tell your children anything. You may be worried about what to say or how they will react. But children and teenagers can often sense that there is a problem. If no one explains to them why things have changed, they may imagine something worse or blame themselves. By talking openly, you can answer their questions and help them to cope with their emotions.

How to tell your children

It's best that you or your partner tell your children about your cancer diagnosis. How you discuss your cancer and treatment with them will depend on their age and character. Your specialist nurse and our cancer nurses can also support you if you have children and aren't sure what to say to them. You could also read our booklet *Talking to Children about Cancer*, which has practical advice about how to talk to children of different ages. It also has information on supporting children and teenagers and helping them to deal with their emotions. The booklet is available free of charge from Daffodil Centres or by calling our Support Line. It's also available on our website www.cancer.ie.



Further information and support

If you want more advice and support, you can ask your nurse or medical social worker. Or call our Support Line on 1800 200 700 or visit a Daffodil Centre to talk to a cancer nurse in confidence.

Supporting someone with cancer

Supporting someone with cancer	105
How to talk to someone with cancer	106
Support for you	107



Supporting someone with cancer



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

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

Learn about cancer

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

Share worries

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

Be kind to yourself

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

Try counselling

You might find it helpful to talk to a counsellor. The Irish Cancer Society funds free one-to-one counselling for friends and family members through many local cancer support centres. Talk to your GP or see page 98.

Find out about support for carers

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

How to talk to someone with cancer



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

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

Support for you



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

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

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

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



'The emotional support I got made a huge difference to me.'

Support Line Freephone 1800 200 700



Support resources

Money matters	111
Irish Cancer Society services	115
Local cancer support services	122

Money matters

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

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

Practical and financial advice from the Irish Cancer Society



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

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

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

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

Medical expenses

Medical expenses that you might have to pay include:

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

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

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

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

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

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

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

Email: supportline@irishcancer.ie

Benefits and allowances

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

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

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

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



If you have money problems

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

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 119 for more details of our Volunteer Driver Service and the Travel2Care fund.

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

Money and finances

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

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

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

Support Line Freephone 1800 200 700

Irish Cancer Society services

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

- **Support Line**
- **Daffodil Centres**
- **Telephone interpreting service**
- **Peer Support**
- **Psychological support services**
- **Patient travel and financial grants**
- **Night nursing**
- **Publications and website information**
- **Support in your area**
- **Practical support and financial solution services (see page 111)**

Support Line Freephone 1800 200 700

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

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



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

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

Daffodil Centres

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



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

Who can use the Daffodil Centres?

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

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

Telephone Interpreting Service

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

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

Peer Support Programme

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

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



Email: supportline@irishcancer.ie

Psychological Support Services

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

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

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

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

Support in your area

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

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



Patient travel and financial grants

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

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

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



Irish Cancer Society Night Nursing

We provide end-of-life care for cancer patients in their own homes. 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 a unique service in Ireland, providing palliative nursing care at night between 11pm and 7am to cancer patients.



The health professional who is looking after your loved one can request a night nurse for you, so talk to your palliative care team member, GP or public health nurse about this.

Support Line Freephone 1800 200 700

Publications and website information

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



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

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

Local cancer support services

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

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

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

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



What does that word mean?

Bilateral An operation to remove both ovaries and the fallopian tubes.

Benign Not cancer.

Biopsy The removal of a small amount of tissue from your uterus to find out if abnormal cells are present.

Cervix The neck of the uterus at the top of the vagina.

Chemotherapy A treatment that uses drugs to cure or control cancer.

Cytology The study of cells under a microscope.

Gynaecologist A doctor who specialises in treating diseases of the female reproductive system (uterus, vagina and ovaries).

Hysterectomy An operation to remove your uterus.

Hysteroscopy A test that allows your doctor to look inside your uterus and take tissue samples (biopsy).

Lymphadenectomy An operation to remove lymph nodes to see if the cancer has spread.

Malignant Cancer.

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

Pelvis The lower part of your abdomen, found between your hip bones. It contains your uterus, ovaries, bladder and bowels as well as lymph nodes.

Precancerous Abnormal changes which are not cancer. But if left untreated they may become cancerous over time.

Radioactive source A radioactive material that gives off high-energy rays. These rays can kill cancer cells.

Radiotherapy A treatment that uses high-energy X-rays to cure or control cancer and other diseases.

Speculum An instrument used by a doctor or nurse to keep your vagina open so that it is easier to examine you.

Total hysterectomy An operation to remove your uterus and cervix.



Support Line Freephone 1800 200 700

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?

Will I have to stay in hospital for the tests?

How long will I have to wait for the test results?

What stage is my cancer at?

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

What type of treatment do I need?

How successful is this treatment for my cancer?

Are there other treatment options?

How long will treatment last?

What are the risks and possible side-effects of treatment?

Who do I contact if I have a problem when I go home?

What support services are available to help me cope with my cancer?

Notes/questions

Acknowledgments

This booklet has been produced by the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible.

UTERINE CANCER ADVISERS

Dr Razia Aslam, Consultant Gynaecological Oncologist
Sarah Mahony, Gynaecology Clinical Nurse Specialist

CONTRIBUTOR

Linda Wilson, Daffodil Centre Nurse

EDITORS

Claire McGinn and Deborah Colgan

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

- *ESGO/ESTRO/ESP guidelines for the management of patients with endometrial carcinoma*, Nicole Concin and others. *Int J Gynecol Cancer* 2021; 31:12–39.
- www.thisisgo.ie/articles/hormonal-treatment-of-uterine-cancer
- www.thisisgo.ie/articles/surgery-for-uterine-cancer
- *National Cancer Strategy 2017-2026*, National Cancer Control Programme
- *Cancer in Ireland 1994-2017 with estimates for 2017-2019*: Annual report of the National Cancer Registry (2019)
- *Cancer Nursing: Principles and Practice*, CH Yarbrow, MH Frogge, M Goodman & SL Groenwald. Jones and Bartlett, 7th Ed (2011)
- *The Chemotherapy Source Book*, M Perry. Lippincott Williams and Wilkins, 5th Ed (2012)

Published in Ireland by the Irish Cancer Society.

© Irish Cancer Society, 2020, 2023

Next revision: 2025

The Irish Cancer Society is a registered charity, number CHY5863.

Product or brand names that appear in this booklet are for example only. The Irish Cancer Society does not endorse any specific product or brand. All rights reserved. No part of this publication may be reproduced or transmitted, in any form or by any means, electronic or mechanical, including photocopying, recording or any information storage and retrieval system, without permission in writing from the Irish Cancer Society.

Join the Irish Cancer Society team

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

Support people affected by cancer

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

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

Share your experiences

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

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

Raise money

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

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

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

Did you like this booklet?

We would love to hear your comments or suggestions.

Please email reviewers@irishcancer.ie

Irish Cancer Society

43/45 Northumberland Road, Dublin 4, D04 VX65

T: 01 231 0500

E: info@irishcancer.ie

W: www.cancer.ie

Support Line Freephone 1800 200 700

Email: supportline@irishcancer.ie

Find us on Facebook

Follow us on Twitter: @IrishCancerSoc

