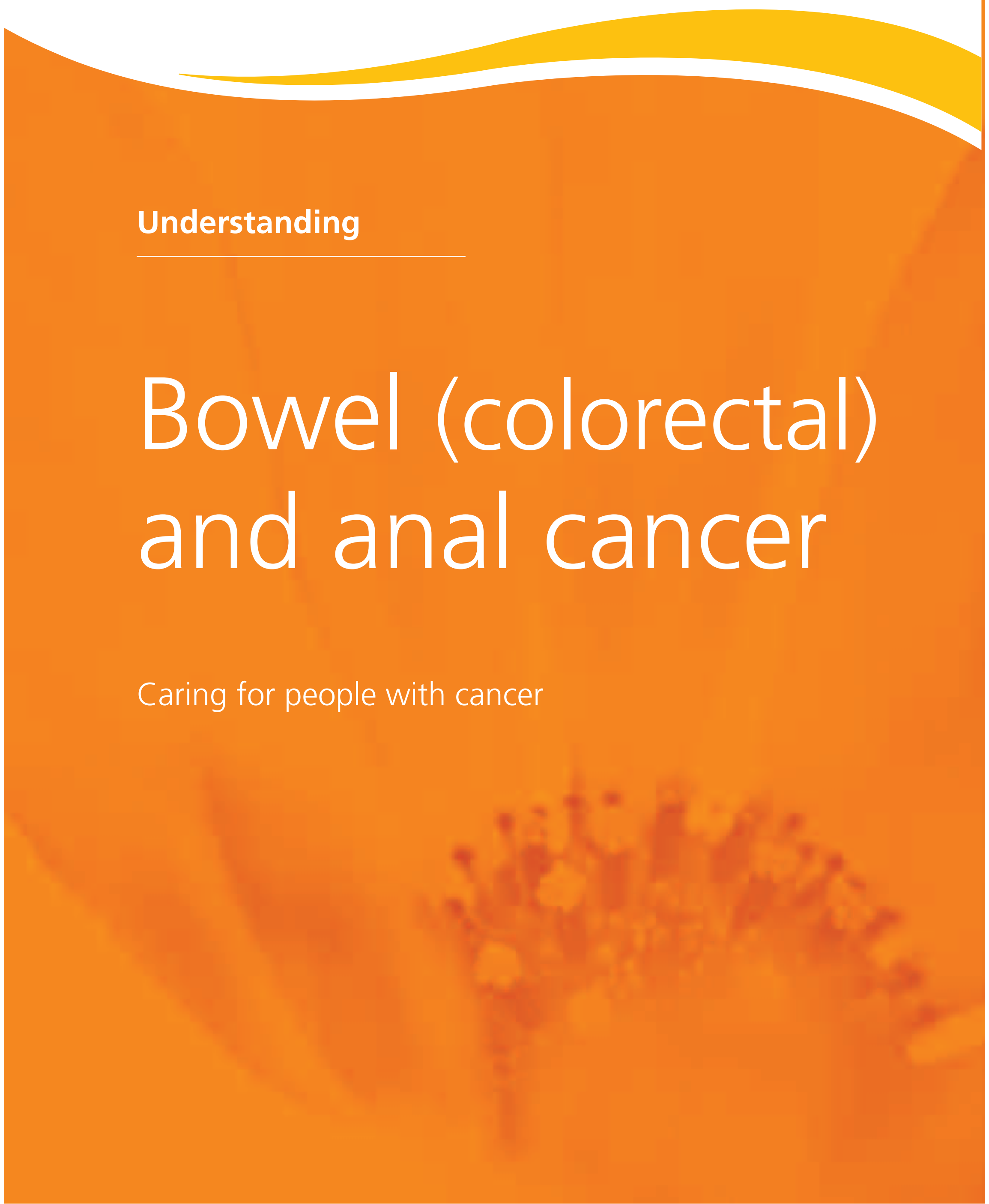
Irish
Cancer
Society



Understanding

Bowel (colorectal) and anal cancer

Caring for people with cancer

Understanding

Bowel (colorectal) cancer and anal cancer

This booklet has information on:

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

Useful numbers

Specialist nurse

Surgeon

Medical oncologist

Radiation oncologist

Radiation therapist

Stoma / colorectal nurse specialist

Medical social worker

Family doctor (GP)

Emergency

Hospital records number (MRN)

Contents

Fast facts

Can my cancer be treated?

Yes. There are treatments for all stages of cancer, and new treatments are being developed all the time. Your doctor will discuss with you what treatments will be of most benefit to you. See page 27 for bowel cancer treatments and page 32 for anal cancer treatments.

Will I be OK? Page 19

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 can talk to you about what is likely to happen in your situation.

What treatments are used? Page 47

Surgery: An operation to remove the cancer (see page 49).

Chemotherapy: Drugs to slow down and control the growth of cancer (see page 56).

Radiotherapy: Using high-energy rays to kill cancer cells and shrink tumours (see page 65).

Chemoradiation: Having radiotherapy and chemotherapy together.

Targeted therapies: Drugs to stop the cancer growing. Usually used to treat bowel cancer that has spread or come back after treatment (see page 63).

Will I get side-effects? Page 87

Most treatments cause some side-effects, but these usually get better after treatment has ended. If you have surgery, an opening (stoma) is sometimes made in your tummy and your poo will pass through this opening into a bag worn outside your body. It's usually temporary but may be permanent, depending on the surgery you have.

Read about the different treatments to learn more about their possible side-effects.

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

Clinical trials Page 70

Clinical trials are when cancer patients get a new type of treatment to see if it works better than existing treatments. Ask your consultant if there are any trials suitable for you.

We're here for you Page 122

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 Cancer Nurseline on 1800 200 700
- Drop in to a Daffodil Centre
- Email us: **cancernurseline@irishcancer.ie**

See page 122 for more about our services.

Reading this booklet

This booklet is for anyone dealing with a diagnosis of bowel (colorectal) or anal cancer. For information about your specific cancer type see:

Pages 23–28 for information about **bowel cancer**

Pages 31–33 for information about **anal cancer**

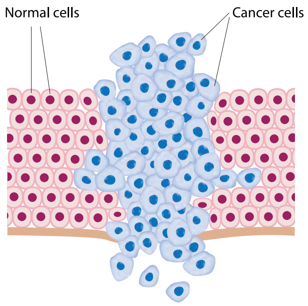
If you need more information or don't understand something, ask your doctor or nurse. You can also ask one of our cancer nurses:

- Call our Cancer Nurseline on Freephone 1800 200 700
- Visit a Daffodil Centre
- Email the nurses at **cancernurseline@irishcancer.ie**

We cannot give advice about the best treatment for you. Talk to your hospital team about your treatment and care – they know your medical history and your individual circumstances.

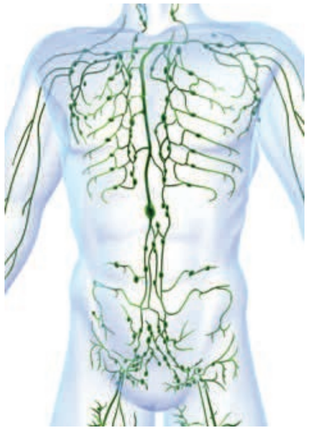
About cancer

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**
  Colon cancer starts in cells in your colon. Rectal cancer starts in cells in your rectum. Anal cancer starts in cells in your anus.
- **Cancers sometimes spread**
  If a tumour is cancerous (malignant), a cell or group of cells can be carried by your blood or lymph fluid to another part of your body, where it can form a new tumour. This is called metastasis.

What is the lymphatic system?



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

What causes cancer?

We don't know exactly what causes many cancers. However, 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 bowel cancer and anal cancer, see our website **www.cancer.ie** or talk to a cancer nurse – call our Cancer Nurseline or visit a Daffodil Centre.

Genetic testing

If there is a history of bowel conditions or bowel cancer in your family, your family may be offered genetic testing. This can check for inherited gene changes that may increase the risk of cancer or other conditions. Ask your medical team about this.

Diagnosis and tests

Being diagnosed with cancer

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

- **Confused** by all the information being given to you
- **Worried** about what will happen next
- **Upset** and overwhelmed by your emotions. See page 103 for more about managing your emotions.

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

- Ask to speak to the cancer liaison nurse or 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 Cancer Nurseline on 1800 200 700. You can email the nurses at **cancernurseline@irishcancer.ie**
- Speak to an Irish Cancer Society Survivor Support volunteer who has had a cancer diagnosis and really knows what you are going through. Our cancer nurses can put you in touch with a volunteer.
- Talk to other people going through the same thing. Join our online community at **www.cancer.ie/community**
- Go to your local cancer support centre. For more information, see page 128.

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

Telling people about your diagnosis

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

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

What tests will I have?

- Tests after diagnosis will tell your medical team more about your cancer and help them to decide on the best treatment for you.
- Tests you may have include MRI scan, CT scan, PET scan and ultrasound scan.
- Some tests may also be used to see how well you are responding to treatment.

The following tests give doctors more information about your cancer. Your doctor will tell you which tests you need.

MRI scan of pelvis

This is a scan that uses magnetic energy to build up a picture of the tissues inside your pelvis. The pelvis is the lower part of your abdomen between your hipbones. This type of scan is usually used for rectal or anal cancer.

During the scan you will lie inside a tunnel-like machine. Some people are afraid they will feel claustrophobic during the MRI scan. Tell the radiation therapist if you're feeling anxious. An MRI can also be noisy, but you will be given earplugs to wear. 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. You shouldn't need to stay in hospital.

CT scan (CAT scan) of chest, abdomen and pelvis

This is a special type of X-ray that builds up a detailed picture of your chest, abdomen and pelvis.

You might be asked to fast (not eat) for a few hours before the test. You may be given a special drink or injection to help show up parts of your body on the scan.

During the scan you will lie on a table which passes through a large ring-shaped machine. Your head won't be closed in — the scanner is open on both sides. The scan is painless and takes between 10 and 30 minutes. You should be able to go home as soon as the scan is over.

Ultrasound scan of abdomen or back passage

A picture is built up of the tissues inside your body using sound waves. First a gel is spread on the area to be scanned. A small device like a microphone is passed over the area (or into the back passage for an anorectal scan). A picture is then made by a computer.

An anorectal ultrasound can be uncomfortable or may cause you some pain, depending on where the tumour is. You may need to have an enema to clear out your back passage before an anorectal scan. This is a liquid-filled pouch with a nozzle on the end. You put the nozzle into your back passage and squeeze so that the liquid goes into your body.

PET scan

A PET scan can show if the cancer has spread to other tissues and organs. A low dose of radioactive sugar is injected into your arm. An hour or so later you will have a scan. The radioactivity can 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) for a few hours. PET is safe to use and there are no side-effects.

CEA test

This is a blood test that can look for substances in your blood produced by the cancer. It can be used to show how well your cancer is responding to treatment as part of your follow-up care.

Waiting for test results

It usually takes a week or two for all the test results to come back. Naturally, this can be an anxious time for you.

It may help to talk things over with the specialist nurse, or with a relative or close friend. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to one of our cancer nurses.

Staging cancer

- Staging cancer means finding out its size and if it has spread.
- 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.

Staging describes **how big the cancer is and where it is** in your body.

Knowing the stage of your cancer is very important, as it helps your doctor to decide the best treatment for you.

What is TNM staging?

There are different ways to describe the stages of cancer.
The staging system normally used is called TNM. This stands for:

Tumour (T)

How deeply the tumour has grown into your bowel or anus.

Nodes (N)

If there is cancer in your lymph nodes. N0 means no lymph nodes affected, N1 means one lymph node is affected and N2 means more than 4 nodes affected.

Metastasis (M)

If the cancer has spread to other parts of your body. M1 means the cancer has spread and M0 means it hasn't.

Your doctor often uses this information to give your cancer a number stage – from 1 to 4.

In general, the lower the number, the less the cancer has spread. See page 26 for more about bowel cancer stages and page 31 for more about anal cancer stages.

Asking about your prognosis

Your prognosis is information about how your disease is likely to progress, including average survival times for your type of cancer (life expectancy). Many people with cancer have questions about their prognosis.

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

Should I ask about my prognosis?

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

If you decide you want information on your prognosis:

- **Think carefully about how you will cope with the information** before asking for your prognosis.
- **Get information on prognosis from your doctor.** They know your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- **Ask a friend or family member to go with you** if you would like some support.
- **Be careful with online information.** It may be hard to understand or even 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.
- **Get emotional support if you need it.** 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 Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or email **cancernurseline@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.

About bowel cancer

What is the large bowel (colon and rectum)?

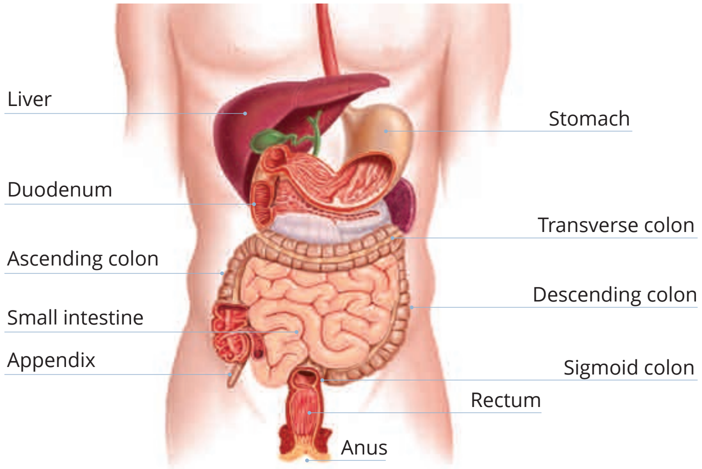
The bowel is part of your digestive system. It can be divided into 2 parts:

The small bowel: This is made up of the duodenum, the jejunum and the ileum. Cancer rarely happens in the small bowel.

The large bowel: This is made up of the colon, rectum and anus. The colon is about 5 feet long. It is divided into 4 sections: ascending colon, transverse colon, descending colon and sigmoid colon.

When you eat, the food goes into your stomach and passes through into the small bowel, which takes in nutrients from the digested food. It passes into the large bowel which absorbs water and salts.

The waste matter that is left is stored in your rectum (back passage) until ready to pass out of your body through your anus. This waste material is known as poo, faeces or stools.



The digestive system

What is bowel cancer?

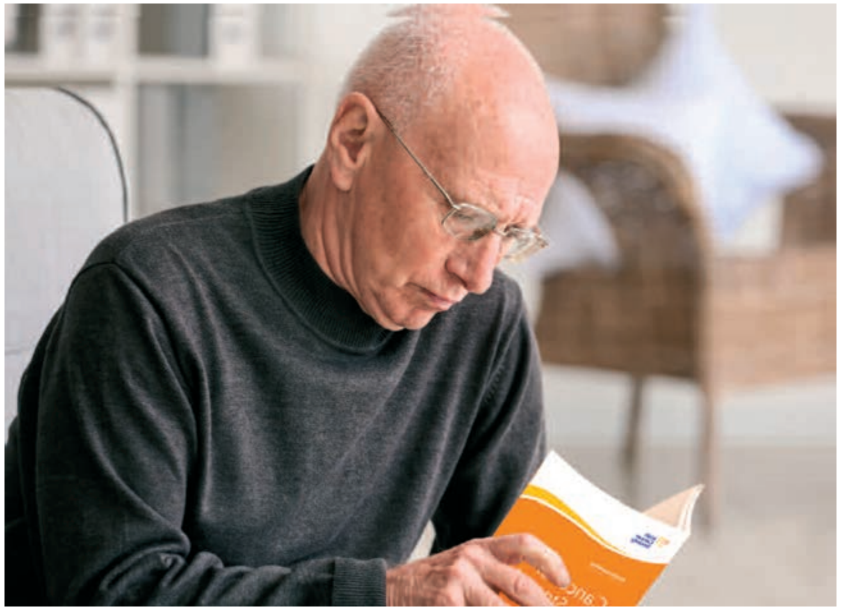
When cancer happens, cells in your bowel change and start to grow faster than normal.

- **Colon cancer** may cause a hold-up or even a blockage in your bowel, which can affect how your bowel works.
- **Cancer of the rectum (rectal cancer)** is found very low down in your bowel close to your anus. It can be treated differently to cancer of the colon.

Some bowel cancers cause no symptoms at all.

How common is bowel cancer?

Bowel cancer is one of the most common cancers in Ireland. Around 2,500 people are diagnosed with bowel cancer every year.



What happens after diagnosis?

Bowel cancer care pathway

Staging
Scans and other tests to find out where the cancer is and if it has spread. This helps doctors plan the best treatment for you.

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Treatment
Often surgery, especially for early-stage bowel cancer.

Treatment before surgery: You may have another treatment like chemotherapy or radiotherapy to shrink the cancer (more common with rectal cancer).

Treatment after surgery: You may have chemotherapy or another treatment to reduce the chance of the cancer coming back or to control cancer that has spread.

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Follow up
You will visit the hospital regularly after treatment so your doctors can check how you are.

What are the stages of bowel cancer?

Stage 1

The cancer is in the inner wall of your colon or rectum only. There's no cancer in the lymph nodes. (T1 or T2, N0, M0)

Stage 2

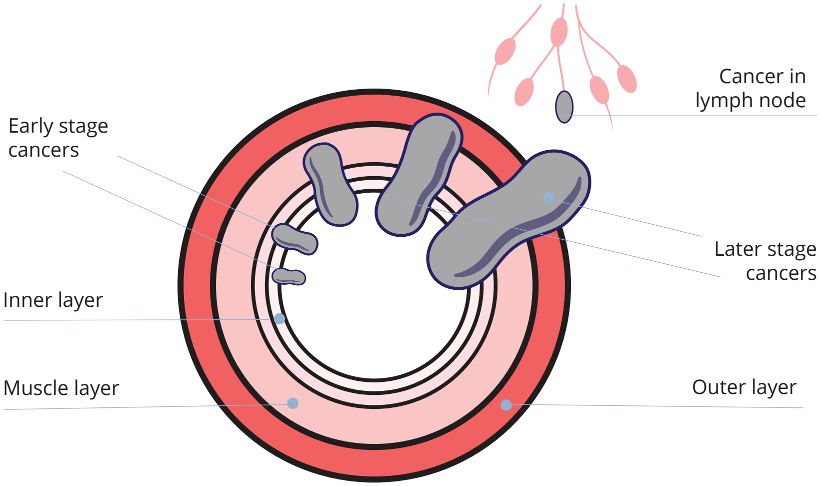
The cancer is in the muscle layer of your colon or rectum or has grown through the muscle layer into nearby tissues. (T3 or T4, N0, M0)

Stage 3

The cancer has spread to nearby lymph nodes. (Any T, N1 or N2, M0)

Stage 4

The cancer has spread to other parts of your body, for example your liver or lungs. It is advanced. (Any T, any N, M1)



Staging can be hard to understand, so ask your doctor and nurse for more information if you need it.

How is bowel cancer treated?

- Surgery is the main treatment for bowel cancer.
- Chemotherapy and radiotherapy may be used before surgery to shrink the tumour, especially with rectal cancer.
- Targeted therapies and chemotherapy may be used to treat cancer that has spread.
- A team of healthcare professionals will be looking after you (multidisciplinary team).

The type of treatment you have will depend on:

- The size of the tumour
- Where the cancer is in your body
- If it has spread to your lymph nodes or other parts of your body
- Your general health

Types of treatment

Surgery

Surgery is the main treatment for cancer in the colon or rectum. Surgery can often cure the cancer, if it's found early. See page 49 for more details on surgery.

Chemoradiation

This means having chemotherapy and radiotherapy together. Chemoradiation can be used before or after surgery for rectal cancer to reduce the risk of the cancer coming back. It can also help to shrink the cancer before surgery. Chemoradiation is the main treatment for anal cancer (see page 32). See page 56 for more about chemotherapy and page 65 for more about radiotherapy.

Chemotherapy

You might have chemotherapy after surgery to reduce the risk of the cancer coming back. It's also used to treat cancer that has spread. See page 56 for more about chemotherapy.

Radiotherapy

Radiotherapy can be used before or after surgery for rectal cancer to reduce the risk of the cancer coming back. It can also help to shrink the cancer before surgery. Radiotherapy may also be used to relieve symptoms if the cancer has spread. This is called palliative radiotherapy. See page 65 for more about radiotherapy.

Targeted therapies

These are drugs that work by stopping cancer cells growing or spreading. They may be given if the cancer has spread to nearby tissues or other parts of the body (metastatic cancer). See page 63 for more details.

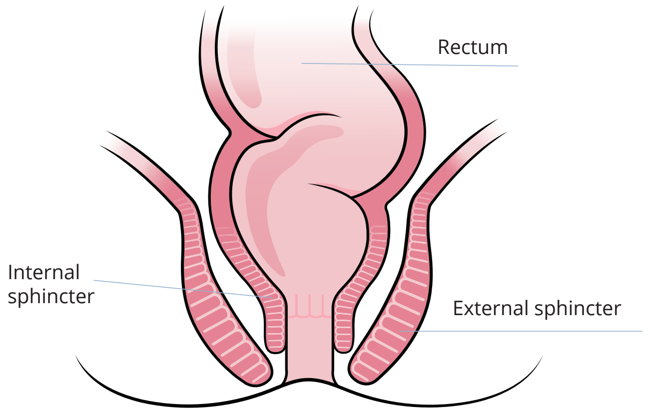
Treatment planning

See page 35 for information on treatment planning, what happens at the hospital and how you can prepare for treatment.

About anal cancer

What is anal cancer?

Anal cancer affects the anus. The anus is the opening below the rectum where waste food passes out of your body as stools (poo).



Staging anal cancer

The stage of cancer describes where the cancer is and how big it is. You will probably have a CT or MRI scan to stage your cancer (see page 15 for more about staging tests).

Stage 1: The cancer only affects your anal area and is smaller than 2cm.

Stage 2: The cancer only affects your anal area but is bigger than 2cm.

Stage 3: The cancer has spread to nearby lymph nodes.

Stage 4: The cancer has spread to other parts of your body, for example, your liver. This can also be called advanced or metastatic cancer.

Knowing the stage of your cancer helps your doctor to plan the best treatment for you.

How is anal cancer treated?

Chemoradiation (chemotherapy and radiotherapy together)

Chemoradiation is the main treatment for anal cancer. The chemotherapy drugs help the radiotherapy to work better. Often you will have radiotherapy every week day for 4-6 weeks along with chemotherapy drugs. You may have to go to different departments for your chemotherapy and radiotherapy, Your medical team will organise this for you and tell you where you need to go.

Chemotherapy drugs are usually given into a vein, but some may be in tablet form.

Chemoradiation is usually very successful at treating anal cancer.

You may also have chemotherapy drugs or radiation treatment alone. See page 56 for more about chemotherapy and page 65 for more about radiotherapy.

Side-effects of chemoradiation

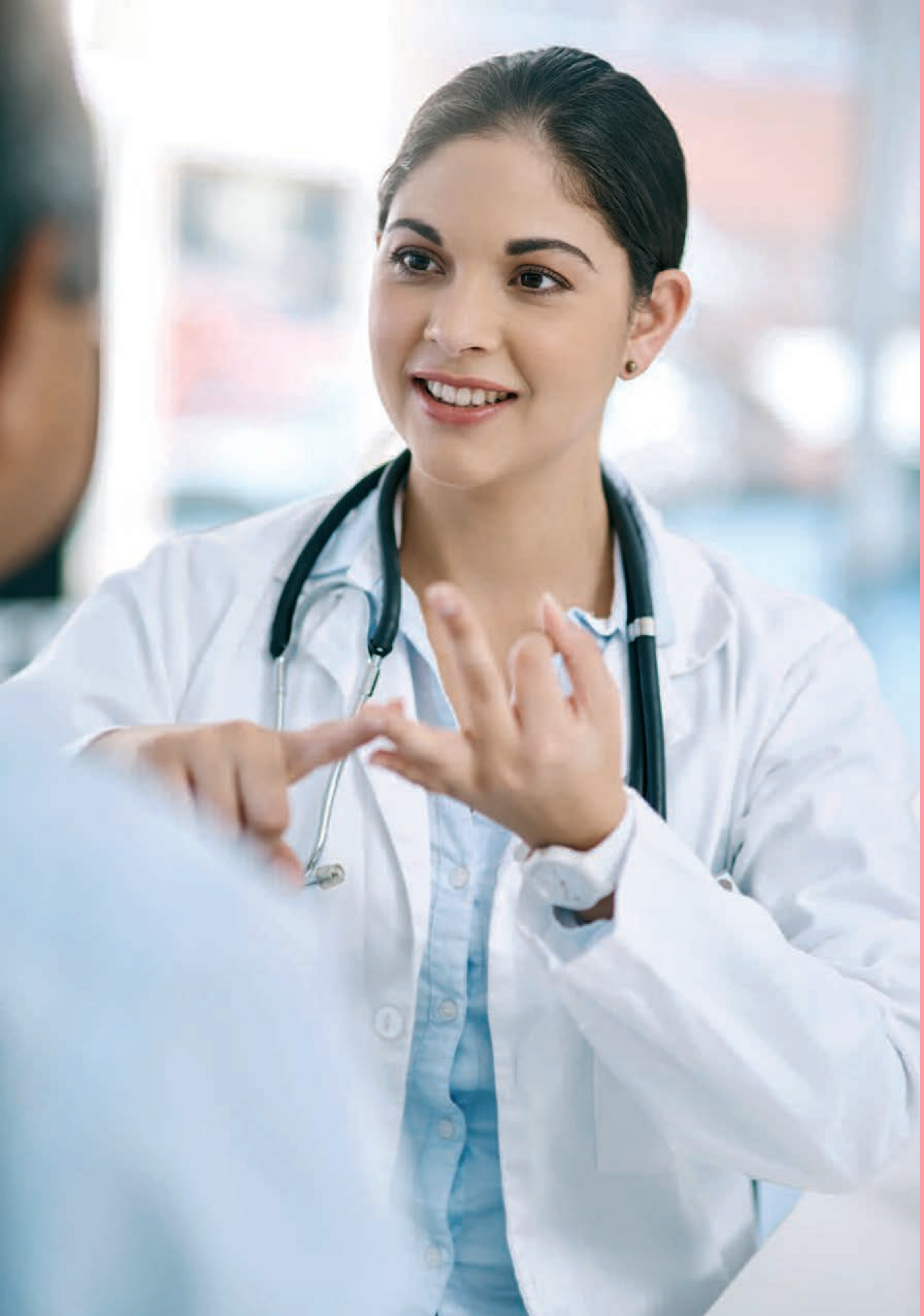
With chemoradiation you can get both radiotherapy and chemotherapy side-effects. For example, skin soreness in the area, fatigue and diarrhoea. Having both treatments together can make any side-effects worse. Most side-effects get better in the weeks and months after treatment. See page 68 for more about radiotherapy side-effects and page 59 for chemotherapy side-effects. If you are bothered by any side-effects or you're worried about anything – at any time during or after treatment – talk to your medical team. We also have information on coping with side-effects on our website, **www.cancer.ie**

Surgery

If your cancer is not fully gone after chemoradiation, you may need some surgery. There are two main types of surgery:

- **Local resection:** This surgery is used for small tumours. It only removes the area where the cancer cells are found.
- **Abdominoperineal resection:** This is where your anus and rectum are removed. Having this surgery means that you will have a permanent colostomy.

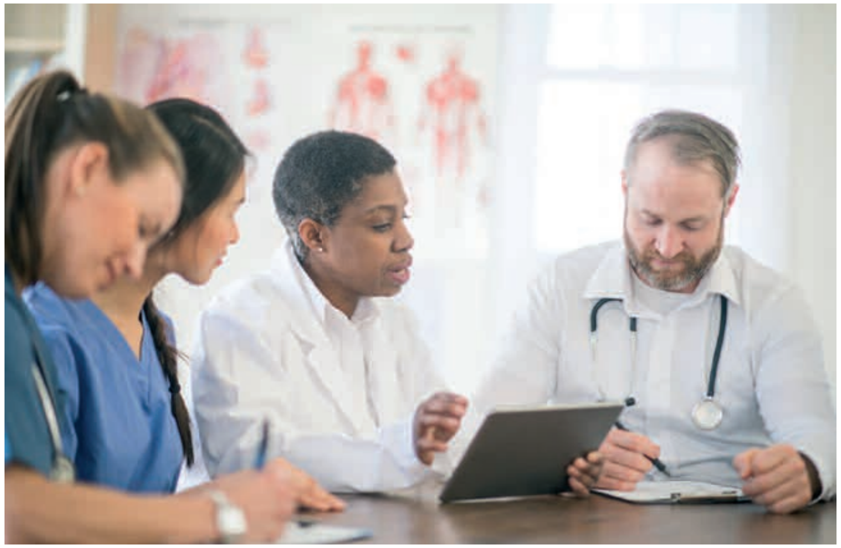
A colostomy is an opening of the large bowel on the surface of your abdomen. Poo passes through this opening and is collected in a bag. There's more information on page 73.



Starting treatment

Specialist centres

Cancer is treated in specialist cancer centres in Ireland. You may be transferred to a specialist cancer centre in a different hospital from the one where you received your diagnosis, depending on your diagnosis and your suggested treatment plan.



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 colorectal surgeon, specialist nurse, radiologist and oncologist (cancer doctor). The team will meet to discuss your test results and decide your treatment plan.

Understanding treatment

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

Ask as many questions as you need to. You could use the fill-in page at the back of this booklet for your questions and answers. If you forget to ask a question or would like more explanations, ask your specialist nurse. You can also talk to one of our cancer nurses – call our Cancer Nurseline 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 your treatment, if you are unsure when it is first explained to you.

Second opinion

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

Accepting treatment

You have the right to find out what a treatment option means for you, and the right to accept or refuse it. If you 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're fully aware of the benefits and risks.

Who will be involved in my care?

Usually a team of healthcare professionals will be involved in your care.

Surgeon

A doctor who specialises in surgery and who can remove tumours.

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 specially trained person who delivers radiotherapy and gives advice to cancer patients about their radiation treatment.

Oncology liaison nurse / Clinical nurse specialist

A specially trained nurse who works in a cancer care unit. She or he gives information and reassurance to you and your family from diagnosis and throughout your treatment.

Stoma/colorectal clinical nurse specialist

A nurse who is a specialist in the care of patients with bowel function problems.

Pathologist

A doctor who examines cells to diagnose cancer and examines the tumour specimens removed during surgery.

Dietitian

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

Physiotherapist

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

Occupational therapist (OT)

A therapist who specialises in helping people who are ill or disabled learn to manage their daily activities.

Medical social worker

A person trained to help you and your family with any social issues and practical needs. They can give counselling and emotional support. They can also give advice on social welfare benefits, financial matters and practical supports and services available to you from the time of your diagnosis, right through to returning to work.

Palliative care team

This team is specially trained in managing pain and other symptoms. They can also help you and your family cope with any emotional distress.

They are sometimes known as the ‘homecare team’ or the ‘hospice homecare team’. A specialist palliative care service is available in most general hospitals.

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.

GP (family doctor)

Your GP can be a great support to you. You can talk to your GP about your planned treatment, your medication and any side-effects you have. You can also contact your GP about any worries you have or if you are finding it hard to cope.

Community health services

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

Giving consent for treatment

Before you start any treatment, your doctor will explain the aims of the treatment to you. You should be asked to sign a consent form saying that you 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 any of the information isn't clear, let your doctor or nurse know straight away. 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.

Tailored treatment

You may notice that other people are not getting the same treatment as you. Don’t worry about this – their cancer may not be the same type or at the same stage as yours. Everyone’s treatment needs will be different.

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're worried, talk to your doctor. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

You might like to make some lifestyle changes while you're waiting for treatment. This can help you prepare for your treatment and feel more in control. For more information, see pages 43–46.

How can I help myself?

- Making healthy lifestyle changes may help you to cope better with treatment.
- Getting support, talking about your diagnosis and learning how to manage your feelings can make things easier for you.

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

Eat well

Eating as well as possible can help you to feel better. It can help to:

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

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

Be active

Being active can help to:

- Reduce tiredness and some treatment side-effects
- Help you to recover after surgery
- 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. You could also ask about pelvic floor exercises, which may help bowel function after treatment for some people.

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 have fewer or less severe side-effects during cancer treatment. For example, chest problems such as chest infections
- Smoking can reduce how well chemotherapy or radiotherapy works
- Quitting can help you to recover faster
- Not smoking can help you heal better after surgery

If you would like advice or support to help you quit, call the HSE Quit Team on CallSave 1800 201 203 or Freetext QUIT to 50100. Some hospitals have smoking cessation officers who can help and support you.

Other ways to help yourself

Get information about your cancer and treatment

Understanding cancer and its treatment and knowing what to expect can help to relieve anxiety and stress for some people. If it makes you anxious, you could ask a friend to do the research for you, and tell you anything important.

Involve your family and close friends

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

Use your support network

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

Try relaxation and stress management techniques

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

Accept change in your life

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

Know that there will be ups and downs

Sometimes people feel they have to be brave or positive all the time, but it’s normal to have bad days. Get help if you’re 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

- Surgery to remove the affected part of the bowel is the main treatment for bowel (colorectal) cancer.
- If the cancer is found early, surgery can often cure it.
- If the cancer is very small you may only need a small surgical procedure to remove it (local resection).
- Most people are ready to go home 3-7 days after surgery.
- You may have a stoma – an opening on your tummy that lets poo leave your bowel into a bag.

Surgery is the main treatment for colon cancer. Surgery, often in addition to radiotherapy and chemotherapy, is also used to treat rectal cancer. The type of surgery you have will depend on:

- Where in the bowel the tumour is found and how big it is
- The type of tumour
- If the cancer has spread to other tissues / organs

Surgery aims to remove the part of the bowel that contains the tumour. Once the part of your bowel with the tumour is removed (bowel resection), the two ends of your bowel are joined together, if possible.

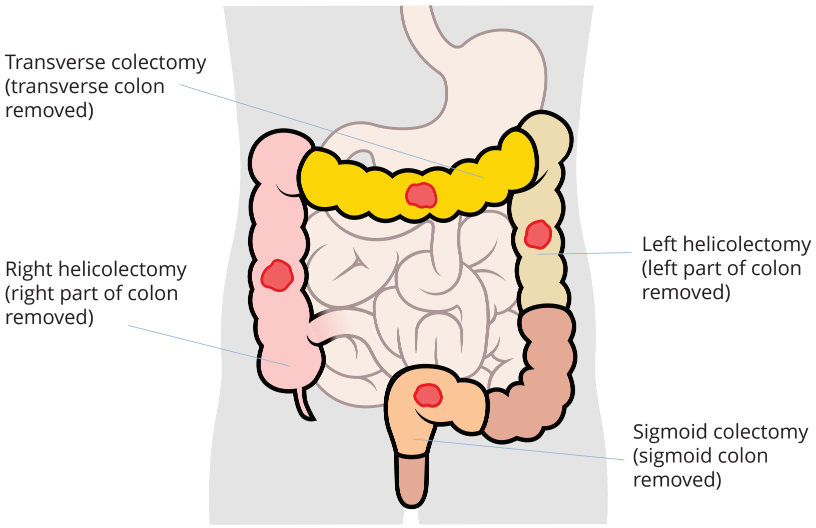
Sometimes part of your bowel is brought out onto the surface of your tummy. This is called a stoma. You may have a temporary stoma to allow the join in your bowel to heal. Or some people have a stoma because it's not possible to join up the ends of your bowel again. See page 73 for more about stomas.

Lymph nodes will also be removed as part of your surgery, to help prevent the cancer spreading.

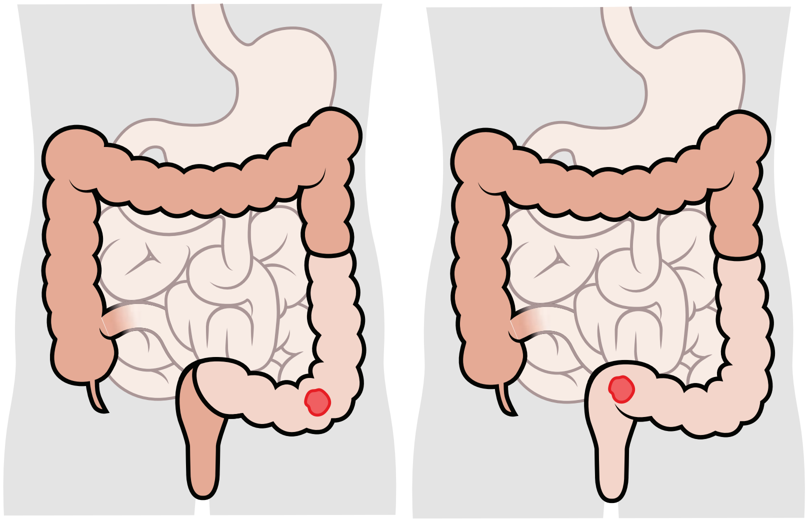
Types of surgery

Which part of your bowel will be removed depends on where the cancer is. For example, a sigmoid colectomy removes the sigmoid part of the colon. A **total colectomy** means removing all of the colon. A **panproctocolectomy** means removing all of the colon and rectum.

Examples of colon surgeries



Examples of rectal / anal surgery



Anterior resection (rectal cancer): Part of the rectum containing cancer is removed

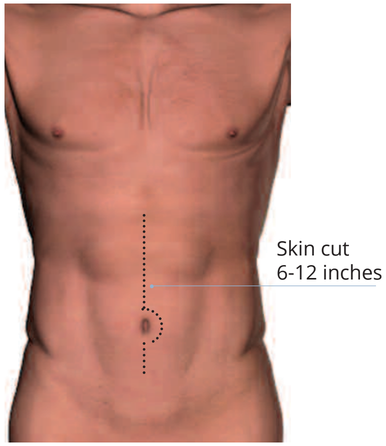
Abdominal perineal resection (rectal / anal cancer): Anus, rectum, and sigmoid colon removed

Ways of doing bowel surgery

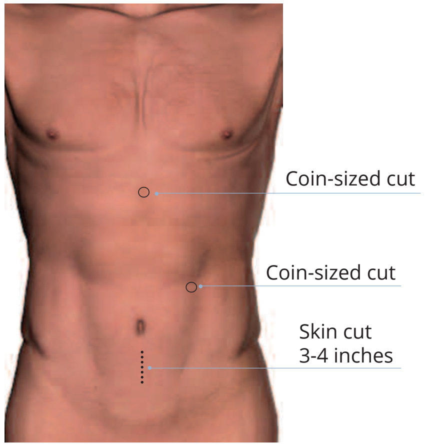
Keyhole surgery (laparoscopic surgery)

With keyhole surgery, a small cut is made in your abdomen. Your surgeon will put a tube with a tiny telescope and light inside your body through a very small cut. Special instruments can then be used to remove the tumour. There is usually a quicker recovery with keyhole surgery and you may spend less time in hospital than with open surgery. Although the scar on your tummy will be smaller, your bowel will still need the same amount of healing – it's important you give yourself time to recover.

Keyhole surgery can be used for some types of bowel cancer. Your surgeon will discuss if you're suitable and if this type of surgery is available in your hospital.



Open surgery



Keyhole surgery

Robot-assisted surgery

This is a type of keyhole surgery that uses a computer and robotic arms to help to remove the tumour.

Open surgery

Here a long cut is made in your abdomen. This means your wound may go from below your breastbone down towards your pelvis in a straight line. The length will depend on where the cancer is.

Surgery for cancer that has spread or come back (recurred)

Sometimes the cancer may have spread beyond your bowel. For example to your liver. In this case, you may still be suitable for surgery. See page 71 for more about treating advanced (metastatic) cancer.

Before surgery

Tests

To make sure you are fit for surgery, some extra tests may be done. These could include a chest X-ray, heart tests (ECG and echocardiogram), breathing tests, blood pressure tests and some more blood tests. Your nurse will give you advice on how to clear your bowels fully before surgery and any changes you might need to make to your diet.

You will be given advice on how to do deep breathing exercises and start moving after surgery. These will help your circulation and reduce the risk of a chest infection and blood clots after surgery. On the day of surgery you will be fitted with elastic stockings to reduce the risk of clots in your legs.

Smoking

Try to quit or cut down before your surgery as this will reduce the risk of chest infection and help with wound healing. See page 45 for more.

Stomas

A stoma is an opening on your tummy that lets poo leave your bowel into a bag. If your surgeon tells you that you might need to have a stoma formed as part of your surgery, they will refer you to the stoma care nurse. You will have an appointment with the stoma care nurse before surgery. You can bring a friend or relative with you.

The nurse will explain your surgery, show you a stoma bag and mark a suitable place on your tummy for the stoma. This will be in the best position for you to be able to take care of your stoma. You should be able to wear your clothes as normal. See page 73 for more about stomas.

Night before surgery

You will not be able to eat anything for a number of hours before your operation. Your doctor or nurse will advise you about this. You may get an injection of an anti-clotting drug like heparin to prevent any clots in your legs later. You may have to give yourself this injection at home.

After surgery

Tubes

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

- **Drip:** A drip will be put into a vein in your arm or neck. This will give you fluids until you can drink again.
- **Catheter:** A small thin tube called a catheter may be put into your bladder. This helps to drain your urine into a bag.
- **Drains:** Small tubes will drain any extra fluid from your surgery site and so help it to heal.
- **Epidural:** There may be a thin epidural tube in your back to help relieve any pain.

Pain and sickness

You are likely to have some pain for the first few days. You may also feel or get sick. Your nurses can give you painkillers and medication to stop you feeling sick if needed. Always ask for help before the pain or sickness get too bad. If the medication isn't controlling your pain, let your nurse know, as it can be changed.

Eating and drinking

Your doctor will tell you when you can start to eat small amounts of solid food again.

Exercising

You will be asked to move your legs in bed and do deep breathing exercises at least once an hour to avoid clots. On the day after surgery, your nurses will help you out of bed and take you for a short walk.

As you get better, these walks will become longer and you can go on your own. Sitting down may not be easy at first but it should get better as your wound begins to heal.

Enhanced recovery programmes

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

Going home

More than likely you will be ready to go home 3–7 days after surgery. If you live alone or have problems getting around the house, talk to the medical social worker on your ward. Do this as soon as you are admitted to the hospital. That way, he or she can organise the community services that you may need after you leave hospital. On the day you go home, you will be given a date to come back for a check-up.

Will I need more treatment after surgery?

The part of your bowel removed will be examined fully in the laboratory. Examining the cancer cells can give your medical team more information about your type of cancer and its stage and grade.

It may take 10–14 days to get the results back. Your medical team will then discuss the results and decide if you need more treatment or not. For example, sometimes chemotherapy is given after bowel surgery to reduce the risk of the cancer coming back.

Chemotherapy

- Chemotherapy uses drugs to cure or control cancer.
- It may also help to prevent the cancer coming back or if the cancer is advanced.
- Any side-effects depend on the drug used and the dose. They usually go away after treatment ends.
- Side-effects include sore mouth, taste changes, loss of appetite, diarrhoea, nausea and vomiting.

Chemotherapy drugs may be given:

- Before surgery to shrink the tumour and make it easier to remove. This is called neo-adjuvant treatment.
- With radiotherapy, to make the treatment more effective (chemoradiation).
- After surgery to reduce the risk of the cancer coming back. This is called adjuvant treatment.
- As a treatment for cancer that comes back after surgery.

Chemotherapy is the most common treatment if the cancer has spread outside your bowel.

The doctor who specialises in chemotherapy and other drug treatments is called a medical oncologist.

How often will I have chemotherapy?

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

How is chemotherapy given?

Usually your treatment will be given in the chemotherapy day care unit. Chemotherapy may be given directly into a vein as an injection and/or through an intravenous infusion (drip). It may also be given in tablet form. If you're having chemotherapy and radiotherapy together (chemoradiation) to shrink your tumour before rectal cancer surgery, you may have the chemotherapy as a continuous infusion. This is where you are attached to a pump which gives chemotherapy continuously into your veins through a drip for a number of weeks.

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, Hickman lines and PICC lines. There's more information on the types of central venous access devices and how to look after them in our booklet, ***Understanding chemotherapy and other cancer drugs.***

If you are continuing your chemotherapy at home you will go home with a chemotherapy pump that will attach to the central venous access device. Your nurse will show you how to look after it at home.

What kinds of drugs are used?

There are several chemotherapy drugs used to treat cancer in the colon, rectum or anus. 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 medicine you have been given. Ask your doctor or specialist nurse for more information about the drugs you're having: what they're for, how to take tablets and any possible side-effects. They may be able to give you a printed sheet to take home with you.

If you have any questions or need any more information, you can speak to our cancer nurses by calling our Cancer Nurseline 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 can be more severe if you have chemotherapy and radiotherapy together. 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:

Diarrhoea

Passing more than 3 watery bowel motions a day is known as diarrhoea. You may also have cramping and/or abdominal pain. Tell your doctor or nurse if you get diarrhoea. There is medication that can help.

If you have an ileostomy, contact your stoma nurse for advice on treating diarrhoea and drinking fluids.

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.

Feeling sick (nausea) or getting sick (vomiting)

There are treatments that work well to prevent nausea and vomiting, so tell your doctor if you have this side-effect.

Hints and tips: nausea, vomiting, diarrhoea

- Find out when is best for you to eat and drink before treatment. Some people need a light snack, while others need an empty stomach.
- Eat small amounts of food regularly rather than 3 big meals.
- Drink plenty of clear fluids, more if you have diarrhoea (1.5 to 2 litres a day).
- Eat bland, easy-to-digest foods and drinks, like toast, crackers or plain biscuits.
- Avoid foods that make you feel sick. For example, foods with a strong smell, like garlic, onions, fried foods, etc.
- Eat warm or cool foods if you cannot tolerate the smell of hot food.
- Avoid milk, alcohol, very hot or cold drinks and spicy or fried foods if you have diarrhoea.
- Eat less raw fruit, cereals and vegetables, if you have diarrhoea.
- Try a complementary therapy, like acupuncture. It may help nausea.

Loss of appetite

You may find that you have little or no appetite. Eating very small amounts of food often can help. Taking special build-up drinks can give you extra proteins and calories too. Talk to your nurse or dietitian for more advice or see our booklet, ***Diet and Cancer***.

Infection

Chemotherapy drugs make you more likely to get infections. You will be asked to watch out for signs of infection at all times. These signs include feeling shivery and unwell, having a high temperature, having a cough, or pain passing urine.

Feeling very tired (fatigue)

Fatigue is where you feel tired and weak and rest does not seem to help. For more about fatigue see page 89.

Hair loss (alopecia)

Hair loss does not happen very often with the drugs used to treat bowel cancer. However, you may notice that your hair thins out a little. If you do lose your hair, it will fall out quite quickly but will grow again when treatment stops.

Peripheral neuropathy

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

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. You will have regular blood tests to measure your red cell count during treatment.

Bleeding and bruising

Chemotherapy can stop your bone marrow from making enough platelets. Platelets help make your blood clot and stop bleeding.

With fewer platelets you may bleed or bruise very easily. You will have regular blood tests to count the number of platelets in your blood. Tell your doctor if you have any bruising or bleeding that you can't explain, such as nosebleeds or bleeding gums.

Skin and nail changes

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

Changes in kidney function

Some drugs can irritate or damage kidney cells. Talk to your doctor if you have decreased urination, swelling of the hands or feet (oedema) or headaches, as these can be a sign of kidney damage.

Hand–foot syndrome

This causes pain, swelling and redness of your hands and/or your feet. It can look like sunburn, where your skin begins to peel as well. It is due to small amounts of chemotherapy leaking out of the tiny blood vessels in the palms of your hands and soles of your feet.

Tell your nurse or doctor if you notice this side-effect. The drug dosage may need to be reduced or stopped. Your doctor can also prescribe medication or creams to help.

If you notice any side-effects or you feel unwell, tell your doctor or nurse straight away. They will tell you what to do.

For more information on the side-effects of chemotherapy and tips to help you cope, go to our website **www.cancer.ie**, read our booklet ***Understanding Chemotherapy and other cancer drugs***, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

If you want more information on side-effects and tips to help you cope, go to our website, **www.cancer.ie**

Targeted therapies

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

Targeted therapies can stop cancer growing or spreading by targeting specific proteins and gene changes that help the cancer to grow. These drugs are often used to control metastatic cancer.

Different drugs work in different ways. For example, with bowel cancer, they can:

- Block or turn off chemical signals that tell cancer cells to divide and grow
- Change proteins in the cancer cells so the cells die
- Stop new blood vessels being made, which can feed the cancer cells
- Carry toxins to the cancer cells to kill them

You may have blood tests to look at your genes to see if you are suitable for particular targeted therapies. For example, with bowel cancer, the RAS gene test will tell your doctors if you are suitable for targeted therapies called cetuximab and panitumumab.

You may have targeted therapies in combination with other treatments. For example, chemotherapy. Some drugs are given in tablet form. Others are given into a vein through a drip.

Side-effects

Side-effects depend on the drugs being used and vary from person to person. Common side-effects include fatigue, flu-like symptoms, rashes, loss of appetite, high blood pressure and blood clotting problems.

These side-effects are usually short term and improve over time. Your doctor can prescribe medication if they become a problem for you, so let your medical team know if you don't feel well or if you are having any symptoms that are troubling you.

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

New treatments

New treatments 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 70). Ask your doctor if there are any targeted therapies available to treat your cancer or if there are any trials that are suitable for you.

Radiotherapy

- Radiotherapy uses high-energy rays to kill cancer cells.
- It is used for rectal cancer and anal cancer, often with chemotherapy. It isn't usually used for colon cancer.
- Side-effects affect the area being treated. They include fatigue and skin reactions.
- Side-effects normally go soon after treatment ends, but some can be long-lasting.

Why is radiotherapy given?

Radiotherapy 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. It isn't usually used for colon cancer.

Radiotherapy 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 (chemoradiation)
- To control and relieve any symptoms you may have (palliative radiotherapy)

The radiation comes from machines that aim rays directly at your tumour. The radiotherapy may also be targeted to lymph glands in the groin, if your doctor thinks this is necessary. The machines are called linear accelerators.

Radiotherapy for metastatic cancer

Radiotherapy may be used to relieve symptoms caused by a tumour where surgery is not possible. It works by shrinking the tumour, which can ease pain and pressure. In some cases you might need more radiotherapy if the tumour has come back, even if you had this treatment before. This is called palliative treatment.

Stereotactic radiotherapy

Stereotactic radiotherapy gives very high doses of radiotherapy to small areas of the body. It is only suitable for a small number of people. Your doctor will tell you if it's an option for you.

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.

CT planning

You will have a CT scan to pinpoint the area to be treated. Your skin will be marked with tiny tattoo dots, so that the machine can be lined up using these marks as a guide when you have your treatment. CT planning can last for up to 30 minutes.

Pregnancy test

It is important that you are not pregnant during your treatment. A pregnancy test can be arranged if there is any chance that you could be pregnant.

Having radiotherapy

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 week day. In some cases they may stay in hospital.

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

How much radiotherapy do I need?

The course can be several treatments over a number of days or weeks (4 to 6 weeks) or between 1 and 10 doses for palliative treatment.

Where will I have radiotherapy?

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

Your radiation therapist will give you information on who to contact if you have any problems between sessions.

Radiotherapy side-effects

Radiotherapy is given directly to the site of the cancer. This means that any side-effects only affect the part of your body being treated.

How severe these side-effects are will vary from person to person, depending on the amount of treatment received. 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. The most common side-effects are:

Diarrhoea

Passing more than 3 watery bowel motions a day is known as diarrhoea. This is a fairly common side-effect. You may also have stomach cramps and wind. If this happens, drink lots of clear fluids to replace the fluid you are losing. It is also best to eat a low fibre diet and cut down on fruit and vegetables, brown bread, porridge and beans. There is also medication that can help to stop diarrhoea. Ask your radiation therapist and nurse for advice.

Bladder irritation

Your bladder may become irritated during radiotherapy. This can make you pass urine more often with a stinging or burning feeling. There may be a trace of blood in your urine too. If you get these side-effects, discuss them with your nurse or radiation therapist.

Irritation to your back passage (rectum)

Radiotherapy can cause irritation to your back passage and anus. It can cause a feeling of fullness and pressure there. You may have the urge to empty your bowel but without success when you go to the toilet. It may be itchy around your anus as well as sore. You may also notice a slimy mucous discharge. Radiotherapy can also irritate piles.

There are creams and suppositories to relieve these problems. So tell your radiation therapist or nurse if you have any side-effects.

Skin changes

During radiotherapy your skin in the treated area may become red, sore and itchy. Your radiation therapist or nurse can give you advice on special creams to help this. You can take baths and showers while on treatment, but avoid using perfumed soaps or powders on the treated area. Do not rub the area. When drying your skin, pat it gently with a soft towel.

Tiredness and fatigue

You may feel very tired (fatigued) while having radiotherapy and for some time afterwards. Fatigue can often come on in the later weeks of treatment. It is best to allow yourself plenty of time to rest, but try to stay as active as possible without getting overtired.

The tiredness usually eases off gradually once treatment has ended. For some people the tiredness may last for several months. See page 89 for more about fatigue.

Feeling sick (nausea)

You may feel sick while having radiotherapy. Eating small meals often should help. Your doctor can also give you medication to prevent you feeling or being sick. Talk to your doctor or nurse if you feel sick.

Sexual problems and infertility

Both men and women can have sexual problems due to radiotherapy treatment. In some cases, it can cause infertility. See pages 90-94 for more details.

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.

If you would like more information on radiotherapy and its side-effects, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to talk to a cancer nurse. You can ask them for a free copy of the booklet, ***Understanding Radiotherapy***.

Clinical trials

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

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

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

More information

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

You can see a list of current cancer trials at **www.cancertrials.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. If bowel cancer spreads, it often spreads to the lung or the liver. Your cancer may be in more than one part of your body when it is first diagnosed.

If your cancer has spread it can still be treated. Treatment is usually to try to control the cancer rather than to cure it.

Often metastatic cancer is treated with chemotherapy or targeted therapies. There may also be treatments that you can have as part of a clinical trial (see page 70).

Some people may be suitable for surgery to remove cancer from the liver or the lung, but it depends on the size and position of the cancer and your general health.

Your doctor will discuss the best treatment option for you with the healthcare team.

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

Palliative care

Palliative care is treatment to help 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. You don't need medical insurance.

Stomas

Stomas

- With a stoma, bowel motions (poo) pass through the stoma (opening) into a bag instead of going through your back passage (rectum).
- It can take a bit of time and practice to get used to managing a stoma. Your stoma care nurse is always there to help you.
- Your consultant and stoma care nurse will advise you if you can have a reversal of your stoma. Reversing the stoma isn't always possible.

Ileostomy and colostomy

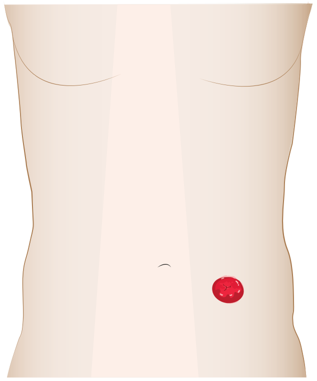
Often with bowel surgery your surgeon will make an opening (stoma) on your tummy. The cut end of your bowel (end stoma) or a loop of bowel with a hole made in it (loop stoma) is brought to the surface. Your poo passes through the stoma into a bag.

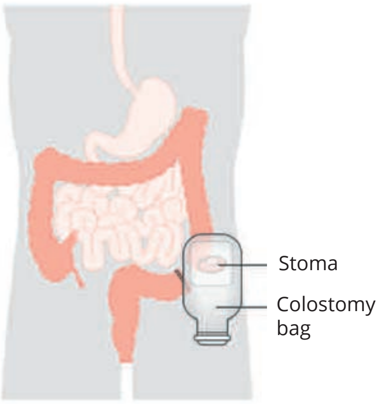
A stoma is made to let your bowel rest and heal. If the ends of your bowel can't be joined together again after surgery you might have a permanent stoma.

If the large bowel (colon) is brought out, it is called a **colostomy**

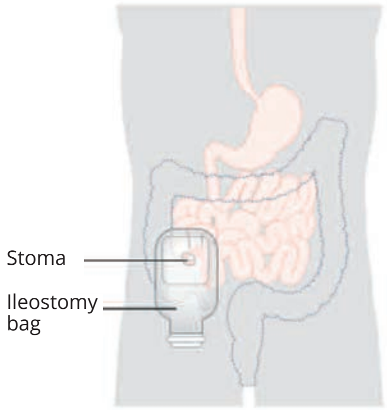
If the small bowel is brought out it is called an **ileostomy**

A stoma is red and moist. Some people say it looks like a strawberry. After the operation it will be quite swollen. The swelling will usually reduce over about 6 weeks.





Colostomy



Ileostomy

Images courtesy of Cancer Research UK/Wikimedia Commons

You will need to wear a bag over the opening to collect your bowel motions (poo).

The stoma nurse will measure the size of the stoma to make sure the bag is cut to the right size.

Your bowel motions (poo) pass through the stoma into a bag instead of going through your back passage (rectum). With a colostomy, the bowel motions should be firm, with an ileostomy they are more liquid.

If the stoma is temporary, you will need to have another operation to reconnect the bowel used to form the stoma to the rest of the bowel. This is called a stoma reversal. See page 83 for more about stoma reversal.

Having a stoma

Having a stoma is a big change to your body. It can take time to get used to having a stoma. Your stoma nurse will support you and can, if you like, put you in contact with others living with a stoma. You are not alone – there are thousands of people in Ireland living with a stoma.

How do I manage my stoma?

After your operation the stoma care nurse will help you to empty and change your bag. When you're feeling better they will teach you how to manage the stoma yourself, so that you are confident with it before you go home. They can also teach your relative or carer if you wish. The stoma / colorectal nurse will support you and guide you with any concerns or issues you may have once you go home.

Getting supplies

Your stoma care nurse will give you supplies to last you for the first couple of weeks at home.

You will be reviewed regularly for the first six weeks and you will receive a prescription for the supplies you need, available from your pharmacy.

If you have a medical card: You must bring your prescription to your GP who will add it to your medical card script.

If you don't have a medical card: Bring the prescription straight to your pharmacy. Make sure you have signed up for the Drugs Payment Scheme, which limits the amount you will pay for prescription drugs and other equipment every month.

Getting support after you leave hospital

You can contact the stoma care nurse at the hospital where you had your surgery if you have any problems at home. You may also be linked with a community stoma nurse who comes to your house.

Tips & Hints – Looking after your stoma

- It takes time to get into the routine of looking after your stoma. Give yourself plenty of time and privacy to practise until you get used to it.
- The stoma nurse will give you written and verbal instructions on the right way to change your bag (pouch).
- Pouch changes depend on the type of stoma you have.
  - If it is a more liquid poo (stool), the stoma care nurse will teach you how to empty the pouch regularly.
  - If the poo is more solid, many people prefer to change the pouch rather than empty it. Your stoma care nurse will advise you about the best pouch for you.
- Before removing your pouch, make sure you have everything ready: A new pouch, wet and dry wipes for cleaning, a rubbish bag for waste and any accessories you use.
- Always bring enough supplies for one pouch change with you when you're out and about. Keep this in your car/pocket/bag for peace of mind.
- When travelling abroad, contact your stoma nurse for a travel cert, which is a special document for people with a stoma. Make sure you have enough supplies to last you and bring extra in case of delays.

Keep in touch with your stoma nurse if you would like to change the products or accessories you're using. Your stoma nurse is there to support you. Don't ever be concerned that you are bothering them.

Will I have to change the foods I eat?

If you have a colostomy

Most people don't need to change how they eat. It's important to eat a well-balanced diet and drink plenty of water.

If you have an ileostomy

You will meet a dietitian who will give you information about the best diet for you. You may be started on a low-fibre diet after the operation. High-fibre foods such as brown bread, green leafy veg, beans and pulses may make your bowels move too much. It's important to eat slowly and chew your food well. It's also very important to have enough fluids, so drink at least 8 glasses a day.
If your bowel motions are very watery, you may need anti-diarrhoea medication to slow down your bowel activity. You may also need to drink special electrolyte drinks to prevent dehydration.

> 'It's important to eat slowly and chew your food well.'

Talk to the dietitian

Ask to talk to the dietitian at the hospital if you want advice about your diet or if you're having any difficulties. They can give you advice on the best diet for you and how to avoid problems.

Food / symptom diary

It might help to keep a note of what you eat and how it affects you – for example, certain foods might affect your bowel motions, cause discomfort or give you wind.

If you notice any symptoms, don't cut foods out straight away. Try them again until you're sure they are causing the symptom. Even if you cut out certain foods, try them again in the future to see if they still have the same effect. You can ask the dietitian about this. There's a printable diary page in the stoma section of our website, **www.cancer.ie**

Food & Symptom Diary

	Breakfast What I ate How did it affect me?	Lunch What I ate How did it affect me?	Dinner What I ate How did it affect me?	Snacks What I ate How did it affect me?	Anything else I noticed today
Monday					
Tuesday					
Wednesday					
Thursday					
Friday					
Saturday					
Sunday					

> 'It can take time to get used
> to having a stoma, but most people
> cope very well. Ask your stoma nurse
> if you need any advice.'

What bowel changes might I have?

Bowel activity

The consistency of your poo – whether it is formed or more watery – and how often you poo will depend on the part of the bowel the stoma is formed from.

- **If you have an ileostomy**
  The consistency is similar to porridge and you can expect to empty your bag between 4 and 6 times a day. If you have very watery poo for a few days and you start to feel unwell or tired or if your mouth is dry, you may be dehydrated. It's important to contact your doctor or stoma nurse for advice if you have these symptoms.
- **If you have a colostomy**
  The poo tends to be formed. Your stoma may work 1-2 times a day, but everyone's bowel habit is individual, so your stoma may work more or less often than this.

You should contact your GP or the hospital for advice if you go longer than three days without having a bowel movement.

Wind (flatulence)

Some foods can cause excess wind. For example, beans, onions, fizzy drinks and chewing gum. If wind is a problem for you, try drinking peppermint tea. Also avoid smoking and chewing gum, allow fizzy drinks to go flat before you drink them and chew with your mouth closed.

Getting advice

It's important to contact your stoma nurse if you're having any difficulty with your stoma. You're not bothering them – they are there to help, support and advise you.

Stoma and sex

If you have a stoma, it may change the way you feel about your body. You may also have concerns about how your partner will react. Try to talk to your partner about the way you're feeling. Talking can help to ease your anxiety. If you need more advice, talk to your doctor. He or she can refer you for special counselling if you feel it would help.

Food and drink

It is best not to eat too much before sex. Also, watch the types of food you eat if you know there are certain foods that affect your bowel movements. You could plan times for sex when a bowel movement is less likely. Empty the bag before sexual intimacy.

Intimacy

You may be afraid that the bag will interfere with sex, become dislodged or cause damage to the stoma. These are all normal fears. But an empty and flat bag will not become loose from the stoma. It can be rolled up or taped down so it won't get in the way.

Decorative covers

It is possible to wear decorative covers as well. There are also a variety of pouches to suit your needs. There are bands you can wear on your tummy for support and discretion. Your stoma care nurse can give you advice about this.

Stoma reversal

Stoma reversal (closing the stoma) is when the bowel used to form the stoma is reconnected to the remainder of the bowel. Patients often look forward to the reversal of the stoma and see it as a return to normal.

If all your rectum has been removed you will not be suitable for stoma reversal, as waste can't leave your body in the normal way without it.

If and when you might have a stoma reversal depends on:

- If you have recovered from your first surgery and your bowel has healed.
- If you need any more treatment such as chemotherapy or radiotherapy. You will need to finish and recover from these treatments before stoma reversal can be considered.
- If your bowel is healthy – for example, there is no disease in your bowel and no narrowing of the bowel.
- If the muscles around your back passage (anal sphincters) are working. These control the flow of waste and wind from your bowel and so are needed for normal bowel function.
- If you're medically fit to have more surgery.

Your surgeon will talk to you about whether you might be suitable for stoma reversal surgery. You may need to have more tests to give your surgeon more information.

Often stoma reversal happens anytime from a few months after the stoma was made to 1 or 2 years later.

Stoma reversal surgery may be delayed or may not be suitable for you, so try not to focus too much on reversal, and instead focus on adjusting to living with a stoma.

You may prefer not to have more surgery, even if reversal is an option for you.

Stoma reversal surgery

Rejoining the 2 ends of the bowel (stoma reversal) is usually a simpler operation than surgery to remove a tumour, but the preparation and aftercare are similar. As with any surgery, there are always risks and possible complications. Talk to your surgeon so that you understand your surgery. See pages 52-55 for more about getting ready for surgery and recovering afterwards.

Getting used to life without a stoma

The vast majority of people who have had their stoma reversed look forward to getting on with their lives without the stoma and they return to normal life.

Some people's bowel pattern may not return to how it was before their cancer treatment, but generally people adapt to a 'new normal' routine for their bowels and manage very well.

Bowel function often improves over time. This can vary from weeks to months and even years for some people. A minority of people will have more significant bowel function problems after stoma reversal. They may need more support from health care professionals and possibly further medical procedures.

Possible bowel changes include:

- Needing to go to toilet more often, including during the night
- Needing to rush to get to the toilet in time (urgency)
- Diarrhoea – looser or more watery poos
- Doing lots of small poos rather than one big one
- Feeling that you need to poo all the time or that you haven't emptied your bowel fully
- Poo leaking from your back passage
- Constipation
- Sore skin around the back passage

These changes can be upsetting. You may feel embarrassed or worry about how bowel changes will affect your day-to-day life or your sexual relationships. Stay in touch with your medical team and let them know if you are having any problems. They can advise you on things that may help such as:

- Changes to your diet
- Medication
- Skin care
- Pelvic floor exercises
- Anal plugs
- Talking to a physiotherapist

It can take time to adjust to life after bowel cancer surgery, but most people learn to manage and adapt to any changes.

Managing side-effects and symptoms

How can I cope with fatigue?

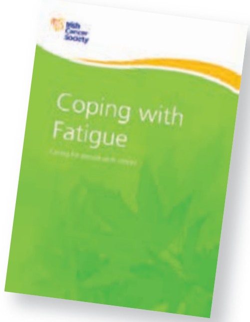
- Fatigue means feeling extremely tired.
- There are things that can improve fatigue, depending on what's causing it.

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

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

Usually fatigue improves 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. For example, if you have a low red blood cell count a transfusion can make you feel better. If you're not eating well, a dietitian may be able to give you some advice to help you.

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



Hints and tips: Fatigue

- Try to do some exercise – ask your doctor for advice about the best exercise for you.
- Build rest periods into your day and save your energy for doing the things that are most important to you.
- Ask for help at work or at home, for example, with cooking, housework or childcare.
- Try to eat well and drink plenty of fluids.
- Try to avoid stress. Talk to friends and family about any worries you have and take time to enjoy yourself.
- If you are not sleeping well, try relaxation techniques and avoid stimulants like caffeine and alcohol before bedtime.

Will treatment affect my sex life?

Sex and sexuality

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 also be hard to relax 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. Or you may be coming to terms with changes in your appearance after surgery or getting used to having a stoma.

There is no right or wrong way to feel about your sexuality and sex life. Even if you don't feel like having sex, you can still enjoy a close and loving relationship with your partner. You can enjoy other forms of closeness, such as touching, caressing and holding each other.

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. He or she may refer you for specialist relationship counselling or sex therapy. This can help you and your partner deal with a change in your sexual relationship and find ways of being close again.

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

You may have physical side-effects that can cause difficulties with sex, depending on the type of treatment you've had. Sometimes surgery to the rectum can affect the nerves and blood supply to the sexual organs. For men, this may result in problems having an erection and ejaculation. This usually clears up over time, but in some cases, it may last much longer or be permanent. Your surgeon should talk to you before surgery about any sexual problems that might happen.

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

A woman's vagina may narrow and shorten after radiotherapy to the rectum or possibly surgery. This can make sex painful. Your nurse can give you advice about treatments to help, such as using vibrators or vaginal dilators, which can help to stretch the vagina. Some women may have a loss of sensation or vaginal dryness. Simple solutions such as lubricants can help with this.

Anal sex may be more difficult after some treatments or you may experience a loss of sensation. You may also be more likely to get infections if the skin in the area is more delicate after radiotherapy. It's best to ask your medical team about when it's safe to have anal sex again and about any precautions you should take.

Anal sex isn't possible after surgery to remove your anus and rectum. This will have a big impact on some people's sex life. Though it will take time to adjust, there are other ways for you to enjoy a fulfilling sex life. Sharing your thoughts and feelings with your partner, if you have one, can help with this. Or ask your medical team about professional counselling or other support services.

If you have a stoma you may feel self-conscious about your body or worry about the bag during sex. See page 82 for more about stomas and sex.

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

Contraception

Some chemotherapy and other cancer drugs may harm a developing baby, so it's important to avoid pregnancy during and for a time after treatment. If you're having sex and you're fertile, you should use a reliable method of contraception during and for some time after treatment.

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

Ask your doctor's advice about contraception or if you're thinking about having children after treatment.

Asking for advice

If you have any questions about how treatment may affect your sex life, you can ask your doctor or nurse. They are well used to talking about these matters, so there's no need to feel embarrassed. You can also call our Cancer Nurseline 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 cancernurseline@irishcancer.ie

Will treatment affect my fertility?

Your fertility may be affected by some of the treatments. For example, radiotherapy, chemotherapy or targeted therapies. This may be temporary or permanent. It depends on the type and amount of drugs you have and on the area being treated by radiotherapy.

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

Dealing with infertility may not be easy, depending on your age and if you have already had children. It can bring feelings of sadness, anger and loss of identity. It can help to talk through your concerns with someone who is a good listener or with a professional counsellor. You can also call our Cancer Nurseline 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, counselling and acupuncture.

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

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

Integrative care

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

What's the difference between complementary and alternative therapies?

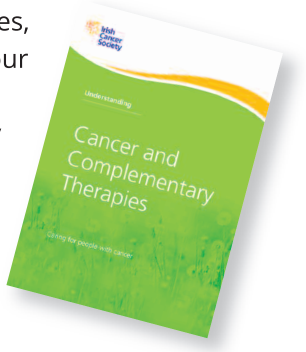
Complementary therapies are used **together with** standard medical treatment.

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

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

More information

To find out more about complementary therapies, you can talk to one of our cancer nurses – call our Cancer Nurseline 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?

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. If you had surgery, your first visit might be 2–6 weeks afterwards. Follow-up usually involves seeing your doctor and having tests such as a physical exam, X-rays, scans, colonoscopies and blood tests.

At first you will see your doctor quite often, sometimes every 3 to 6 months, especially for the first 2 years. The follow-up will continue for at least 5 years. In general, if the cancer has not returned after 5 years, you are considered cured. As there is a genetic link in bowel cancer, you might like to talk to your doctor about getting other family members screened.

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
- If you're finding it hard to cope

Sometimes it helps to write down what you want to say before you see the doctor, so you don't forget anything.

It's important to go to your follow-up appointments. They give your doctor the chance 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)

It is better to be aware of any changes as early as possible so that suitable treatment can be given.

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

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

Blocked bowel

If you have pain or tenderness in your tummy area (abdomen) or vomiting, let your medical team know straight away. It could be caused by a blockage in your bowel, which will need to be treated as soon as possible.

Life after cancer

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

Feelings you may have include:

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

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

You can also call our Cancer Nurseline or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 107 for other ways to get support.

> 'The physical and emotional effects of cancer can sometimes affect people months or years after their diagnosis. Don't be afraid to seek medical help or go back to counselling or support services if you feel you need them.'

Healthy lifestyle changes

Many people want to make positive changes to their lives after their treatment has ended.

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

- Feel better
- Heal and recover faster
- Keep up your energy and strength
- Reduce your risk of more cancer

A healthy lifestyle includes:

- Exercising
- Eating a balanced diet
- Staying at a healthy weight
- Not smoking (see page 45)
- Avoiding alcohol
- Protecting yourself from the sun

If you want more information or advice, call our Cancer Nurseline 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 what your treatment options are.

Coping and emotions

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.

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

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

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

Anxiety and depression

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

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

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

Counselling

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

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

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

Ways to get emotional support

> 'Counselling has helped me with every part of my life.'

Find out about cancer support services in your area: Most provide a range of helpful services like counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 128 for more about cancer support services.

Join a support or educational group: Many people find it very reassuring to talk to other people who are in a similar situation and facing the same 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 doctor, specialist nurse or medical social worker can refer you to psycho-oncology support services.

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

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

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

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

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

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

Positive feelings

'I am very happy and content … even though I have to live with this.'

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

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

You and your family

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

Further information and support

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

Changing relationships

You may feel that people are treating you differently. Some may seem distant or not contact you as much because they are afraid or 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.

Supporting someone with cancer

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 them, 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 Cancer Nurseline for free copies of our publications.

Share worries

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

Be kind to yourself

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

Try counselling

You might find it helpful to talk to a counsellor. Free one-to-one counselling is available to friends and family members at our affiliated cancer support centres. Talk to your GP or see page 106.

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 Cancer Nurseline on 1800 200 700. Ask for a copy of our booklet ***Lost for Words – How to talk to 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 Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or email **cancernurseline@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 Cancer Nurseline, or download it from our website **www.cancer.ie**

Support resources

Coping with the financial impact of cancer

- If you have cancer you may not be able to work for a time. You may also have extra expenses, such as medical and household expenses.
- 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, like 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.

Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Visits to hospital
- Overnight stays in 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 treatment to check you're covered.

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: 0761 074 000
- Department of Employment Affairs and Social Protection (DSP) – Tel: 1890 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 before posting them.

If you have money problems

If you're 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 0761 07 2000 for information.

If you're 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 125 for more details of our Volunteer Driver Service and the Travel2Care fund.

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

More information

For more information go to **www.cancer.ie/publications** and check out our booklet, ***Managing the Financial Impact of Cancer***. This explains:

- **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**

The booklet also has lots of other information to help you manage the cost of cancer. For example, disability and mobility supports, help for people in financial difficulty, help for carers and living at home and nursing home supports.

Irish Cancer Society services

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

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

Cancer Nurseline Freephone 1800 200 700

Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information. The Cancer Nurseline is open Monday–Friday, 9am to 5pm. You can also email us on **cancernurseline@irishcancer.ie** or visit our Online Community at **www.cancer.ie**

For the deaf community, our Cancer Nurseline is using the Sign Language Interpreting Service (SLIS) using IRIS. Contact IRIS by text 087 980 6996 or email: remote@slis.ie

Daffodil Centres

Visit our Daffodil Centres, located in 13 hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer.

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

You can email **daffodilcentreinfo@irishcancer.ie** or visit **www.cancer.ie** to find your local Daffodil Centre.

Survivor Support

Speak to someone who has been through a cancer diagnosis. Our trained volunteers provide emotional and practical support to anyone going through or finished with their treatment.

Support in your area

We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support, including counselling. See page 128 for more information.

Patient travel and financial support services

We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:

- **Travel2Care** is a limited fund, made available by the National Cancer Control Programme, for patients who are travelling for cancer tests or treatment to one of the national centres of excellence or their approved satellite centres. Patients must be travelling over 50km one way to access the fund.
- **Irish Cancer Society Volunteer Driver Service** is for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments in our partner hospitals.

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

Irish Cancer Society Night Nursing

We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is the only service of its kind in the Republic, providing palliative nursing care at night to cancer patients.

Publications and website information

We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer, and financial concerns. Visit our website **www.cancer.ie** or call our Cancer Nurseline for free copies of our publications.

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

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 and their families, during and after treatment, many of which are free.
For example:

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of free one-to-one counselling in many affiliated support services)
- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- **Special exercise programmes**, like the Irish Cancer Society's *Strides for Life* walking group programme
- **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 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 Cancer Nurseline on Freephone 1800 200 700 to find your nearest cancer support centre. Or see our online directory at **http://www.cancer.ie/support/support-in-your-area/directory**

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 will I need?

Will I have to stay in hospital for the tests?

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

At what stage is my cancer?

What type of treatment do I need?

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

How successful is this treatment for my cancer?

How long will treatment last?

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

How long will it take me to get over the effects of treatment?

Do I have to eat special foods?

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?

Your own questions

Acknowledgments

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

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

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Join the Irish Cancer Society team

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

Support people affected by cancer

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

- Help people needing lifts to hospital by becoming a volunteer driver
- Give one-on-one support to someone newly diagnosed with cancer as part of our Survivor 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 Cancer Nurseline on Freephone 1800 200 700 if you want to get involved!

Did you like this booklet?

We would love to hear your comments or suggestions.
Please email reviewers@irishcancer.ie

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