

Understanding

Cancer of the Oesophagus

Caring for people with cancer

Understanding

Cancer of the Oesophagus

This booklet has information on:

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

Useful numbers

Specialist nurse

Family doctor (GP)

Medical social worker

Gastroenterologist

Surgeon

Medical oncologist

Radiation oncologist

Radiation therapist

Dietitian

Emergency

Hospital records number (MRN)



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Fast facts

Can my cancer be treated? Page 27

Yes. There are treatments that aim to cure oesophageal cancer, treatments to keep the cancer under control and treatments to help with side-effects. Your doctor will discuss with you what treatments will be of most benefit to you.

Will I be OK? Page 24

What is likely to happen to you (your prognosis) is hard to predict. It depends on a lot of things, such as the type and stage of your cancer. Everyone is different, so it's best to ask your consultant about your own situation.

What kind of treatment will I have? Page 27

Your treatment will depend on several factors such as the type of oesophageal cancer you have, its stage, which part of the oesophagus it's in and your general health. Treatments include:

Surgery: An operation to remove the cancer.

Chemotherapy: Drugs to slow down and control the growth of cancer.

Radiotherapy: High-energy rays to destroy the cancer cells.

You may also have other treatments to help with side-effects, such as difficulty swallowing.

Will I get side-effects? Page 69

Most cancer treatments cause some side effects, but these usually get better after treatment has ended. Problems with eating and drinking, such as having little appetite, swallowing difficulties and weight loss are common with oesophageal cancer. You may need to be fed through a tube for a time if you have problems eating normally.

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 66

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 106

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 106 for more about our services.

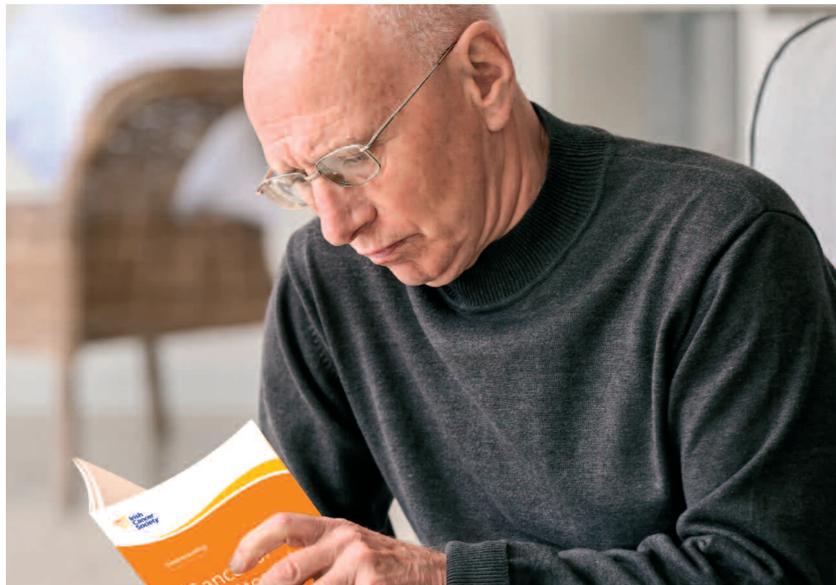
Reading this booklet



This booklet is to help you throughout your cancer treatment and afterwards. You will probably find different sections useful at different times, so keep it for reference. If you need more information or don't understand something, ask your doctor or nurse. You can also ask one of our cancer nurses:

- Call our 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 oesophageal cancer

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What is cancer?

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

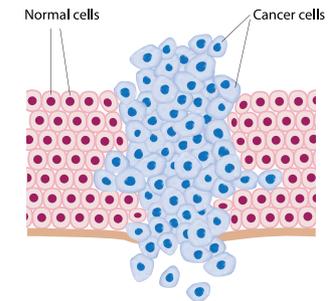
Cancer cells are abnormal cells that grow without control. They can form a lump (tumour).

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

Oesophageal cancer starts in cells in the oesophagus.

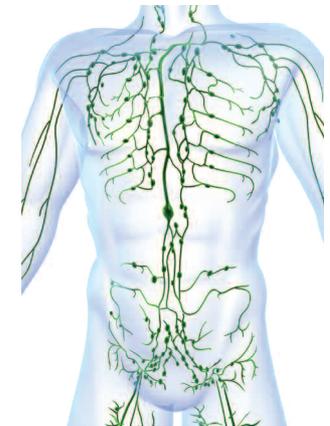
- **Cancers sometimes spread**

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 caused my cancer?

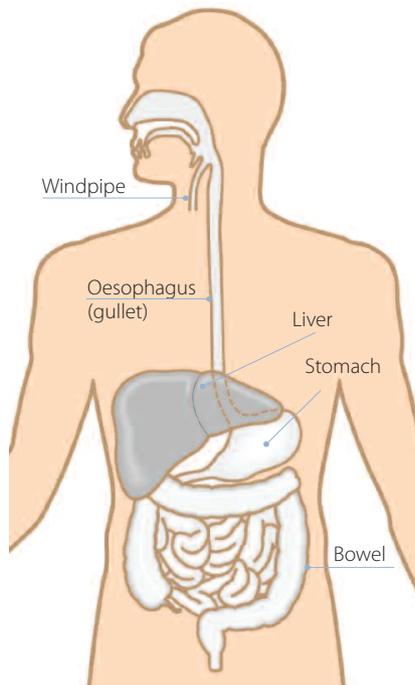
We don't know exactly what causes many cancers. But there are things that can increase your risk of getting cancer. If you want to know more about why cancer happens or to learn about risk factors for oesophageal cancer, see our website www.cancer.ie or talk to a cancer nurse – call our Cancer Nurseline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

What is the oesophagus?

The oesophagus is part of the gastrointestinal tract within your digestive system. Most people know it as the gullet or food pipe. It is a long muscular tube that links your throat to your stomach. In adults it is about 25–30 cm long and runs behind your windpipe (trachea).

When you swallow food, the muscles in your oesophagus move the food down into your stomach. A muscle valve at the end of your oesophagus prevents food and fluid from going back up. A valve at the top of your oesophagus stops food from going into your lungs.

The area where the oesophagus joins the stomach is called the gastro-oesophageal junction.



The wall of your oesophagus has 4 layers:

- **Inner layer or lining (mucosa):** The lining of your oesophagus is moist so that food can pass easily into your stomach. It is made up of skin-like cells called squamous cells.
- **Submucosa:** The gland cells in this layer produce secretions (mucus). Mucus helps to keep your oesophagus moist.
- **Muscle layer (muscularis):** The muscles in this layer push the food down to your stomach.
- **Outer layer (adventitia):** The outer layer which covers the oesophagus, attaching it to nearby parts of the body.

Lymph nodes are also found near your oesophagus. For example, in your neck, the middle of your chest and where your oesophagus joins your stomach.

What is oesophageal cancer?

When cancer happens, the cells in the oesophagus change and grow in an abnormal way. Usually the tumour does not cause symptoms at first, but as it grows it can cause difficulty with swallowing (dysphagia). This is because it narrows the oesophagus and makes food lodge or stick there. After that, it can be hard to swallow liquids.

Cancer can develop anywhere in your oesophagus and there are different types. See the next page for more about the different types.



Cancer Nurseline Freephone 1800 200 700

What are the types of oesophageal cancer?

A tumour can grow anywhere along your oesophagus. When diagnosing and treating cancer, doctors think of the oesophagus in three sections: upper, middle and lower.

Oesophageal cancers are usually named after the type of cell where the cancer first starts to grow. More than 9 in every 10 oesophageal cancers are squamous cell carcinomas or adenocarcinomas:

- **Squamous cell cancer:** Squamous cells are skin-like cells that line your oesophagus. They are found mainly in the upper and middle of your oesophagus. This type of oesophageal cancer is usually due to smoking and alcohol.
- **Adenocarcinoma:** Adenocarcinoma means a cancer that starts in the gland cells that make mucus. This cancer usually starts in the lower part of your oesophagus. It is linked to acid reflux and Barrett's oesophagus.

Gastro-oesophageal cancer

This type of oesophageal cancer happens in the area of the oesophagus that joins to the stomach. It may be treated as oesophageal cancer or as stomach cancer, depending on where the cancer is found.

Email: cancernurseline@irishcancer.ie

Rarer types of oesophageal cancer

- **Neuroendocrine cancers:** These are cancers that arise from the endocrine (hormonal) system.
- **Soft-tissue sarcomas:** These are cancers that start in muscle tissues such as gastrointestinal stromal tumours (GISTs)
- **Small cell cancers:** More commonly happen in the lung, but they can affect the oesophagus.
- **Undifferentiated:** Cancer where the doctors cannot tell if the cancer started in the gland cells (adenocarcinoma) or skin-like cells (squamous cells)

Tests and treatments for these rarer types of oesophageal cancer are different from those included in this booklet. Your medical team will give you more information or you can call our Cancer Nurseline on 1800 200 700.

How common is oesophageal cancer?

Oesophageal cancer is not common in Ireland. Around 430 people are diagnosed with it each year. More men than women get the disease.





Diagnosis and tests

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Being diagnosed with oesophageal cancer

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

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

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

- Ask to speak to the cancer (oncology) liaison nurse or the medical social worker at the hospital. They can help you and your family to cope with your feelings and advise you about practical matters
- Talk to one of our cancer nurses in confidence – call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. 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 111.



'However you feel,
you are not alone.'

Telling people about your diagnosis



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

If you would like to talk things over with a cancer nurse, call our 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 you may have after being diagnosed with cancer include CT scan, endoscopic ultrasound, PET scan, MRI scan and occasionally a laparoscopy.
- The tests will tell your medical team more about your cancer and help them to decide on the best treatment for you.

CT scan

This is a special type of X-ray that builds up a detailed picture of the tissues inside your chest. During the scan you will lie on a table which passes through a large doughnut-shaped machine. The scan is painless and takes between 10 and 30 minutes. You might be asked to fast (not eat) for a few hours before the test.

You may also be given an injection or a special drink to help show up parts of your body on the scan.

Before you take the drink, let the radiographer know if you are allergic to iodine or have asthma. The injection may make you feel hot all over for a few minutes. Preparations for a

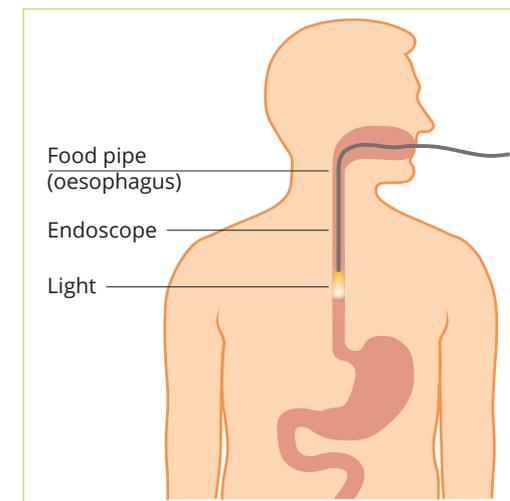
CT scan can vary. The doctor or nurse in your hospital will tell you what to do. This test is usually done as an outpatient, so you should not need to stay in hospital.



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Endoscopic ultrasound (EUS)

An ultrasound probe is passed through a tube into your body through your mouth. This probe makes sound waves that allow your doctor to see the tissues inside your oesophagus and nearby areas. This can help your doctor assess the size and depth of the tumour.



He or she can also check if nearby lymph nodes are enlarged due to cancer or infection. A sample of the lymph nodes can be taken and examined under a microscope to check for signs of cancer. An EUS is usually done under local anaesthetic and you can usually go home the same day of the procedure. If your doctor recommends you have a general anaesthetic you may have to stay in hospital overnight.

PET CT scan

A PET CT scan is a combination of a CT scan and a PET scan. It 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. An hour or so later you will have a scan. The radioactivity can highlight cancer. During the scan, you will lie on a table which moves through a scanning ring. 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.

MRI scan

Sometimes you will have an MRI scan if your doctors want to have a closer look at areas outside the oesophagus, such as the liver. This scan uses magnetic energy to build up a picture of the tissues inside your body. During the test you will lie inside a tunnel-like machine. It does not hurt but can be very noisy. You will be given earplugs / headphones to wear during the scan. You may have an injection before the scan to show up certain areas of your body. During the scan you cannot wear any metal jewellery or hair clips. If you have certain medical devices implanted, like a pacemaker or metal pin, you may not be suitable for the test. Your doctor will advise you about this. Usually you can go home soon after the scan. You shouldn't need to stay in hospital.

Laparoscopy

You may have this test if your doctor needs more information after other tests have been done. A laparoscopy is a small operation that is performed under general anaesthetic. A mini telescope is passed through a small cut in your abdomen (tummy) so that your doctor can see the organs close to your oesophagus and check the lining of your abdomen for cancer.

Your doctor may make another cut in the tummy if a small sample of tissue (biopsy) needs to be taken and checked for cancer.

During the test, carbon dioxide gas is passed into your abdominal cavity. This can give you uncomfortable wind and/or shoulder pains for 3 or 4 days. Walking about or taking sips of peppermint water often eases the pain. After a laparoscopy you will have one or two stitches at the wound site. Usually they dissolve as your wound heals. Once the effect of the anaesthetic wears off, you will usually be able to go home.

Your doctor will discuss this test with you if you need it.

Waiting for test results



It usually takes about a week 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 a specialist nurse, 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.

Cancer Nurseline Freephone 1800 200 700

Staging oesophageal 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 and a grade.

- Staging describes **where the cancer is** in your body, its size and whether it has spread beyond the area it started
- Grading describes **the cancer cells** – what they look like and how they might grow

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

How is oesophageal cancer staged?

The TNM staging system is often used. It describes:

T – Tumour

The size of the tumour and how far it has grown into the lining of the oesophagus. Doctors put a number next to the T to describe the size and spread of the cancer.

N – Nodes

This describes whether the cancer has spread to the lymph nodes and how many nodes are affected. N0 means there is no cancer in the nodes. If cancer has spread to the lymph nodes (positive nodes) the N will have a number to describe how many lymph nodes are affected. NX means the doctors cannot tell if the nodes are affected.

M – Metastasis

This describes if the cancer has spread to another part of the body, such as the liver or lungs. The M may have a number next to it. This gives extra information about where the cancer has spread to.

What are the stages of oesophageal cancer?

Your doctor often uses the TNM information to give your cancer a number stage – from 0 to 4. A higher number, such as stage 4, means a more serious cancer. Some stages are further divided into stage A and B.

- **Stage 0:** This means the cancer is at a very early stage. Cancer cells are found in the lining of your oesophagus but are completely within the lining. This stage is also known as carcinoma in situ.
- **Stage 1:** This also means the cancer is at an early stage. The cancer cells are found only in the surface layers of the lining of your oesophagus. Or it may be found in only a small part of your oesophagus. There is no sign of it spreading anywhere.
- **Stage 2:** Here the cancer has spread to the muscle layer of your oesophagus or to nearby lymph nodes. But it has not spread to any other organs. If the cancer has not spread to nearby lymph nodes, it is stage 2A. If the cancer has spread to nearby lymph nodes, it is stage 2B.
- **Stage 3:** In this stage the cancer has spread beyond the wall of your oesophagus. It may also have spread to nearby lymph nodes and other tissues next to your oesophagus. But there are no signs of it spreading to other parts of your body.
- **Stage 4:** This means the cancer is advanced and has spread to your lymph nodes and other parts of your body. For example, your liver, lungs or stomach. Cancer in another part of your body is called metastatic oesophageal cancer.

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

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.** He or she knows 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, it might not really apply to your situation or to your particular cancer type. Ask your doctor or specialist nurse for advice and 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.



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How is oesophageal cancer treated?



- The main treatments for oesophageal cancer are surgery, radiotherapy and chemotherapy.
- You may have a combination of treatments.
- A team of healthcare professionals will be looking after you (multidisciplinary team).

The type of treatment you have will depend on:

- The type of oesophageal cancer you have
- The size of the tumour
- Where it's found
- If it has spread to your lymph nodes or other parts of your body
- Your symptoms
- Your age and general health

Types of treatment

Surgery

If the cancer is found in only a small section of the oesophagus, it may be possible to remove the entire tumour along with the affected part of the oesophagus. Often you will have chemotherapy or chemoradiation (chemotherapy and radiotherapy together) to reduce the size of the tumour before surgery. See page 39 for more about surgery.

Radiotherapy

Radiotherapy is often used to reduce the size of a tumour. It can be used to relieve symptoms like pain and difficulty swallowing. Sometimes it is used to shrink the tumour so a surgeon can remove it more easily. It can be used on its own or with chemotherapy. It can also be used after surgery to prevent cancer coming back. (See page 52.)

Chemotherapy

Chemotherapy may be used alone or with radiotherapy before or after surgery. It can help to reduce the size of the tumour before surgery or to prevent it from coming back after surgery. It may be used to control the cancer if it recurs after surgery or radiotherapy or to relieve symptoms. See page 60 for more details about chemotherapy.

Treatments for difficulty swallowing

If you have difficulty swallowing you may have treatment to relieve this. The most common treatment is stenting. See page 72 for more information.

Specialist cancer centres

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

Who will be involved in my care?

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

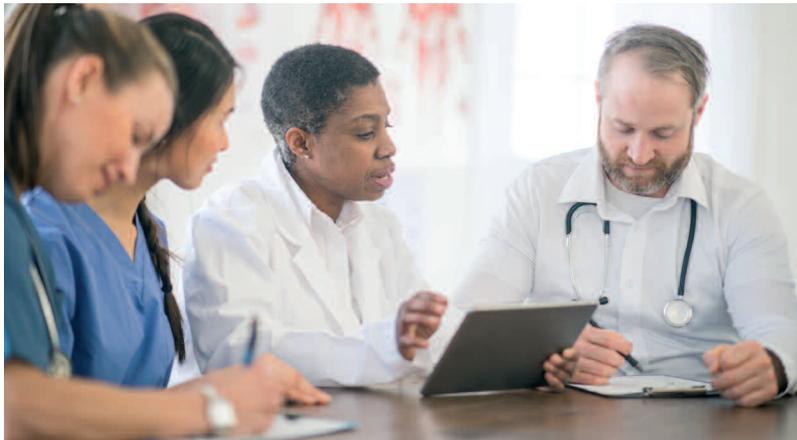
- **Gastroenterologist** A doctor who specialises in treating diseases of the digestive system.
- **Surgeon** A doctor who specialises in surgery and who can remove a tumour from your body.
- **Clinical nurse specialist /oncology liaison nurse** A specially trained nurse who works in a special cancer care unit. She or he can give you and your family information and reassurance from diagnosis and throughout treatment and may help to organise care for you after you leave hospital.
- **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 specialist in giving radiotherapy and advice to cancer patients.
- **Dietitian** An expert on food and nutrition. They are trained to give advice on eating and artificial feeding during your illness and use diet to help your symptoms.
- **Speech and language therapist** A therapist who treats speech and swallowing difficulties
- **Physiotherapist** A therapist who treats injury or illness with exercises and other physical treatments.
- **Medical social worker** A person specially trained to help you and your family with all your social issues and practical needs. They are skilled in giving counselling and emotional support to children and families at times of loss and change. They can also give advice on benefits, entitlements and services available to you when you go home.
- **Psychologist** A specialist who can talk to you and your family about emotional and personal matters and can help you make decisions.
- **Counsellor** A person specially trained to give you emotional support and advice when you find it difficult to come to terms with your illness.
- **Palliative care team** This team is specially trained in managing pain and other symptoms. They can 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.

Deciding on treatment

Multidisciplinary team

A multidisciplinary team (MDT) is a team of specialists involved in caring for your type of cancer, to make sure you get the best possible treatment. The team involves surgeons, medical oncologists, radiation oncologists, specialist nurses, pathologists, radiologists. They will meet to discuss your test results and decide your suggested treatment plan.



Treatment options

Your doctor and nurse will discuss your treatment options with you. Ask as many questions as you like.

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, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre and talk to one of our cancer nurses.

Time to think

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

Second opinion

You might also find it reassuring to have another medical opinion to help you decide about your treatment. Your 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 treatment, let your doctor or nurse know your concerns first. It may help to talk to your GP as well. The important thing is that you are fully aware of the benefits and risks.

Giving consent for treatment

Before you start any treatment, you should be asked to sign a consent form saying that you give permission for treatment to be given.

Before treatment, you should have been given full information about:

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

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

Individual treatment

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

Waiting for treatment to start

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

Cancer treatment should start soon after diagnosis. But for most cancers, waiting for scans or treatment for a few weeks does not usually affect how well the treatment works. If you are worried, talk to your doctor. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

Having some time can give you the chance to talk through your feelings and try to come to terms with your diagnosis. If you want to talk to a cancer nurse, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. The nurses can also put you in touch with someone who has had treatment for cancer, if you think this would be helpful.

You might like to make some healthy changes while you're waiting for treatment. It can be hard to make changes during an anxious time like this, but it can help you prepare for your treatment and feel more in control.

How can I help myself?

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

Eat well

Eating well when you have cancer can help you to cope better with treatment and any side-effects. Ask to talk to the dietitian at the hospital for advice on how to eat as well as you can.

Exercise

If you are feeling well enough to take some exercise, it may help you to feel better - physically and emotionally. Talk to your doctor or nurse if you're interested in getting more active.



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 and less severe side-effects during cancer treatment. For example, it reduces the risk of chest problems such as chest infection
- Smoking can reduce how well chemotherapy or radiotherapy works
- Not smoking can help you heal better after surgery

If you would like advice or support on quitting, 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

Gather 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 your worries or any 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 positive all the time, but it's normal to have bad days. Get help if you are finding it hard to cope.

Try to cope day by day

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

Types of treatment

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Surgery



- Surgery aims to remove all or part of a tumour.
- There are different types of surgery, depending on the size of the tumour and where it is found.

Surgery is the most common treatment for oesophageal cancer which has not spread outside the oesophagus. It is mainly done when the tumour is found in one section of your oesophagus only. The aim of surgery is to remove all the cancer cells. The type of surgery you have will depend on your general health and on:

- The type of tumour
- Where the cancer is
- The size of the tumour

Sometimes your surgeon will only find out the exact size and position of the tumour during surgery. If this happens, your treatment plan may change. Your doctors may recommend a different type of surgery or another treatment.

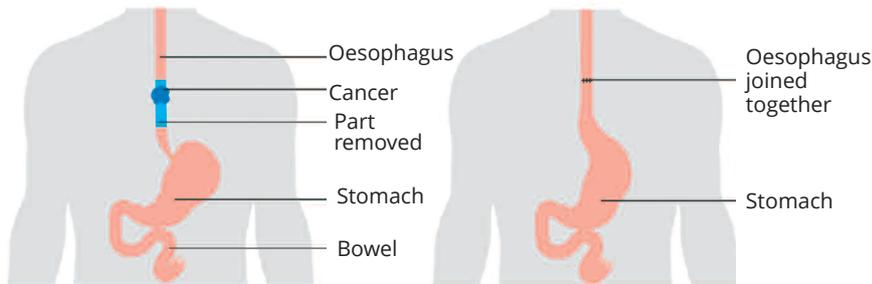
If the tumour is attached to nearby tissues and organs, radiotherapy and/or chemotherapy before surgery can shrink it and make it easier to remove.

Types of surgery

There are many types of oesophageal surgery. Your surgeon may remove the whole oesophagus or just the part that has cancer. Because the oesophagus is a long tube going from one body part to another, the surgery can be done in different ways. Your surgeon may need to make a cut (incision) or cuts in your chest, tummy (abdomen) or neck to remove the tumour, depending on where it is.

Oesophagectomy

The part of your oesophagus with cancer is removed along with lymph nodes and nearby soft tissues. The surgeon pulls up your stomach and joins it to the remaining part of your oesophagus. Rarely it's not possible to join your stomach to the remaining part of the oesophagus. In this case, a section of your bowel (colon) will be used to replace part of the oesophagus.



Images courtesy of Cancer Research UK / Wikimedia Commons

Oesophago-gastrectomy

If the cancer has spread to your stomach, the upper part of your stomach can be removed, as well as the affected part of your oesophagus. This is called an oesophago-gastrectomy. A piece of bowel may be used to join the remaining part of your oesophagus to your small bowel.

Total oesophagectomy

You may need to have your entire oesophagus removed. This is called a total oesophagectomy but it is rarely done.

Removal of lymph nodes (lymphadenectomy)

During the surgery your surgeon will take out some of the lymph nodes from around your oesophagus. This is called lymphadenectomy. If the lymph nodes contain cancer, removing them can help to stop it spreading. The lymph nodes removed will be looked at under a microscope to give your doctor more information about the stage of your cancer.

Getting ready for surgery

Extra tests

You will have tests to make sure you are fit for surgery. These might include a chest X-ray, heart tests (ECG and echocardiogram), breathing tests, and blood tests to check your liver and kidneys.

Smoking

Giving up smoking as soon as possible before your operation will improve your breathing and reduce the risk of a chest infection after surgery. See page 35 for where to get support.

Your diet

A dietitian will visit you and explain how best to manage eating before your surgery. Your dietitian or doctor will also talk to you about:

- How to make swallowing easier, if you're having trouble with this
- Ways to prevent further weight loss and keep up your strength
- What dietary/eating changes to expect after surgery

Feeding tube

If swallowing becomes very difficult, you may not be able to eat enough food. As a result, you may need to be fed by a tube for a while. Your nurse will pass a thin plastic feeding tube into your nose and down into your stomach. Through this you will be fed liquid supplements high in protein and energy. Your family and friends may find it helpful to meet with the dietitian too. That way, they can learn about any changes to your diet.

Deep breathing and leg exercises

A physiotherapist will show you how to do deep breathing and leg exercises. These exercises will help to prevent a chest infection or blood clot after surgery. You will be given special elastic stockings to wear that can also prevent a blood clot in your legs. Your nurse may also give you an injection of heparin to prevent blood clots.

Feeling anxious

It's normal to feel anxious about having surgery. Talk to your nurse or doctor, especially if there's something you're worried about or don't understand.

Community services

If you live alone or have problems getting around at home, talk to your nurse or the medical social worker on your ward. Do this as soon as you are admitted to the ward. That way, he or she can organise any community services you may need after you leave hospital. For example, the public health nurse or home helps.

Before surgery

You cannot eat anything for a few hours before your surgery. Your doctor or nurse will tell you when you should have your last meal. On the day of surgery, your nurse may give you a tablet before you go to theatre. This will make you feel more relaxed and sleepy.



After surgery

- For a few days you will be in the intensive care or high-dependency unit.
- You may be fed through a tube in your bowel until you can eat normally again.
- Most people can go home 10-14 days after surgery.
- Possible side-effects of surgery include poor appetite, feeling full and uncomfortable after eating only small amounts, weight loss, nausea and vomiting.

Drips, drains and tubes

After your operation, you will spend about 2-5 days in an intensive care unit or high dependency unit. At first you may be put on a machine called a ventilator that helps you to breathe until the anaesthetic wears off. When you wake up, you might notice some tubes attached to your body. They might look alarming but are normal after an operation like yours.



Intra-venous (IV) drip: A drip will be put into a vein in your arm. You will be given fluids through the drip until you are able to take fluids by mouth again.

Drains: One or more thin tubes called drains will be attached to you near your wound. These help to drain blood and fluid from the operation site to let your wound heal.

Nasogastric tube: A thin plastic tube may be placed in your nose leading to your stomach or small bowel. Your nurses can then draw up fluid to keep your stomach empty. This will stop you feeling sick and allow the area to heal more quickly.

Urine tube: A thin flexible tube called a catheter may be put into your bladder to drain urine into a bag. This will save you having to get out of bed to go to the toilet. Also, your nurses can check how much fluid you are passing.

Chest drain: These drainage tubes are inserted into your chest during the surgery. They drain any fluid around your lungs into a bottle beside your bed.

Feeding tube: You may have a small feeding tube placed directly into your small bowel. This is called a jejunostomy or JEJ tube. The tube is put in through your tummy during surgery. It can be used to give you all the calories, protein and nutrients you need until you are ready to eat and drink again.

Epidural: You may have a thin tube called an epidural in your back. This is to help relieve any pain you might have.



What happens after surgery?

A team of doctors, nurses, physiotherapists and dietitians will work towards your full recovery. They will help with any problems you have after surgery.

Pain

You may have some pain after surgery, especially when you cough or try to move, but most patients are very comfortable with the epidural pain relief. If needed, you will be given painkillers to ease any pain. You may have a patient controlled analgesia pump (PCA). This sends pain medication into your blood when you press a button. A nurse will show you how to use it. It can help to take your painkillers before getting out of bed or before other activities. If your medicine isn't controlling your pain, tell your doctor or nurse. Always ask for help before the pain gets too bad.

Nausea (feeling sick) and vomiting

You might feel sick (nausea) or vomit after surgery. Your nurses can give you medicine to prevent this, if needed.

Breathing and coughing

A physiotherapist will visit you regularly after surgery. She or he will help you with breathing and leg exercises. Doing these exercises regularly will help to prevent a blood clot in your legs or lungs. You should move your legs and do deep breathing exercises at least once an hour, even when you're in bed. Your physiotherapist will also help you to clear any build-up of mucus (sputum) in your chest to help to prevent an infection. You will also feel more comfortable if you can breathe easily. If you're in pain you may not feel able to do your breathing or leg exercises, so let your nurse or doctor know if you need medication to help with pain. The physiotherapist can also show you other exercises to help loosen up any shoulder stiffness due to surgery.

Wound / infection

Your medical team will keep a close eye on your wound to make sure you're healing well. They will also check the wound and tubes regularly for signs of infection. Let your nurse know if any leakage happens at the wound or tube sites or if you feel hot or unwell.

Starting to eat and drink again

You will only be allowed sips of fluid after the surgery until your surgeon is happy that the join made in your oesophagus has healed. If you had a feeding tube inserted during your surgery, feeding through this begins the day after surgery to meet your nutritional requirements. The amount of fluids you can take will be increased over the next few days. When you are managing fluids, you can start to eat small amounts of soft food. Eat slowly and chew your food well to help you to feel more confident with swallowing. Your dietitian will be there to support you and advise you on what foods to eat to make sure you're getting enough calories and nutrients.

Once you begin to eat and drink reasonable amounts, the tube feeding may be gradually reduced and then stopped altogether. If you cannot take enough food by mouth, the tube feeding can be continued for as long as needed. Managing tube feeding at home can be done easily (see page 48).

Weight loss

It's normal to lose some weight after surgery. Once you're eating and drinking again weight loss should improve. The dietitian will help you to manage your weight and support you with any eating problems.

Moving around

On the day after surgery, your nurses and physiotherapists will help you get out of bed and take you for a short walk. These walks will become more frequent and longer as you feel stronger. Soon you will be able to go for walks on your own.



How long will it take for me to recover?

Every patient is different so the recovery period can vary. If your wound does not heal as quickly as expected, it may delay you getting back to normal eating and drinking. Most people are ready to go home 10–14 days after surgery. But you will feel very tired at times and will need plenty of rest. You may feel weak and lacking in energy for at least 3 months or up to a year afterwards.

For at least 3 months, avoid strenuous activity like vacuum cleaning or lifting heavy bags of shopping. Also avoid bending over from the waist. If you need to pick up something from the floor or tie your shoes, bend from the knees and crouch down. You will not be able to drive for 6–8 weeks after surgery. Your doctor and nurse will discuss this with you.

Before you go home you will be given a date to come back for a check-up. It is usually about 4–6 weeks later.

Tube feeding at home

If you need to continue with tube feeding at home, training will be arranged for you before you go home. Your family members can also learn how to use the tube. Your dietitian will order the tube equipment and give you and the public health nurse all the information you need.

Even if you are no longer being fed through the feeding tube, the tube may be left in place when you go home. It will need to be flushed through regularly to prevent blockages. Your nurse will show you how to do this. The feeding tube will be removed after your check-up if your doctor is satisfied with your weight and food intake.

Healthcare team

You will be given contact numbers so you can reach the healthcare team if you have a problem. Contact a member of the team as soon as possible if you:

- Have a problem with the feeding tube
- Have diarrhoea for more than 24 hours or feel unwell
- Are worried about your wound

If you have a worry or symptom that is causing you concern before your check-up date, contact your specialist nurse for advice. See page 83 for more about follow-up.

If you're feeling sick, your medical team can give you medicine to help with this.

Will I be able to eat and drink normally again?

It may take a while before you get back to normal eating and drinking. It depends on the type of surgery you have and the time it takes for your wounds to heal. You might experience:

- Feeling full and uncomfortable after eating only small amounts
- Having little or no appetite
- Weight loss
- Nausea and vomiting

Eating difficulties often last for a few months after surgery. Getting better can be a slow process. But there are things you can do to help reduce these problems.



Dietary advice

The hospital dietitian will help you with any eating difficulties and advise you on how to have the best possible diet, including if you need any nutritional supplements. Eating well will help your strength and energy levels to improve. Your wounds may heal faster and further weight loss may be prevented.

Feeling full

Feeling full and uncomfortable after eating only small amounts often happens because your stomach is higher up in your chest after surgery. It can also happen if part of your stomach has been removed.

Tips & Hints – feeling full after eating small amounts



- Eat small portions – half portions at the most.
- Reduce the amount of liquids you drink at mealtimes.
- Eat frequently, about 5–6 times each day.
- Eat slowly.
- Do not lie down flat after eating.
- Take anti-sickness medication if advised by your doctor.

Weight loss

Weight loss may continue after you are discharged from hospital. Some weight loss is expected at first. But if you continue to lose weight, let your doctor or dietitian know as soon as possible. You may need more dietary advice, other nutritional supplements or tube feeding. Most likely, you will not get back to the weight you were before your illness.

Finding suitable foods

Finding a pattern of eating and drinking that suits you may take time. You may find that certain foods disagree with you and should be avoided, or your taste may change. Remember you will gradually be able to eat more varied and larger amounts of food. See the middle section of this booklet for ideas about helpful meals and snacks.

Tips and Hints - poor appetite



- Make the most of your appetite when it's good.
- Keep nutritious snacks with you so you can eat when you feel like it
- Try eating something every 2–3 hours.
- Use a small plate for your meals, as large portions can be off-putting.
- Don't fill up on drinks that have little nutritional value. This includes tea, coffee and diet minerals.
- Limit fluids at mealtimes as they will only make you feel fuller.



Radiotherapy

- 
- Radiotherapy uses high-energy rays to kill cancer cells.
 - You normally have treatment every week day for a number of weeks.
 - Any side-effects affect the area being treated. They include sore mouth and throat, difficulty swallowing, pain, tiredness and feeling sick.
 - Side-effects normally go soon after treatment ends, but some can be long-lasting.

Why is radiotherapy given?

The aim of radiotherapy is to destroy cancer cells with as little damage as possible to normal cells. Radiotherapy can be given:

- **Before surgery:** Radiotherapy is given to reduce the size of the tumour and make it easier to remove. It may also improve swallowing. Chemotherapy makes the cancer cells more sensitive to radiotherapy and so you may have both chemotherapy and radiotherapy. This is called chemoradiation.
- **After surgery:** Radiotherapy can be used if there is a risk some cancer cells have been left behind after surgery or that the cancer may return.
- **Relieving symptoms:** Radiotherapy can be used on its own to relieve symptoms such as pain or difficulty in swallowing. This is called palliative radiotherapy.

Radiotherapy can be given in two ways:

External beam radiotherapy

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

Internal radiotherapy (brachytherapy)

The radiation source is placed inside your body in special applicators on or near your tumour. Internal radiotherapy is also known as brachytherapy (“brack-ee-thera-pee”). See page 59 for more about brachytherapy.

Sometimes, external radiotherapy is followed by brachytherapy when treating oesophageal cancer.

Planning external radiotherapy

Radiotherapy must be carefully planned so that the highest dose is given to the tumour area and as little as possible to the nearby cells.

You will have a CT scan to pinpoint the area to be treated. The treatment field or area will then be marked carefully on your skin, usually using tiny tattoo dots. The dose of radiation will be decided and tightly controlled for your treatment.

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

Getting 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. It doesn't hurt but you will have to lie very still, which can be uncomfortable.

Most people receive radiotherapy as outpatients, travelling to the radiotherapy unit each week day, with a break a weekends.

Radiotherapy is normally given in special cancer treatment centres, so you may have to attend a different department or hospital from where you had surgery. If you are having chemotherapy and radiotherapy together, your team will coordinate your treatment.

How much radiotherapy do I need?

The course can be several treatments over a number of days or weeks (5 to 6 weeks) or between 1 and 10 doses for palliative treatment.

For more information on radiotherapy and possible side-effects read our booklet *Understanding Radiotherapy*, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

Will I get any side-effects?

Radiotherapy is given directly to the site of the cancer. The areas that are most likely to be affected by treatment are your throat and chest.

How severe side-effects are will vary from person to person. It depends on the amount of treatment you need and the exact part of the oesophagus needing treatment. The effects of radiotherapy may be more severe if you have had surgery as well. Your doctor, nurse or radiation therapist will explain how these effects can be managed before you start treatment. The side-effects may include:

- Sore mouth and throat
- Difficulty swallowing
- Pain below your ribs in your upper abdomen
- Poor appetite and weight loss
- Feeling sick (nausea)
- Voice changes
- Feeling very tired (fatigue)
- Hair loss in chest area

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.

Sore mouth and throat

Radiotherapy to the oesophagus can make your throat and oesophagus inflamed. This happens because the cells that line these areas are very sensitive to treatment. If your mouth or throat becomes very painful, let your doctor or nurse know as soon as possible. Your doctor will prescribe painkillers if you need them. If you have an infection in your mouth or throat, you may need to be treated with antibiotics or other medication.

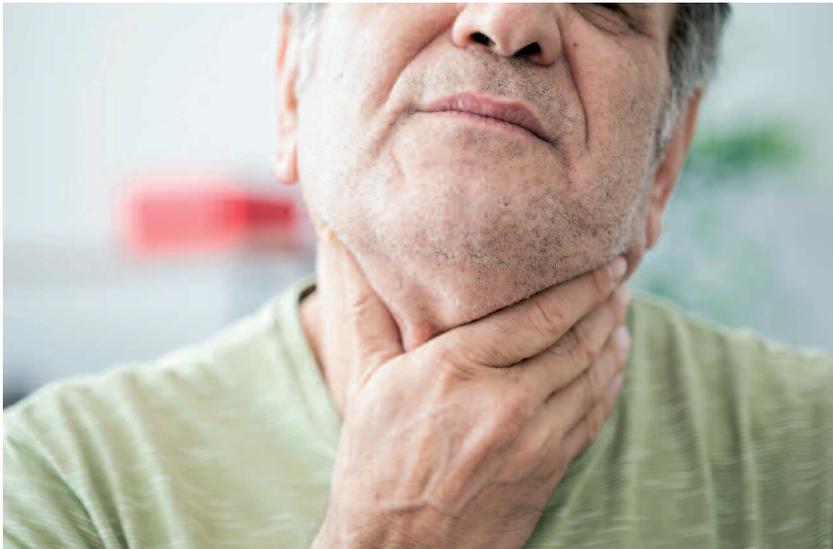
Hints and tips: sore mouth and throat



- Keep your teeth, gums and mouth clean to control soreness and prevent infection.
- Clean your teeth after every meal, using a soft toothbrush.
- If you have dentures, remove them if your mouth is sore.
- Use mouthwashes recommended by your radiation therapist or nurse to keep your mouth clean and ease mild soreness.
- Choose soft moist foods.
- Avoid very hot foods and drinks, salty and spicy foods and citrus fruit drinks.
- Avoid alcohol, especially spirits, and tobacco during treatment and for a few weeks afterwards. They can irritate the lining of your mouth and throat.
- Take cold foods and drinks to soothe your mouth.

Difficulty swallowing

After a week or two of treatment your chest might feel tight and you might have difficulty swallowing. It may feel like you have a lump in your throat all the time. Food or drink may seem to go down the wrong way, making you cough as you try to swallow. If you have difficulty swallowing, ask to see a dietitian. He or she will give you advice on the best foods to eat. Your doctor may also give you medication to take before meals to make swallowing easier. The discomfort will usually ease 5–8 weeks after your treatment ends. See page 71 for more about swallowing difficulties and tips to help you.



Pain

Sometimes radiotherapy to the oesophagus can cause pain when swallowing or pain in your chest. If you are in pain, your doctor can prescribe painkillers. Take them regularly so that the pain can be controlled. The pain normally goes away 4–6 weeks after treatment has ended.

Poor appetite and weight loss

If the part of your oesophagus nearest your mouth is treated with radiotherapy, it can affect the taste buds in your mouth. You may get a loss of taste or a metallic taste in your mouth. If this happens, you may lose interest in food and eat less than you did before treatment.

Remember eating well can speed up wound healing. Ask your nurse to refer you to a dietitian if you have a poor appetite. He or she will watch your weight and give you advice. Your appetite should improve once treatment is over.

Feeling sick (nausea)

You might also feel sick during treatment. Let your doctor know as he or she can prescribe medication to prevent or reduce nausea. Eat six small meals or snacks a day rather than three large meals. Avoid fatty, spicy, very sweet foods or foods that have a strong smell as these may make the nausea worse. If you have been vomiting, drink plenty of fluids to replace the fluids you have lost.

Voice changes

Sometimes radiotherapy to the oesophagus may cause the sound of your voice to change. Your voice may become quieter or sound hoarse. It may even become sore for you to talk. This common effect of treatment usually doesn't last long. The quality of your voice should start to improve about 2 to 3 weeks after treatment.

Skin changes

During radiotherapy the skin in the treated area may become red and sore. It may even look like sunburn. Only use creams advised by your nurse or radiation therapist. If you need to wash the area, use warm water and pat it dry with a soft towel. Do not rub the skin while washing and drying. If you shave, only use an electric razor. It is best to avoid all aftershaves, perfumed creams or powders.

Feeling very tired (fatigue)

Tiredness can build up over the course of your treatment, so you may feel more tired towards the end of your treatment or after treatment is finished. Tiredness can be a side-effect of the radiotherapy or it can happen because of the demands of a busy treatment schedule, especially if you're travelling long distances for treatment. See page 74 for more about fatigue.

Hair loss in treated area

Any hair in and around the treatment area will fall out, for example chest hair. The hair loss is usually temporary, but it may be thinner when it grows back.

Cough and shortness of breath

You may develop a dry or mucus-type cough and some shortness of breath with radiotherapy. Sometimes this side-effect may not appear until several months after your treatment. If it happens, you should tell your doctor as soon as possible.



NUTRITIOUS SNACKS

- 🍷 Cereals – hot or cold
- 🍷 Beans on toast
- 🍷 Cheese and crackers
- 🍷 Custards
- 🍷 Hot chocolate (make with milk)
- 🍷 Milk puddings
- 🍷 Milkshakes
- 🍷 Creamy soups
- 🍷 Yoghurt or fromage frais
- 🍷 Smoothies
- 🍷 Mousses



- 🍷 Sandwiches
- 🍷 Nuts
- 🍷 Omelettes
- 🍷 Quiche



- 🍷 Muffins or scones
- 🍷 Scrambled eggs
- 🍷 Baked potatoes with beans, cheese, tuna
- 🍷 Dips made with cheese or yoghurt



LIQUIDS



CLEAR LIQUIDS



- Water
- Fruit juices without fruit pieces
- Clear broth
- Consommé
- Ice pops
- Honey
- Clear fizzy drinks like flat lemonade drinks
- Sports drinks
- Strained vegetable broth



FULL LIQUIDS

- Milk
- Fruit juices
- Fruit nectars
- Fresh or frozen yoghurt
- Milkshakes
- Fruit purée
- Smooth ice cream
- Liquidised soup
- Tomato juice
- Vegetable juice
- Build-up drinks
- Soft custard
- Drinking chocolate



SOFT DIET

- Omelette or scrambled egg
- Baked egg custard
- Egg mayonnaise
- Creamed soups
- French toast
- Baked beans with grated cheese
- Tinned spaghetti with grated cheese
- Macaroni cheese
- Cauliflower with cheese
- Casseroles or stews
- Shepherd's pie or cottage pie
- Bolognese sauce
- Lasagne
- Savoury mince



- Pasta with creamy tomato sauce
- Soft poached or flaked fish in sauce
- Salmon mousse
- Fish and potato in a creamy sauce
- Mashed carrots with honey and cream
- Vegetables mashed with butter and melted cheese
- Chicken in cream sauce
- Quiche
- Jacket potato with butter, grated cheese or cream cheese
- Dips like hummus, pesto, guacamole, cream cheese

HOW TO INCREASE CALORIES

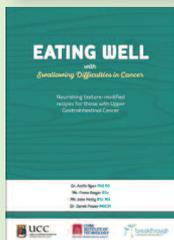


- Add butter or margarine to soups, mashed and baked potatoes, sauces, cooked vegetables, rice.
- Add whipped cream to desserts, puddings and fruit. Add it unsweetened to mashed potatoes and puréed vegetables.
- Add milk or cream to soups, sauces, puddings, custards, cereals. Use cream instead of milk in recipes.
- Add cheese to casseroles, potatoes, vegetables, omelettes, sandwiches. Melt where possible.
- Add chopped hard-boiled eggs to salads, vegetables, casseroles.
- Sauté or fry foods if you can tolerate them.
- Add sauces or gravies to your food.

HOW TO INCREASE PROTEIN

- Eat more hard and soft cheeses. Add them to food where possible.
- Use milk instead of water as a drink and in cooking when possible. Use full fat milk.
- Take build-up drinks.
- Add ice cream or yoghurt to drinks, fruit and cereals.
- Add eggs to your food whenever possible. Avoid raw eggs.
- Add nuts, seeds and wheat germ to your food. Add to casseroles, salads, breads, biscuits.
- Add chopped meat or fish to vegetables, salads, casseroles, soups, baked potatoes.
- Eat more beans and peas. Add to soups and casseroles.

If you want tips and recipe ideas, ask your medical team for our booklet *Diet and Cancer* or the booklet *Eating Well with Swallowing Difficulties* (from Breakthrough Cancer Research). Or call our Cancer Nurseline for copies.



Brachytherapy (internal radiotherapy)

Sometimes radiotherapy is given by putting a radioactive source inside your body for a few minutes. This can help to slow down the growth of cancer cells. Different doses can be given but often a high dose rate is given for a very short time.

Treatment

Your doctor will first spray the back of your throat with local anaesthetic. A fine tube is then placed in your oesophagus through your nose. Then your doctor will take an x-ray to help him plan the treatment.

Once the planning has been done, the radioactive source will be put into the tube. It will travel to the area to be treated, gives the treatment and then returns safely to the machine. The planning X-ray lasts about 1 hour and the treatment itself takes about 10 minutes. Once the tube is removed, you can go home. No radioactivity will be left in your body so it is safe for you to mix with family and friends. Usually, only one or two treatments are needed.

Side-effects

The treatment may cause nausea and soreness when swallowing. These may happen a few days after treatment and last for a few days. Your doctor can prescribe medication to help with swallowing and ease any nausea and soreness. You will not have any hair loss with this treatment.

If you feel unwell or have any other side-effects or symptom - during or at any time after treatment - tell your doctor, nurse or radiation therapist.

Chemotherapy

- Chemotherapy uses drugs to kill cancer cells.
- Possible side-effects of chemotherapy include infections, sore mouth, feeling sick or vomiting, hair loss, tiredness and poor appetite.
- Side-effects normally go after treatment ends.

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

When is chemotherapy given?

Chemotherapy can be given at different times and for different reasons:

With radiotherapy

Chemotherapy is often given with radiotherapy, usually before surgery or if surgery isn't possible. This is called chemoradiation. You may have to go to 2 different departments to get the different treatments.

After surgery or radiotherapy

This is given to kill any cancer cells left behind or prevent them coming back.

To relieve symptoms

If cancer has spread beyond your oesophagus, chemotherapy can help to shrink and control it. The aim of treatment is not to cure the cancer but to improve your symptoms and quality of life.

How often will I have chemotherapy?

Chemotherapy is often given in cycles with a rest period between treatments. For example, you might have 4–5 days of treatment every 3 weeks with a rest period in between. This rest period allows your body time to recover from the side-effects of treatment. The number of cycles can vary, depending on your cancer type and how well it is responding to treatment.

How is chemotherapy given?

Chemotherapy drugs may be given directly into a vein as an injection or through an intravenous infusion (by drip or pump). They may also be given in tablet form. Usually you will go home on the same day.



Most chemotherapy treatments are given in day care.

What kinds of drugs are used?

There are several chemotherapy drugs used to treat oesophageal cancer. You will probably have a combination of different drugs. Your doctor or nurse will discuss your treatment with you.



Understanding your drug treatment



It's important that you understand the drugs you have been given. Don't be afraid to ask your doctor or specialist nurse for more information about your drug treatment 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 happen because chemotherapy affects both cancer cells and normal cells.

Most side-effects can be well controlled with medication. Usually the side-effects go away when treatment ends or soon after. Side-effects include:

Infection

Chemotherapy can make you more likely to get infections.

Watch out for signs of infection. These signs include feeling shivery and unwell, having a high temperature, having a cough, or pain passing urine. If this happens, tell your hospital doctor or nurse straight away. He or she will tell you what to do.

Sore mouth

Some drugs can cause problems like a sore mouth or mouth ulcers. Try to keep your teeth, gums and mouth very clean, as this will reduce the risk of getting a mouth infection. Clean your teeth after every meal, using a soft toothbrush. If you have dentures remove them if your gums are sore. There are special mouthwashes that you can use too. Your nurse will advise you about these.

Bleeding and bruising

Chemotherapy drugs can stop your bone marrow from making enough platelets. This is called thrombocytopenia ("throm-bow-sigh-toe-pee-knee-a"). Platelets help your blood to clot and stop bleeding. With fewer platelets you may bleed or bruise very easily. Let your doctor or nurse know straight away if you have any bruising or bleeding that you can't explain, such as nosebleeds or bleeding gums or if you notice tiny red spots under your skin that can look like a rash (petechiae ["peh-tee-kee-ay"]). You may need a platelet transfusion.

Feeling sick (nausea) or being sick (vomiting)

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

Numbness or pins and needles in your hands and feet (peripheral neuropathy)

Some chemotherapy drugs can affect your nerve endings. This may cause tingling, numbness or burning sensations in your hands and feet. Tell your doctor if it happens, as changes may need to be made to your treatment.

Hair loss (alopecia [“allo-pee-see-a”])

Some chemotherapy drugs can cause hair loss from all over your body. How much hair falls out depends on the drug given, the dose and your own reaction to it. Hair will grow back after you stop chemotherapy.

Hand-foot syndrome

This is 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 can help to avoid friction and heat, so do not rub your skin or put pressure on it. Ice packs may help. Tell your nurse or doctor if you notice this side-effect. They can give you medication and creams to help and may change your treatment.

Ongoing tiredness (fatigue)

Fatigue is where you feel tired and weak and rest doesn't seem to help. See page 74 for more about fatigue.

Poor appetite

It is best to eat as well as you can while on chemotherapy to keep up your strength. Eating smaller amounts more often can help. If you don't feel like eating during treatment, ask to see a dietitian who can give you specific dietary advice. See page 51 for tips to help with poor appetite.

Our booklet *Diet and Cancer* has tips and recipe ideas to help you to eat as well as possible. Call our Cancer Nurseline or visit a Daffodil Centre for free copies.

Other side-effects

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 chemotherapy and possible side-effects, see our booklet *Understanding Chemotherapy and other cancer drugs*. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a free copy. You can also download it at www.cancer.ie



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 part of a trial, you will 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.

There are active clinical trials on-going in the cancer centres. These include studies in immunotherapy, chemotherapy, diet and exercise. There may also be the opportunity to enrol in international studies.

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.

Treating cancer that has spread (metastatic cancer)

Metastatic cancer is when the cancer has spread to other parts of your body.

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

There is a range of treatment options for most advanced cancers, and new treatments are being developed all the time.

Often metastatic cancer is treated with chemotherapy or targeted therapies. There may also be treatments that you can have as part of a clinical trial (see page 66).

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

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

Palliative care



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

The palliative care team can include specially trained doctors, nurses, social workers, physiotherapists, occupational therapists, complementary therapists, chaplains and counsellors. Palliative care can be arranged by your family doctor (GP), public health nurse or by the hospital. Palliative care is a free service for all patients. You don't need medical insurance.



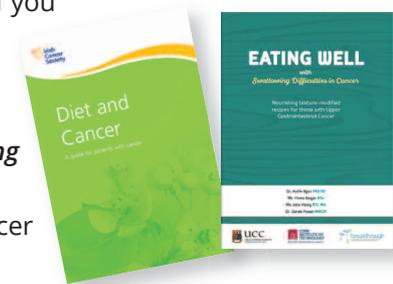
Managing side-effects and symptoms

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Difficulty swallowing (dysphagia)

Difficulty swallowing can be a problem if you have oesophageal cancer. It can be caused by the tumour itself or if the oesophagus is narrowed after surgery or radiotherapy. Remember do tell your doctor or nurse straight away if you have difficulty swallowing or a poor appetite.

Ask your dietitian for advice on eating. She or he can advise you on ways to make foods easier to swallow and ways to get the most nutrition possible into your diet. If you want tips and recipe ideas, ask your medical team for our booklet *Diet and Cancer* or the booklet *Eating Well with Swallowing Difficulties* (from Breakthrough Cancer Research). Or call our Cancer Nurseline for copies.



Hints and tips: difficulty swallowing



- Ask your dietitian for advice about how to make eating easier and if you need to take supplements or eat special foods
- Eat foods that you can swallow comfortably
- Chew food well before swallowing
- Finely chop, mince, mash or liquidise your food
- Have sips of liquid between mouthfuls to help you to swallow.

Treatments for swallowing difficulties

Sometimes, the cancer can cause the oesophagus to be permanently narrowed. If you continue to have problems with swallowing, your doctor may suggest one or more of the following treatments. Sometimes they may need to be repeated.

Oesophageal dilatation

Oesophageal dilatation is a treatment that stretches and widens a narrowed area in your oesophagus so food and drink can pass through again. It uses an instrument called a dilator and it can be done quickly under general or local anaesthetic.

The dilatation may last only a short time and need to be repeated a few weeks or months later. A different type of dilator might be used instead. Your doctor and dietitian can advise you on the best consistency of food to take after the dilatation.

Oesophageal stent

Another way to make swallowing easier is to put a hollow tube called a stent into your oesophagus. The stent is made of plastic or wire mesh. It is put in under local or general anaesthetic like during an endoscopy. Once in place, it expands to keep your oesophagus open so you can swallow more easily.

Once you are awake, you can start taking fluids. Gradually you will be given small amounts of soft food to eat. Your dietitian will advise you on the type of foods you should eat. You will need to chew your food thoroughly before swallowing so the stent does not get blocked. Foods that are soft and moist are generally the most suitable. But you may need to blend your food too. Having drinks with your food and after food can help to keep the stent clean.

Laser therapy

Some patients may be suitable for laser therapy. Here the heat from a laser beam will burn the cancer away. It will not destroy the entire tumour but will allow food to pass down to your stomach and so make swallowing easier. Laser therapy is usually done under general

anaesthetic. Once you are asleep, your oesophagus may be dilated so that an endoscope can be passed through. Then a flexible tube is passed through the endoscope so the laser beam can reach the tumour. The laser beam is then turned on and most of the tumour is burned away.

Another session may be needed if you have a severe blockage in your oesophagus. It can also be repeated after 4–6 weeks if needed. Your doctor will discuss this with you.

The treatment does not hurt but you might get some swelling in your oesophagus for a short while. You may find it more difficult to swallow at first, but this will pass. There may also be some discomfort in your tummy. Let your doctor know if you have any pain or discomfort.



How can I cope with fatigue?

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

It's common to feel fatigued 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

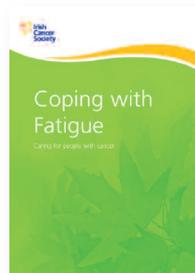
Usually fatigue improves once treatment is over, but it can carry on for some people. Tell your doctor or nurse if fatigue is affecting you, so that they can help you.

Finding out what is causing your fatigue makes it easier to treat.

For example, if you have a low red blood cell count a transfusion can make you feel better.

If you are not eating well a dietitian may be able to give you some advice to help you.

Our booklet, *Coping with fatigue* has more advice. Call our 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, especially 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?

Cancer can affect how you feel about sex and your relationships. Coming to terms with the fact that you have cancer can take a while. It can be hard to relax when you have a lot of worries on your mind. You may also feel tired from the effects of treatment and lose interest in sex as a result. Some people fear that cancer can be passed on to a partner during sex. This isn't true.

There's 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 eases 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 relationships 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 and depends on your treatment. Some people fear that cancer can be passed on to a partner during sex. This isn't true.

Sex after surgery

It may be some weeks before you will feel well enough to have sex after surgery.

If you have had all or most of your oesophagus removed, this may change the way you feel about your body. If you have a feeding tube in place, it may affect your body image. You may also have concerns about the way your partner will react. Try to talk to your partner about the way you are feeling.

Contraception

If you are having sex and are fertile, you should use a reliable method of contraception for some time after treatment. For example, some chemotherapy and other cancer drugs may increase the risk of miscarriage or birth defects in children conceived during or for a time after treatment.

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

Ask your doctor's advice about contraception or if you are 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 so that you may not be able to have a child in the future.

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

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

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.



After treatment

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What follow-up will I need?

Once your treatment for cancer is over, you will need to go back to hospital for regular check-ups. This is called follow-up. The follow-up may involve having a physical exam, blood tests and scans. Your doctor may check if there is scarring of the oesophagus or where the surgeon has made the joining. You can also meet with the dietitian to discuss any eating problems you might have. If your mobility has not improved or you have trouble breathing, the physiotherapist can help you.



At first you will see your consultant every 3 months but these check-ups will become less frequent over time.

Tell your doctor or nurse how you have been since your last appointment. Remember to tell them about any eating problems or other symptoms you have, especially difficulty swallowing. You can also tell the doctor if you are feeling anxious or depressed or finding it hard to cope.

Sometimes it helps to write down what you want to say before you see the doctor. That way you won't forget what you wanted to say.

At first the check-ups will be quite often. They will continue for a number of years but will become less frequent over time.

If you 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.

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-aftercancer-treatment. You can also call our Cancer Nurseline or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 91 for other ways to get support.

Healthy lifestyle changes

Many people want to make positive changes to their lives after a diagnosis of cancer.

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

- Feel better
- Heal and recover faster
- Keep up your energy and strength

A healthy lifestyle includes:

- Exercising
- Eating well
- Not smoking
- 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 the cancer does come back it can often be treated again. Your cancer doctor will advise you on what your treatment options are.

Planning ahead

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

Planning ahead might include:

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

Who can help me plan?

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

Coping and emotions

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How can I cope with my feelings?

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

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

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

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

A helpful booklet that discusses in detail how you may be feeling is called *Understanding the Emotional Effects of Cancer*. Call our 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



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

Ways to get emotional support



Find out about cancer support services in your area: Most provide a range of helpful services like counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 111 for more about cancer support services.

Join a support or educational group: You may 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.

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

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

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

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

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.

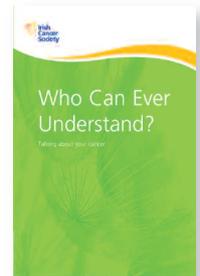
In time, some people say they can find positive things in their cancer experience. They say that cancer brought them closer to the people around them or made them appreciate what's important in life. Or it opened up new experiences and relationships.

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

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

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.



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

Changing relationships

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



Supporting someone with cancer

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Supporting someone with cancer

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

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

Learn about cancer

Try to go to hospital visits and also read any information from the hospital so you can understand your loved one's illness and treatment, how it might affect them, physically and emotionally, and how you can best support them. Visit our website www.cancer.ie or call our 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 90.

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

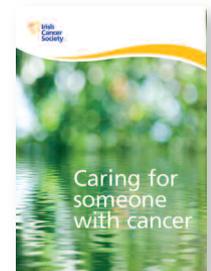


Our cancer nurses are there to support you. Call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or email cancernurseline@irishcancer.ie for confidential support, advice and information.

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 and our Cancer Nurseline, or download it from our website www.cancer.ie





Support resources

Coping with the financial impact of cancer 103

Irish Cancer Society services 106

Local cancer support services 111

Coping with the financial impact of cancer

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're worried about money.

Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Medicines
- Visits to hospital
- Appliances, like wigs
- Overnight stays in hospital

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** – 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 photocopy completed forms 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 are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 108 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

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. 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 are available to provide emotional and practical support to anyone going through or finished with their treatment.

Support in your area

We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support including counselling. See page 111 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 having difficulty getting to and from their treatments while attending one of the national centres of excellence or their approved satellite centres.
- **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>

What does that word mean?

Abdomen	The part of your body that lies between your chest and hips. Also known as your tummy.
Adjuvant	Treatment given soon after surgery.
Alopecia	Loss of hair or no hair where you normally have hair.
Anaemia	A shortage of haemoglobin in your red blood cells. This causes fatigue, weakness and shortness of breath.
Benign	Not cancer. A tumour that does not spread.
Biopsy	Removing a small amount of tissue from your body to find out if cancer cells are present.
Cells	The building blocks that make up your body. They are tiny and can only be seen under a microscope.
Dilatation	Stretching or widening. Can be used to help open up the oesophagus to help you to swallow
Malignant	Cancer. A tumour that can spread.
Metastasis	The spread of cancer from one part of the body to other tissues and organs.
Nausea	Feeling sick or wanting to be sick.
Neo-adjuvant	Treatments such as chemotherapy and radiotherapy given before surgery to reduce the size of a cancer.
Oncology	The study of cancer.

Questions to ask your doctor

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

What tests 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?

What are the expected benefits of treatment?

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?

Did 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?

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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Published in Ireland by the Irish Cancer Society.

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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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