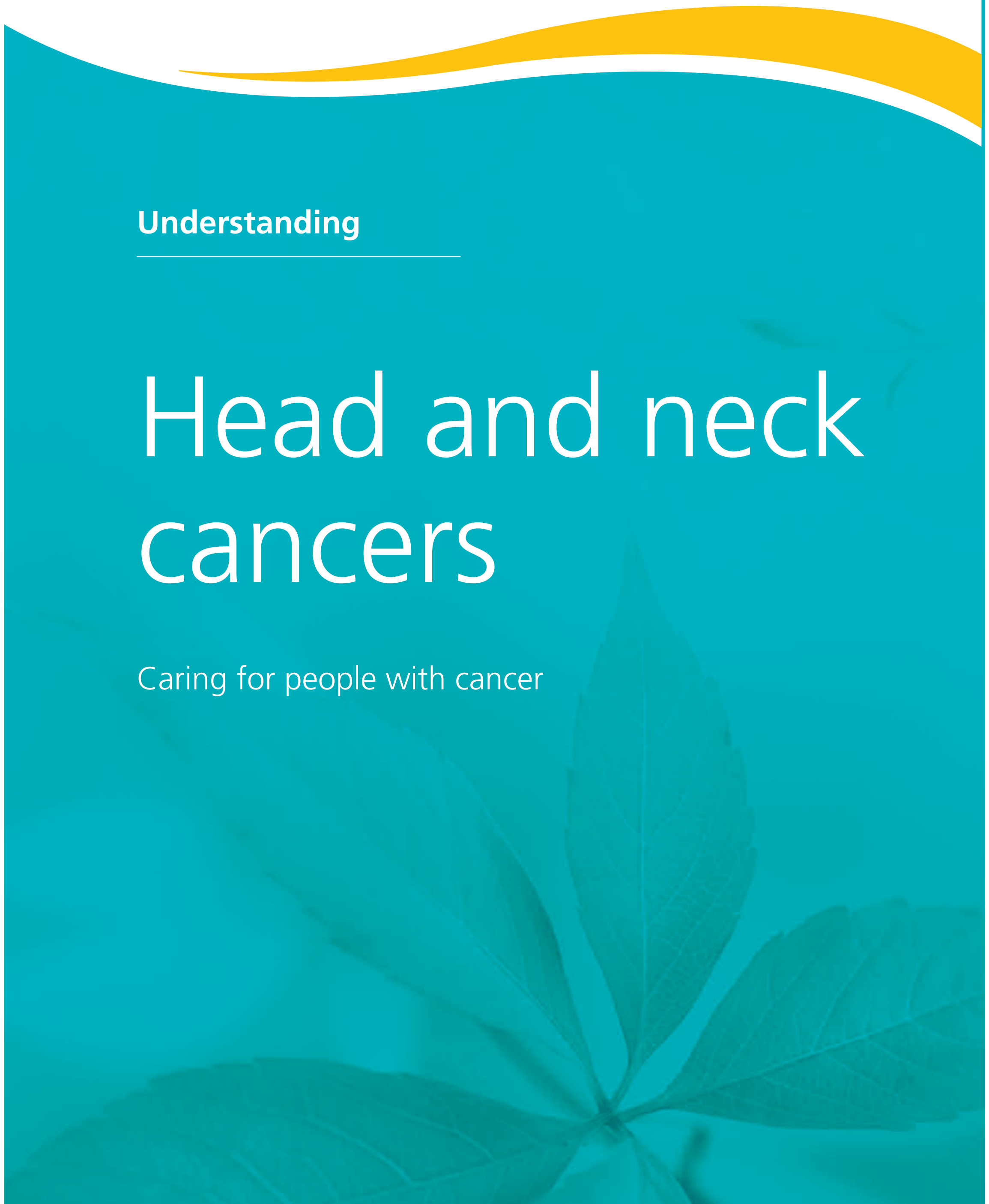
Irish Cancer Society



Understanding

Head and neck cancers

Caring for people with cancer

Understanding

Head and neck cancers

This booklet has information on:

- Treatment for cancers affecting the mouth, head and neck area
- Side-effects and how to manage them
- Coping with the emotional side of cancer
- Financial and practical matters

Brain tumours are not classed as head and neck cancers. Please see our booklet ***Understanding brain tumours*** for more information.

Useful numbers

Specialist nurse	
Family doctor (GP)	
Surgeon	
Medical oncologist	
Radiation oncologist	
Radiation therapist	
Medical social worker	
Emergency	
Hospital records number (MRN)	

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Fast facts

Can my cancer be treated? Page 33

There are treatments for all types of head and neck cancer. The best treatment for you will depend on the type of cancer you have, where it is and how big it is. Your doctor will advise you about this.

What treatment might I have? Page 47

Surgery: An operation to remove the cancer. You may also need surgery to reconstruct the area if a lot of tissue or bone has been removed (see page 50)

External radiotherapy: High-energy rays used to kill cancer cells (see page 59)

Chemotherapy: Drug therapy used to destroy cancer cells or to control cancer growth (see page 78)

Targeted therapies: Drugs that target cancer cells in different ways to stop the cancer growing (see page 83)

Immunotherapy: Drug therapy that helps the person's immune system to slow down and control the growth of cancer cells (see page 85).

Clinical trials Page 88

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

How will treatment affect me? Page 47

Some treatments can cause side-effects, but these usually get better after treatment has ended. You may also have temporary or permanent changes to the way you look, eat or breathe after some treatments. You can read about the different treatments to learn more about any possible side-effects.

We're here for you Page 132

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

Ways to get in touch

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

See page 132 for more about our services.

Reading this booklet

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

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

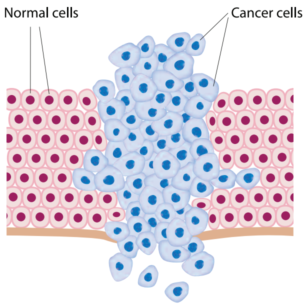
- Call our Support Line on Freephone 1800 200 700
- Visit a Daffodil Centre
- Email the nurses at **supportline@irishcancer.ie**

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 head and neck cancers

What is cancer?

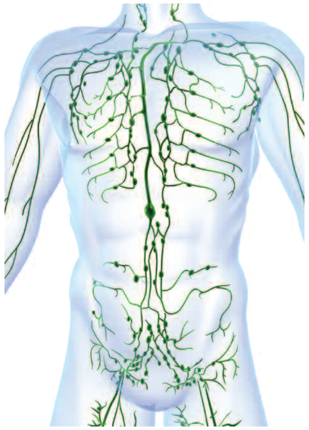
- **Cancer is a disease of the body's cells**
  Cancer cells are abnormal cells that grow without control. They can form a lump (tumour).



- **Cancers are named after the organ or cell where the cancer starts**
  For example, mouth cancer starts in cells in the mouth, laryngeal cancer starts in cells in the larynx.
- **Cancers sometimes spread**
  If a tumour is cancerous (malignant), a cell or group of cells can be carried by your blood or lymph fluid to another part of your body, where it can form a new tumour. This is called metastasis. Sometimes cancer cells spread into nearby lymph nodes.

What is the lymphatic system?

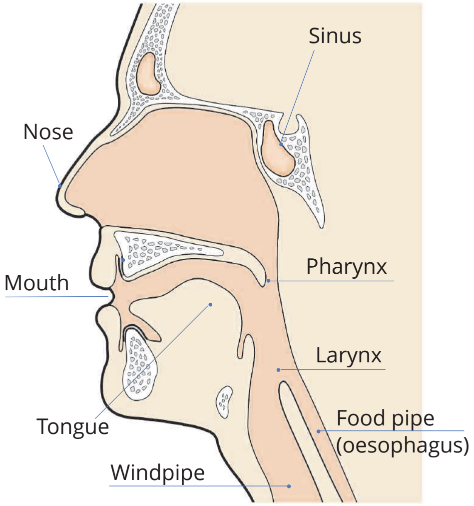
- The lymphatic system is part of our immune system. It protects us from infection and disease and removes extra fluid and waste from the body's tissues.
- It is made up of lymph nodes connected by tiny tubes called lymph vessels.
- Lymph nodes are found mainly in the neck, armpit, groin and tummy.
-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



What are head and neck cancers?

Head and neck cancers are cancers of the mouth and throat as well as rarer cancers inside the nose, sinuses, salivary glands, middle ear and larynx. These include:

- **Oral cavity (mouth) cancer**
- **Laryngeal (voice box) cancer**
- **Pharyngeal (throat) cancer** – including cancer of the nasopharynx, oropharynx and hypopharynx
- **Salivary gland cancer**
- **Nasal and paranasal sinus cancer**
- **Cancer of the base of tongue and tonsils**
- **Upper oesophageal (food pipe) cancer**
- **Cancer of the head and neck lymph nodes** – either as primary disease (lymphoma) or as secondary spread of other tumours
- **Cancer involving the base of the skull**
- **Thyroid cancer** – while thyroid cancer affects the thyroid gland at the front of your neck, and head and neck surgeons treat thyroid cancer, we do not cover thyroid cancer in this booklet. See our booklet ***Understanding thyroid cancer*** for more information on thyroid cancer.

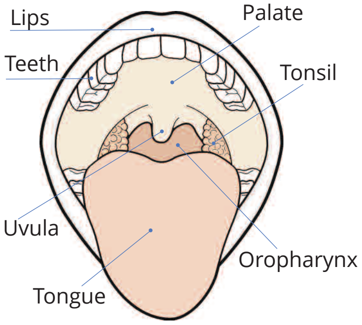


Cancer starts when the cells change and grow in an abnormal way. They then form a mass or tumour.

Mouth (oral) cancers

Mouth cancers can affect your lips, tongue, gums, cheeks, roof of your mouth (the hard palate) and the side or floor of your mouth (under your tongue).

The soft part of the roof of your mouth (soft palate), the back and side walls of your throat, tonsils and the back of your tongue (the part you can't see) are called the oropharynx. Oropharyngeal cancers affect this part of your mouth and throat. Cancers to the side of your tongue and the floor of your mouth are the most common.



Treatment for mouth and oropharyngeal cancers

Surgery is the main treatment for many mouth (oral cavity) cancers. Chemoradiation (radiotherapy and chemotherapy together) is often the first treatment for oropharyngeal cancers (such as tonsil and tongue base). Early cancers may be treated with laser surgery using a tube passed into your mouth which has a laser on the end (trans-oral endoscopic surgery). See page 49 for more about surgery. If you have tissue or bones in your jaw or mouth area removed as part of your surgery, you may also have reconstructive surgery (see page 50).

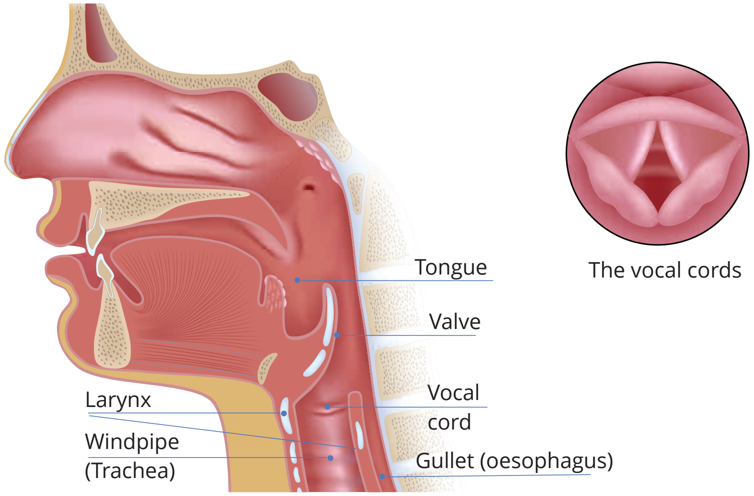
Radiotherapy can sometimes cure an early-stage cancer or it can be used after surgery to reduce the risk of the cancer coming back. You may also have other treatments such as **chemotherapy** (see page 78), chemoradiation (chemotherapy and radiotherapy together) or targeted therapies (see page 83).

Mouth and oropharyngeal cancers side-effects

Treatment for mouth and oropharyngeal cancer might affect how you look, eat, speak or breathe. It can take time to get used to these changes. See page 91 for information and tips to help you with these changes.

Cancer of the larynx (laryngeal cancer)

The larynx is also called the voice box. It is a tube at the front of your throat that contains the vocal cords. It is a rare cancer, but it is the second most common cancer in the head and neck area.



The vocal cords

Treatment for laryngeal cancer

Laser surgery is a common treatment for early cancer in the larynx. Radiotherapy and surgery to remove all or part of the larynx are other possible treatments, as well as chemotherapy and targeted therapies (see page 47). How much tissue will be removed and what other treatments you might need will depend on the stage of the cancer (see page 28).

Laryngeal cancer side-effects

Treatment for laryngeal cancer might affect how you eat, speak or breathe. See page 91 for more on coping with these changes. If you have surgery to remove your whole larynx you will need to learn to speak in a new way (see page 99).

Other head and neck cancers

Cancer can also affect your nose, ear, eye or salivary glands. Various treatments are used, depending on the cancer type. For example, surgery, radiotherapy, brachytherapy (a radioactive implant). See page 47 for more about the different treatments. Melanoma eye cancer can be treated with laser therapy. See our website for more about this.

If you want more information on these rare cancers, visit our website or talk to one of our cancer nurses by visiting a Daffodil Centre or calling our Support Line on 1800 200 700.

Head and neck cancers – different cell types

Squamous cell cancers (carcinomas) start in the squamous cells lining your mouth, nose, throat, tongue or ear. Most head and neck cancers are squamous cell cancers.

Lymphomas begin in the cells of the lymphatic system and travel to areas of your head and neck.

Sarcomas are tumours in the muscle, cartilage, bone or blood vessels around your head and neck.

Melanomas are cancer cells that grow in the pigment cells that give colour to your skin and eyes. They can also occur in the cells that line your mouth.

What caused my cancer?

We don't know exactly what causes many cancers. Some types are caused by viruses, such as the human papillomavirus (HPV). See page 26 for more.

If you want to know more about why cancer happens or to learn about risk factors for head and neck cancers, see our website **www.cancer.ie** or talk to a cancer nurse – call our Support Line or visit a Daffodil Centre.

How common are head and neck cancers?

Over 700 people are diagnosed with head and neck cancers in Ireland each year. This does not include people diagnosed with thyroid cancer.

Preparing for your hospital appointments

Preparing for your hospital appointments

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

Before your appointment

- **Write down a list of questions** and things you would like to discuss.
- **Know where you are going and plan your journey** (build in extra time for unexpected delays).
- **Dress in warm comfortable clothes and shoes** – sometimes you can be waiting around for a while. Layers are best, as the temperatures in hospitals can vary a lot. Loose-fitting clothing will be easier to manage if you are having your blood pressure taken, blood tests or a physical examination.
- **Try to drink clear fluids** (water or juice without pulp) if you are having a blood test as it makes it easier for the nurse or doctor to find a vein. If you are told to fast, you may only drink water.
- **Check with the hospital if it is okay to bring someone with you.** Ask a friend or family member to go along for extra support.

What to take to your appointment

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

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

Before leaving the appointment

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

After the appointment

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

Note

If you have to cancel your appointment...

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

Diagnosis and tests

Being diagnosed with cancer

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

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

However you feel, you are not alone.

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

- **Ask to speak to the cancer (oncology) liaison nurse or the medical social worker at the hospital.** They can help you and your family to cope with your feelings and advise you about practical matters.
- **Talk to one of our cancer nurses in confidence** – visit a Daffodil Centre or call our Support Line on 1800 200 700. You can email the nurses at supportline@irishcancer.ie
- **Speak to an Irish Cancer Society 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 affected by cancer.** Join our online community at **www.cancer.ie/community**
- **Go to your local cancer support centre.** For more information, see page 138.

> ‘However you feel,
> you are not alone.’

Telling people about your diagnosis

Telling people about your diagnosis can help you to get support from friends and family. But you may feel you don't want to tell people straight away. You may be unsure how to break the news. You may also worry about how other people will react. For example, they may fuss over you or be upset. If you would like to talk things over with a cancer nurse, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

You can also ask for a copy of our booklet ***Understanding the Emotional Effects of Cancer.*** It can help you find ways to talk about your cancer and to ask for the help and support you need.

What tests will I have after diagnosis?

- Tests you may have after your diagnosis include CT scan, MRI scan, PET scan and ultrasound scan.
- The tests will tell your medical team more about your cancer and help them to decide on the best treatment for you.

The following tests give doctors information about your health and your cancer – its size, where it is and if it has spread. Some tests may also be used to see how well you are responding to treatment.

Chest X-ray

This is a routine test to show any abnormalities or disease in the airways, lungs or heart.

Ultrasound scan

In this test, a picture is built up of the tissues inside your body using sound waves. Any part of your body can be scanned. The scan is painless and only takes a few minutes. Some gel is first put on the area to be scanned. A small device like a microphone is then passed across the area to take the scan. The test does not hurt and only takes about 10 minutes. You can go home afterwards.

CT scan (CAT scan)

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

Testing for viruses

Some types of cancers can be caused by viruses. Knowing if your cancer is positive or negative for a particular virus can help your doctors decide which treatments will be most effective for you.

HPV test for mouth cancers

Your doctors may do a test (called p16) on a sample of cancer cells removed during a biopsy to see if your cancer was caused by the human papillomavirus (HPV).

Epstein Barr virus (EBV) test for nasopharyngeal cancer

Your doctors may do a blood test to see if your cancer is linked to the EBV.

MRI scan

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

An MRI can also be noisy, but you will be given earplugs / headphones to wear to help block out the sound. You might get an injection before the scan to show up certain parts of your body. You cannot wear metal jewellery during the scan. If you have a medical device implanted, like a pacemaker or metal pin, you may not be suitable for the test. Usually you can go home soon after the scan.

PET scan

A PET scan can show if the cancer has spread to other tissues and organs. A low dose of radioactive sugar is injected into your arm. An hour or so later you will have a scan. The radioactivity can highlight cancer cells in your body.

During the scan, you will lie on a table which moves through a scanning ring. The scan can last up to an hour. Before the scan, you may have to fast (not eat) for a few hours.

PET is safe to use and usually there are no side-effects. You may have to travel to a specialist centre to have a PET scan, as not every hospital has these scanners.

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

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

Waiting for test results

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

Staging and grading head and neck cancers

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

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 if it has spread

Grading describes the cancer cells — what they look like under the microscope and how they might grow

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

How are head and neck cancers staged?

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

- **Tumour (T)**: What is the size and extent of the main tumour? For example, T1 is a small tumour and T4 is large.
- **Nodes (N):** Is there cancer in the lymph nodes? N1, for example, means the cancer is also in nearby lymph nodes.
- **Metastasis (M)**: Has the cancer spread to other parts of the body? M1 means the cancer has spread to other organs such as liver or lungs and M0 means it hasn't.

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 advanced cancer. Some stages are further divided into stage A and B.

Other terms your doctor may use

- **Early cancer (stage I or 2)**: These cancers are small (less than 4cm in size) and have not spread.
- **Advanced cancer (stage 3 or 4)**: These cancers are bigger (more than 4cm), have grown into nearby tissues, are in the lymph nodes, or have spread to other parts of the body.

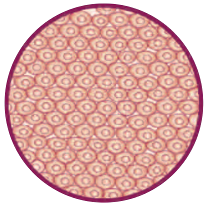
In general, the chance of cure is greater with lower-stage cancers, but it's best to talk to your doctor about staging and what it means for your treatment.

Staging can be hard to understand, so ask your doctor and nurse for more information if you need it. Sometimes you may need surgery to find out the exact stage. This means that your treatment plan may only be decided or may change after you have had surgery.

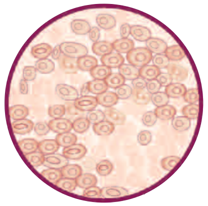
What are the grades of head and neck cancers?

Grading refers to how abnormal the cells look under a microscope. Grade 1 means the cells look similar to normal cells, whereas grade 3 means they look very different from normal cells.

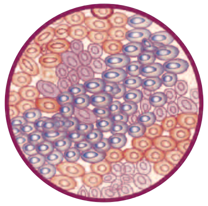
Grade 1



Grade 2



Grade 3



Lower grades are usually slower growing and less likely to spread. Higher grades tend to grow more quickly and are more likely to spread, but this isn't always the case. Knowing the grade will help your doctor to recommend the best treatment for you.

Asking about your prognosis

Your prognosis includes information about how your cancer is likely to progress, including average survival times or life expectancy. It's not 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:

- **Get the information from your doctor.** They know your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- **Ask a friend or family member to go with you**, if you would like some support.
- **Be careful with online information.** It may be hard to understand or even incorrect. Also, the information may not really apply to your situation or to your particular cancer type. Ask your doctor or nurse specialist for recommended websites.
- **Accept that you will need some time to think about what you have been told.** You may forget some things or there may be things you didn't understand. You may need to talk to your doctor again after you have thought about everything.
- **Get emotional support if you need it.** If you feel upset or anxious about your prognosis you can get support from friends, family or your hospital team. You can also call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie. Our cancer nurses can give you support, information and advice. They can also tell you about free counselling and other services that can help you.

Treatment overview

How are head and neck cancers treated?

- Surgery, radiotherapy, or a combination of radiotherapy and chemotherapy can be used to treat head and neck cancers.
- A team of healthcare professionals will be looking after you (multidisciplinary team).

The type of treatment you have will depend on:

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

Types of treatment

Surgery

Surgery is one of the main treatments for head and neck cancers. If found early, the surgery can often cure the cancer. Skin, muscle, bone or lymph nodes in the area may also need to be removed. You may also have surgery to reconstruct the affected area, perhaps using a skin flap or bone graft. See page 49 for more details on surgery.

Radiotherapy

This is the use of high-energy X-rays to kill or shrink the cancer cells. It can be used alone or with other treatments such as surgery or chemotherapy. Given after surgery, radiotherapy can destroy any cancer cells left behind. See page 59 for more about radiotherapy.

Chemotherapy

This is the use of drugs to cure or control cancer. Chemotherapy can be given together with radiotherapy (chemoradiation). See page 78 for more about chemotherapy.

Other cancer drugs

Targeted therapies and immunotherapy drugs can stop cancer cells growing or spreading. They may be given if the cancer has spread to nearby tissues or other parts of the body (metastatic cancer). See pages 83-88 for more details.

Specialist centres

Head and neck cancers are mainly treated in specialist cancer centres in Ireland. The staff at these centres have a lot of experience in managing patients with head and neck cancers. As a result, you may be transferred to another hospital from the one where you received your diagnosis.

Deciding on treatment

Multidisciplinary team

A multidisciplinary team (MDT) is a team of specialists involved in caring for your type of cancer. For example, a maxillofacial surgeon, plastic surgeon, medical oncologist (cancer doctor who prescribes chemotherapy and other anticancer medications), radiation oncologist (cancer doctor who prescribes and supervises radiotherapy treatments), ear, nose and throat (ENT) specialist, dental specialist/oncologist, radiologist, specialist nurses, dietitian and speech and language therapist. The team will meet to discuss your test results and decide your treatment plan.

Understanding your treatment

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

Time to think

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

Second opinion

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

Accepting treatment

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

Who will be involved in my care?

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

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

Ear, nose and throat (ENT) surgeon (with further training in head and neck surgery) A doctor who specialises in treating injuries and diseases affecting the ear, nose and throat, and head and neck, including surgery to remove a tumour.

Oncology liaison nurse/Clinical nurse specialist A specially trained nurse who works in a specialist cancer care unit. They give information and reassurance to you and your family throughout your treatment journey.

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

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

Plastic surgeon A doctor who specialises in reconstructive surgery, to repair changes in how a body part looks or works after surgery to remove a tumour.

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

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

Maxillofacial surgeon A doctor who specialises in treating injuries and diseases affecting the head, neck, face, mouth and jaw, including surgery to remove a tumour from your body.

Speech and language therapist A therapist who treats any speech and swallowing defects and disorders that happen after treatment.

Advanced nurse practitioner (ANP) Specialist nurse who can give expert information and is specially trained to carry out tests and help review your treatment.

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

Dental specialist/oncologist A dentist who specialises in the dental care of cancer patients undergoing treatment.

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

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

Occupational therapist (OT) A therapist who helps people adapt their living and working environment so they can manage their daily activities.

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

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

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

Psycho-oncology team These are specialists in psychological care and support for cancer patients. Usually the team includes psychiatrists, clinical psychologists and nurses. A psychologist is a specialist who can talk to you and your family about emotional and personal matters and can help you to make decisions.

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

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

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

Giving consent for treatment

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

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

If you are confused about the information given to you, let your doctor or nurse know straight away. 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 head or neck cancer are not getting the same treatment as you. Their cancer may not be the same type or at the same stage as yours. Everyone's treatment needs will be different. Don't be afraid to ask your doctor about your treatment.

Waiting for treatment to start

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

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

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

You might like to focus on your own health while you're waiting for treatment to start. For example, eating well and staying active (see page 43).

Pre-treatment education workshops

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

Before treatment: what your doctor may suggest

Dental check-up

Before you begin your treatment, your doctor will advise you to have a dental check-up. It's best to deal with any dental problems before you start treatment. Chemotherapy can lower your immune system and make you more vulnerable to getting infections, so it's best to avoid dental work during and for a time after treatment. Radiotherapy can affect the blood supply to your jaw bone, which may increase the risk of problems if you have dental work after treatment.

Hearing tests

Some treatments for head and neck cancers such as nasopharyngeal cancer can affect your hearing. You may have hearing tests before chemotherapy or radiotherapy and again afterwards so that your doctors can check if your hearing has been affected.

Dietitian visit

A dietitian may visit you to advise you about how to eat well and keep a healthy weight during and after treatment. If you are finding it hard to swallow, you may have a PEG feeding tube fitted until your swallow improves. A PEG tube is a small tube inserted through the wall of the abdomen into the stomach. Liquid food can then go straight into your stomach. Or, sometimes a nasogastric feeding tube is inserted. This goes from your nose into your stomach. (See page 53 for more on tube feeding.)

Speech and language therapist visit

A speech and language therapist may visit you to talk about possible speech or swallowing difficulties you may have after your treatment and how they can support you.

How can I help myself?

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

Eat well

Eating well can help you feel better. It can also help you to:

- Feel stronger and maintain a healthy weight
- Cope better with the side-effects of treatment
- Recover

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

Stay active

Keeping active has many benefits. It can help to:

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

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

Give up smoking and alcohol

If you have been diagnosed with a head and neck cancer, quitting smoking and alcohol can allow treatment to work more effectively. Quitting will also lessen the side-effects of treatment and reduce your chances of a future cancer developing. Smoking can increase your risk of complications following surgery such as delayed wound healing and chest infections.

Help to quit smoking

This is most likely a difficult time for you and you may find it stressful to give up smoking.

If you would like advice or support on quitting, call the HSE Quit Team on CallSave 1800 201 203, visit **www.quit.ie** or Freetext QUIT to 50100. Some hospitals have smoking cessation officers who can help and support you – you can ask your doctor or nurse for a referral to this service.

Other ways to help yourself

Get information about your cancer and treatment

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

Involve your family and close friends

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

Use your support network

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

Try relaxation and stress management techniques

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

Accept change in your life

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

Know that there will be ups and downs

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

Try to cope day by day

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

Treatments and side-effects

Surgery

- Surgery is one of the main treatments for head, neck and mouth cancers.
- A team of specialists will decide if surgery is the best option for you and the kind of approach that would suit you best.

Ways of doing surgery

Trans-oral endoscopic surgery

The cancer is removed through the mouth, rather than through a skin incision (cut), using a tube with a laser or surgical instruments on the end. This type of surgery is most often used for early cancers of the mouth, throat and larynx.

Nasal endoscopic surgery

This is where a tumour is removed through the nose, using an endoscope, which is a tube containing a light source and camera. The surgery is done with very small tools, and does not need an external incision (cut). This type of surgery is sometimes used for nasal cavity or paranasal sinus cancers.

Robot-assisted surgery

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

Open surgery

Here an external cut is made to allow your surgeon to access the tumour and remove it.

Surgery for early-stage cancers

Some early cancers of the mouth, throat and larynx may be treated using laser surgery or endoscopic surgery. Removing the cancer without cutting your skin is called minimally invasive surgery. Your surgeon and care team will decide if you are suitable for this type of treatment.

Surgery for higher-stage cancer

Depending on where the tumour is found, your surgeon may need to remove skin, muscle or bone along with the cancer. This can be replaced by a skin or muscle flap or a prosthesis (see page 51). In general, where a part of your body is being removed, doctors use ‘ectomy’ after the name of the body part. For example, laryngectomy is removing your larynx, hypopharyngectomy is removing your hypopharynx. If the whole part is being removed the operation may be described using the word ‘total’ or ‘radical’. For example, total laryngectomy means removing the whole larynx. Partial means only removing some of the body part.

Surgery to remove lymph nodes

Your surgeon may also remove lymph nodes in your neck to reduce the chance of the cancer spreading or coming back. This is called neck dissection. The nodes are sent to a laboratory to be checked for cancer cells. Your surgeon may also remove a muscle, nerve or vein in the area, depending on where the cancer is.

Reconstructive surgery

The surgery might affect how you eat or drink or how you look. As a result, another specialist (plastic/maxillofacial surgeon) might work with your surgeon to reconstruct the affected area. This can give you the best possible function and appearance after treatment. Reconstructive surgery may be done at the same time as the primary surgery, or at a later date. Your doctor will advise on the surgeries planned for you.

Skin flaps: If your surgeon needs to remove part of your mouth, throat lining or facial skin, it may be replaced by a skin flap. A skin flap is a thick layer of skin taken from another part of your body, for example, your thigh, arm, back or tummy (abdomen).

Microvascular free flap: This is where your surgeon takes tissue from another part of the body including the blood vessels (artery and vein) that supply this tissue. Using a microscope, they connect these vessels to a blood supply in the head or neck. The ‘free flap’ tissue taken includes skin, muscle, bone or a combination of each depending on what needs to be reconstructed. You will be carefully monitored after the operation to ensure there is an adequate blood supply getting to the area.

Bone graft: If the cancer is affecting part of your jawbone, your surgeon may need to remove the affected area and replace it with a piece of bone taken from another part of your body, usually the leg. This is known as a bone graft.

Prostheses: Depending on the type and extent of the cancer, your surgeon may need to remove some of your facial bones. For example, your cheekbone or palate. If you need this type of surgery, you may be offered a prosthesis. A prosthesis is a special soft plastic device which replaces the area where bone has been removed and closes the opening.

A common type of prosthesis is an obturator. This is like a retainer or denture, with an extension to replace the missing section of your upper jaw or palate. This prosthesis is provided by a special dentist called a maxillofacial prosthodontist. During your surgery a temporary obturator will be put in place. Once the area is healed, this obturator will be replaced by a new one.

Tests before surgery

You may have some extra tests to make sure you are fit for surgery. These might include:

- **A chest X-ray**
- **Heart tests** (ECG and echocardiogram)
- **Breathing tests**
- **Blood tests** to check your liver and kidneys

Understanding your surgery

Discuss your surgery fully with your surgical team so that you know exactly what is going to be removed and how it may affect you afterwards. You may have short-term, long-term or permanent changes. For example:

- Changes to how you look
- Changes to how you eat
- Changes to how you speak

Talk to your consultant about any possible changes after surgery. There's more about coping with these changes on page 91.

After surgery

Depending on your surgery, you may need to stay in hospital for several days or even weeks. For the first few days after surgery, you will probably stay in an intensive care unit, high dependency unit or special ward.

Drips and drains

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

- You may have a drip in a vein in your arm. You will be given fluids through this until you can drink again.
- A thin tube called a catheter may be in your bladder to drain urine – so you don't have to get out of bed. It is usually removed after 24 hours.
- Drainage tubes may be in place at the wound site.

Clips/stitches

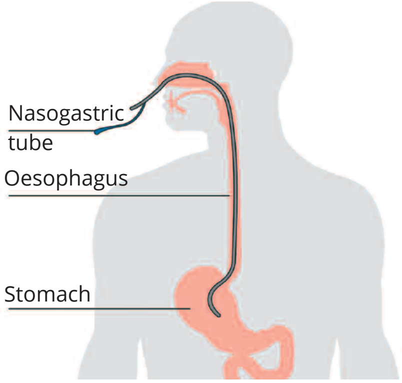
You may have clips / stitches in your neck. These will usually be removed 7-10 days after your operation.

Feeding tubes

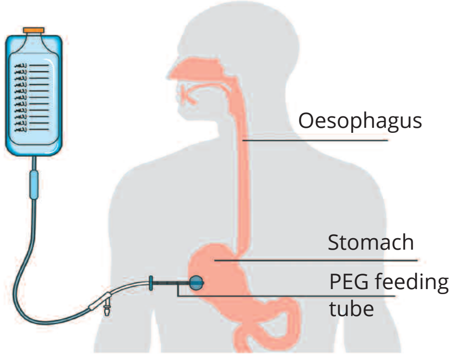
You may have a tube in your nose or stomach to allow you to heal and give you nutrition until you can eat again. Tube feeding can start the day after surgery. The tube will be removed once your doctor is satisfied with your weight and food intake. Your dietitians will help to make sure you get enough nutrition after surgery. They will discuss your nutritional needs with you and your doctors and prescribe supplements if needed.

Nasogastric tube:

A nasogastric tube (NG tube) is a thin tube passed down your nose all the way to your stomach. It can also be used to give you medicine. The NG tube can be removed easily once you are ready to eat again.



PEG tube: PEG stands for percutaneous endoscopic gastrostomy. This is a feeding tube passed through the wall of your abdomen to deliver liquid food into your stomach. PEG tubes can be left in permanently, if needed.



Images courtesy of Cancer Research UK / Wikimedia Commons

Parenteral feeding

Sometimes nutrition can be given directly into a vein after surgery. This is called parenteral feeding.

Tube feeding at home

If you need to continue with tube feeding at home, you will be shown what to do. 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. Sometimes the feeding tube suppliers provide training at home on how to use the equipment.

Pain

For the first few days after open surgery you will probably have some pain and may feel sick at times. Your nurse can give you medicine to control the pain. You may have an epidural tube in your back to relieve pain after the surgery. If you have a patient-controlled analgesia pump (PCA), your nurse will show you how to use it.

If you are not able to take medication by mouth, you will be given painkillers by injection, through a drip or in liquid form through your nasogastric or PEG tube.

If the medicine isn't controlling your pain, tell your doctor or nurse. Always ask for help before the pain gets too bad. Being as pain-free as possible will help you to speak, eat, drink and move about.

Getting up and about

For the first few hours after surgery, while you are in bed, you will be encouraged to move your legs and do deep breathing exercises at least once an hour. On the day after surgery the physiotherapist or nurse will help you get out of bed and move around.

Appearance

It can be a shock to see yourself after surgery if your appearance has changed. Some changes may be temporary – such as bruising or swelling. Other changes may be permanent. It may help to wait a few days before looking in a mirror. You might like to have someone else with you when you first look in the mirror, ideally a nurse, who can answer any questions you have. There's more about coping with changes to your appearance on page 93.

Speech

Some surgery to your mouth and throat can affect the way you speak. Your mouth, tongue, teeth, lips, nose, throat (pharynx) and soft palate are all involved in speech. Surgery to any of these areas can affect the way you speak. Some people may not notice a change in the way they speak, but for others speech can be changed temporarily or permanently. For example, if your larynx is removed you will not be able to speak in the normal way. See page 97 for more about speech changes.

Difficulty opening mouth after surgery – trismus

Some operations to the back of the mouth can cause a stiff jaw and it can be harder to open and move your mouth. This is called trismus and is usually temporary. Your speech therapist can give you exercises and exercise devices to help with this.

Neck lymphoedema

Lymphoedema is a swelling caused by a build-up of lymph fluid. This can happen if lymph nodes have been removed as part of your cancer treatment. It can also be caused by radiotherapy to the neck. Lymphoedema is different from the normal swelling that can happen after surgery, which usually goes down within a few weeks. Lymphoedema can happen later on. It's important to manage lymphoedema as early as possible, so let your doctor know if you have:

- Swelling or feeling of pressure or tightness around the eyes, face, lips or neck
- Difficulty moving your neck, jaw, or shoulders
- Difficulty swallowing, speaking, or breathing

Nerve issues

Sometimes surgery can affect the nerves that control your lip or shoulder movement. You may notice your smile is crooked or your shoulder might feel stiff. This may last a few months but it usually gets better in time. Your doctor will refer you to a physiotherapist who will show you some exercises to help with this.

If your accessory nerve, which is essential for neck and shoulder movement, is removed the damage is permanent. This could happen, for example, during surgery to remove lymph nodes in your neck.

Tracheostomy

Sometimes your surgeon may decide to make a surgical opening (stoma) into your windpipe, held open by a tube. This is called a tracheostomy ("track-ee-ostohmee"). A tracheostomy allows air to go directly into your lungs without having to pass through your mouth, nose or larynx.

This is done if your doctors feel that your airway or throat is at high risk of becoming blocked due to the tumour or to swelling caused by your treatment.

A tracheostomy will allow you to breathe safely and prevent the risk of your airway becoming blocked during your treatment or following your surgery.

Once a tracheostomy is formed, most patients can speak following a short time with it.

For most patients the tracheostomy is temporary. Once removed, the opening (stoma) will usually close over by itself. You will have a dressing over the wound until it heals.

Laryngectomy stoma

If your larynx is fully removed (during a 'laryngectomy'), your surgeon will create a permanent opening from your windpipe to the front of your neck. A small soft plastic tube will keep the stoma open initially following surgery. Your nurses and physiotherapists will help you to care for your stoma and do breathing exercises after your surgery.

Speaking

After a laryngectomy, air cannot pass through your larynx (voicebox) to produce your voice in the same way as before your operation. A speech and language therapist will support you in learning to speak using a specially created 'speaking valve' that allows you to develop a voice following your operation.

Caring for your stoma

For a few days after surgery, your nurse will look after your stoma and replace or change the tube as needed. You may have a lot of secretions or phlegm initially after the surgery but this will reduce by the time you go home. It's important to keep the stoma clean and free from crusts, or the skin around the stoma may become sore.

When you are feeling better, you will be shown how to look after the stoma yourself. Using a small freestanding, table-top mirror can make it easier to see what you are doing.

You may feel anxious about how you will manage the stoma at first. Most people with a stoma learn how to look after it themselves, but help is always available if you need it. It might be helpful to have a relative or close friend with you when you're learning to look after the stoma.

There's advice on our website **www.cancer.ie** on adjusting to daily life with a stoma, if you've had your larynx removed. For example, stoma covers, coughing and sneezing, your body image, and bathing, showering and swimming with a stoma.

Going home

If you have any concerns about going home after surgery discuss them with your doctor or nurse. There is a team of experts available to help you, including dietitians, medical social workers, speech and language therapists and physiotherapists.

If you have a stoma when you leave hospital, you will be shown how to look after your tube at home.

Radiotherapy

- Radiotherapy uses high-energy rays to kill cancer cells.
- It can be used alone or with other treatments like surgery or chemotherapy.
- Side-effects affect the area being treated.

Why is radiotherapy given?

Radiotherapy uses high-energy rays to kill cancer cells. The aim of radiotherapy is to destroy the cancer cells with as little damage as possible to normal cells. Radiotherapy may be given at different times and for different reasons:

- **Before surgery** to shrink the cancer, making it easier to remove.
- **On its own** to cure some early-stage cancers.
- **After surgery** to destroy small amounts of the cancer that may be left.
- **With chemotherapy (chemoradiation).** Chemotherapy can help radiotherapy to work better. Chemoradiation can be given as the main treatment for some cancers or it can be given after surgery, to help to prevent the cancer coming back.
- **To help with symptoms.** If a cure is not likely, radiotherapy can also be used to control and relieve symptoms you may have, such as pain or bleeding. This is called palliative radiotherapy.

What are the types of radiotherapy?

There are different types of radiotherapy used for head, neck and mouth cancers:

External beam radiotherapy

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

Conformal radiotherapy (CRT): This is the most common type of external beam radiotherapy for head and neck cancers. It is also called 3D conformal radiotherapy. CT or MRI scans are used to make a three-dimensional (3D) computer image of your tumour and nearby tissues.

The radiation beams are focused precisely on the tumour, so that nearby healthy tissue is spared. This results in fewer side-effects, allowing a higher dose of radiation to be given.

Intensity-modulated radiotherapy (IMRT): Intensity-modulated radiotherapy (IMRT) can shape the radiotherapy beams so that different doses of radiotherapy can be given to different parts of the treatment area. For example, if you are having radiation to your throat for throat cancer, the lymph nodes in your neck will also need treatment but at a much lower dose. With IMRT you will receive a higher dose to your throat and a lower dose to your neck lymph nodes. IMRT also helps to reduce doses of radiation to normal, healthy tissues compared to standard radiotherapy.

Internal radiotherapy (brachytherapy)

The radiation source is put directly into your body. The radiation is sealed in an implant. It will release radiation and kill the cancer cells. Internal radiotherapy is also known as brachytherapy.

Planning external radiotherapy treatment

Radiotherapy must be carefully planned so that the highest dose is given to the tumour area and as little as possible to the nearby cells. You will meet the radiation oncologist before treatment. Ask them about your treatment and any possible side-effects.

Dental check-up

If you're having radiotherapy to your head or neck, you will need a check-up by a dental specialist (dental oncologist) beforehand. They will:

- **Give you advice on how to care for your mouth** (oral hygiene), on your diet and on any physiotherapy exercises that you may need during or after radiotherapy.
- **Check that your mouth and teeth are healthy.** You may need to have fillings done or teeth removed before treatment starts, as it's usually best to avoid having dental work done during and after radiotherapy.
- **Check your dentures, if you have them,** to make sure they are correctly fitted so that they do not cause damage or infection.
- **Advise you on special mouth care products you might use** during treatment such as gum guards, artificial saliva drops, enzyme gels and mouthwashes, which can help you to cope with side-effects.

> Dental checks before treatment can help to prevent serious mouth problems from developing during or after your treatment.

X-ray

Before treatment, you are likely to have a special X-ray of your jaw and teeth called an orthopantomogram (OPG). This can see how healthy your jaw and teeth are and help your medical team decide if you need any dental work done before you start treatment.

Dental mouth bite

You may have a dental mouth bite, or stent, made to protect your mouth and teeth from the radiotherapy and reduce the risk of side-effects. To make a dental mouth bite, you will be asked to bite into a plastic mould full of putty. This mould is like a gum shield. The putty will dry in 10 minutes and makes a mould of your upper teeth. The radiation therapist will then attach a small frame to your mould. They might ask you to remove your mouth bite a few times to check that it fits correctly.

Mask fitting

You will probably need to wear a plastic mould or mask during radiotherapy treatment. The mask makes sure that your head and shoulders are kept perfectly still and the radiation is delivered to exactly the right place.

You will only have to wear the mask for a few minutes each time you are being treated. Because treatment marks are put on the mask, there is usually no need to put marks on your skin. On your first visit to the radiotherapy unit, you will be taken to the mould room to be fitted for a mask. If you have a beard or moustache you will probably be asked to shave it off, as it might stop the mask from fitting properly.

Perspex mask: The mould room technician will put some cream on your face. They then put strips of plaster of Paris bandage on top of this to make a mould. This takes a few minutes to set and is then removed. A Perspex mask is made from this mould. This mask will fit your face and neck snugly, with holes cut for your eyes, nose and mouth.

Thermoplastic mask: This uses a type of mesh plastic that becomes soft and pliable when heated in warm water. The warm plastic is draped carefully over your head. It will feel like a warm face cloth placed over your face at first but it cools very quickly. The holes in the plastic will allow you to breathe. The radiation therapist and mould room technician mould the plastic to the shape of your head as it cools. Talk to your nurse or the person making the mask if you are worried about being fitted for your mask or other device.

CT planning

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

Pregnancy test

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

Getting your treatment

During treatment you will first be positioned carefully on a treatment table. Then the machine will move around you so that you receive the precise treatment at different angles.

The treatment normally takes several minutes. It doesn’t hurt, but you will have to lie very still and often you will be wearing a face mask or other device, which can make you feel uncomfortable. You will be on your own in the room, but the radiation therapist will be able to see and hear you. If you need anything just speak or raise your hand.

Most people receive radiotherapy as outpatients, travelling to the radiotherapy unit each day with a break at weekends. External radiotherapy does not make you radioactive. It is safe for you to mix freely with family and friends, including pregnant women and children.

Where is radiotherapy given?

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 or chemotherapy.

How much radiotherapy do I need?

The course can be several treatments over a number of days or weeks (4 to 7 weeks) or between 1 and 10 doses for palliative treatment.

More information

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

Side-effects of radiotherapy

Any side-effects from radiotherapy tend to affect the part of your body being treated. Side-effects vary from person to person and depend on the size of the area being treated, the amount of radiotherapy and length of treatment. If you have chemotherapy as well as radiotherapy, side-effects tend to be more severe. Most side-effects get better 6-8 weeks after radiotherapy ends.

- **Short-term (acute) side-effects** normally develop within 2 weeks of starting treatment. They usually last for a few weeks.
- **Long-term (chronic) side-effects** are much less common. They last longer and may even be permanent.
- **Late side-effects** develop months or years after 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.

What can I do to reduce side-effects?

To make sure that your radiotherapy works as well as possible and to reduce side-effects, it may help to stop smoking during treatment. Your doctor may recommend that you give up alcohol and smoking completely. (See page 45 for more on giving up smoking.) Taking good care of your teeth and gums can also reduce the risk of problems after treatment, as radiotherapy can increase the risk of tooth decay and other problems (see page 70). Moisturise your skin regularly to help reduce or delay a skin reaction, and avoid any exposure of the area to the sun.

When the head and neck area is being treated the most common side-effects are:

Voice changes

Radiotherapy can make your voice hoarse for a time.

Tips

- Rest your voice as much as possible and avoid smoky places.
- Ask to see a speech and language therapist, who can advise you on exercises to help.

Dry mouth

Radiotherapy can make your salivary glands produce less saliva (spit) than usual. This can make your mouth and throat feel dry all the time. This is called xerostomia. You may find that your saliva becomes thick and stringy, making swallowing and speech a little difficult. The dryness may improve with time but it can be permanent.

Tips

- Take sips of fluids like water often. Keep a bottle of water with you when you're out. Sucking ice cubes or ice pops may help too.
- Moisten your food with sauces or gravy.
- Rinse your mouth regularly, especially before and after meals.
- Take care with foods like sandwiches, chocolate, pastry and freshly baked bread as they may stick to the roof of your mouth.
- Use special mouthwashes, gels and moisturisers often. For example, products that contain saliva enzymes. Your doctor or pharmacist can advise you about products to try.
- If you have thick saliva, rinse your mouth often. See page 69 for making your own bland mouthwash.
- Brush your teeth after every meal or snack. Use a soft toothbrush. Put it into a container of warm water to soften the bristles.
- Stimulate the flow of saliva with sugarless gum, boiled sweets or pastilles.
- Keep your lips moist with a lip balm.

Sticky mucus

You may find that you have a lot of thick, sticky or stringy mucus in your mouth or throat. Keep tissues with you in case you need to spit out the mucus. If the mucus turns green or yellow, tell your doctor. They may want to treat you with medication.

Sore mouth and throat

Your mouth and throat will probably become red and sore and you may get mouth ulcers (mucositis). You might find it hard to eat or swallow. If your mouth or throat is too sore to eat or drink, you may need to be fed by a nasogastric tube or PEG tube for a short while (see page 53). The soreness should get better within a few weeks of finishing your radiotherapy.

Let your radiation therapist or nurse know if your mouth or throat become very sore or if you are having trouble eating. They can advise you on products to help, what to eat and prescribe painkillers if you need them.

Tips

- Take sips of fluids like water or milk often. Drink through a straw if your mouth is painful.
- Eat soft, moist food like omelettes, scrambled eggs, mashed potatoes, cream soups, natural yogurt, milkshakes, stews, puddings.
- Moisten your food with sauces or gravies.
- Purée or liquidise foods in a blender to make them easier to swallow. For example, try soups or smoothies.
- Cold foods and drinks like milkshakes and smoothies might help to soothe your mouth.
- Take care with the following as they can make a sore mouth or throat worse:
  - Pickled, salty or spicy foods
  - Rough food, like crispy bread, dry toast or raw vegetables
  - Alcohol and tobacco
  - Citrus juices, like orange, lemon, lime, grapefruit or pineapple
  - Mouthwashes that are acidic or contain alcohol
- Ask your doctor about mouthwashes, gels and medications to help with your sore mouth. You can also make your own bland mouthwash (see box).
- Ask your doctor and nurse for painkillers if your mouth is painful. They may prescribe some antiseptic or local anaesthetic gels or lozenges.
- Visit your dentist regularly after your treatment has finished. They can give you advice about caring for your mouth and special mouthwashes.

Make your own mouthwash

Dissolve 1 level teaspoon of salt or baking soda (sodium bicarbonate) in half a litre of warm water.

Dental problems

A lack of saliva can lead to teeth problems as saliva washes your teeth and protects them from decay. You may also have bad breath. Decay can happen very quickly and can cause your teeth to break. You will usually be asked to put fluoride on your teeth every day to help prevent decay. This can be as a mouthwash, special toothpaste or in a gum shield made by your dentist. If you are likely to develop dental problems, a dental specialist will check your progress during radiotherapy. After the course has finished, you will need to have regular dental check-ups (every 4-6 months).

Tips

- Avoid sucking sugary sweets when your mouth feels dry as it increases your risk of tooth decay. Drink water or use sugar-free chewing gum or sweets.
- Avoid having teeth taken out (extractions) after radiotherapy, as your gums may not heal well afterwards or you may get a bone infection called osteoradionecrosis (ORN). See page 72 for details.

- Avoid sugary foods and look for the ‘hidden sugars’ on the labels.
- Gently brush your teeth with a small soft toothbrush and unflavoured toothpaste 5 or 6 times a day, especially after meals and before bedtime. It may help to soften the brush in warm water before brushing.
- If you have dentures, remove them at night and if your gums are sore.
- Mouthwashes can help, but many contain alcohol and are too harsh. Ask your dentist, radiation therapist or nurse for advice on which are suitable. You can also make your own bland mouthwash (see page 69).
- If you need any dental work after radiotherapy, tell your dentist that you have had radiotherapy.
- Check your mouth for any changes or signs of infection and tell your dentist or medical team if you notice anything.
- Go to your dentist for regular check-ups − every 4-6 months – after your treatment has finished.

Osteoradionecrosis (ORN)

After radiotherapy you're more at risk of a rare but serious side-effect called osteoradionecrosis (ORN). ORN is where the bone in your jaw starts to die. This happens because your jaw bone can have less blood supply and not heal so well after radiotherapy, so any damage to your jaw bone may cause problems. For example, damage from surgery, tooth extractions or denture irritations. It can happen years after radiotherapy. Your consultant may recommend hyperbaric oxygen treatment. This is where you sit in a special chamber and breathe oxygen at a higher pressure than normal. Sessions last an hour or so.

Tips

- Keep your teeth in good condition and treat any tooth decay (cavities) quickly.
- If a tooth has to be taken out after radiotherapy, you should see a dentist who is used to dealing with patients who have had radiotherapy, as they will take extra precautions to avoid infection.
- Avoid smoking and drinking alcohol, as these increase the risk of ORN.
- Tell your doctor or dentist immediately if you develop any problems with your teeth or gums, or swelling, pain, stiffness, heaviness or numbness of your jaw.

Difficulty swallowing

You may notice after a week or two of radiotherapy that you find it hard to swallow. The discomfort usually eases 5 to 8 weeks after you finish treatment, but if you're having any problems, talk to your doctor, radiation therapist or nurse as soon as possible.

You may need to see a speech and language therapist who can assess your swallow and recommend safe foods and fluids for you to eat and drink. Sometimes, people may need to use a thickener which they can add to their fluids to make it safer to swallow.

Tips

- Eat your favourite foods but soften them with sauces and gravies, where possible.
- Try eating soft, liquid foods like soups, milkshakes, custards, natural yogurt. But vary them so you don't get bored. Make sure soups have potato, lentils, tender or minced meat or fish in them for extra nourishment.
- Put small amounts of food into your mouth and chew them properly before you try to swallow.
- Chop up meat and vegetables finely for stews or casseroles.
- Blend or liquidise cooked foods if required.
- Eat small, frequent meals.
- Sit up for all your meals if possible. Try to remain seated upright for 20–30 minutes after eating.
- Take build-up drinks, which are high in calories and protein. Your dietitian can advise you about these and your doctor may prescribe them.
- Drink at least 6 to 8 cups of fluid each day.

Taste changes

Radiotherapy can affect your sense of taste – you may find that food tastes salty, metallic or like cardboard. This can affect your appetite, so you may lose weight. Your taste and appetite should improve once treatment has ended. But in some cases it may take 6-9 months to recover fully.

Weight loss

You might lose weight if you lose your appetite or find it hard to eat. If you continue to lose weight, you may need to be fed in another way. This may mean you have to spend a short time in hospital. Liquid food can be given into a vein or by a PEG tube into your stomach until you can eat properly again (see page 53).

Help with eating problems and weight loss

Always tell your nurse or radiation therapist if you are having any problems with eating or weight loss. They can advise you on diet and medication to help. They may refer you to a dietitian or speech and language therapist, if necessary. There's more about eating difficulties on page 95.

You might also like to read our booklet *Diet and Cancer*. Call our Support Line on 1800 200 700 or drop into a Daffodil Centre to ask for a copy of this useful booklet.

Jaw stiffness

Sometimes radiation to your head and neck can cause a stiffness in certain facial muscles. This is called trismus. The stiffness can prevent you opening your mouth and jaw fully. You will be shown some simple mouth-opening exercises to keep your mouth as flexible as possible. These should be done at least twice every day. You may also be advised to use an exercise device.

Hair loss (alopecia)

Radiotherapy can cause hair loss, but only in the area being treated. For example, it might affect a beard or moustache, if you have one. In general, it does not affect your head hair. Most hair loss is temporary. Your hair should start to grow back within 2 to 3 months of finishing treatment. The colour and texture might be a little different. For example, it may not be as thick as before.

Tiredness and fatigue

Fatigue is where you feel tired and weak and rest does not seem to help. It's quite common during radiotherapy, especially towards the end of treatment. The fatigue may last for some time afterwards. Tell your doctors, radiation therapist or nurse if tiredness becomes a problem for you. For more information on coping with fatigue, see page 100.

Skin reactions

Any skin reactions usually happen after 3-4 weeks of treatment. The skin may become red, sore or itchy, or it may peel and flake. This only happens in the treated area. Your radiation therapists will be checking for any skin reactions, but you should also let them know if you feel any soreness or have any other changes. Skin reactions usually settle down 2-4 weeks after treatment has finished. The skin may remain a little darker than the surrounding skin.

Tips

- Do not scratch or rub the treated area as it may become sore.
- Avoid soaps, talcum powders, deodorants and perfumes as they may irritate the treated area.
- Moisturise your skin. Only use creams and dressings prescribed or recommended by your doctor or nurse.
- Do not wet shave the treated area or use shaving lotion or hair removal products.
- Wash the area gently with lukewarm water and pat it dry.
- Never expose the treated area to the sun. Always use a total sunblock on the treated area and use a sunscreen (SPF 30) on non-treated skin. Cover treated skin with clothing when outdoors.
- Do not apply sunscreen before radiation treatment.
- Do not apply heat or cold to the treated area (heating pads, hot water bottles, ice packs). Avoid saunas and steam rooms.
- Do not use adhesive tape on the treated skin.
- Wear loose clothing made from natural fibres. Avoid tight collars and ties.

Other side-effects

Nausea and vomiting can sometimes happen on the first day of treatment to the throat area.

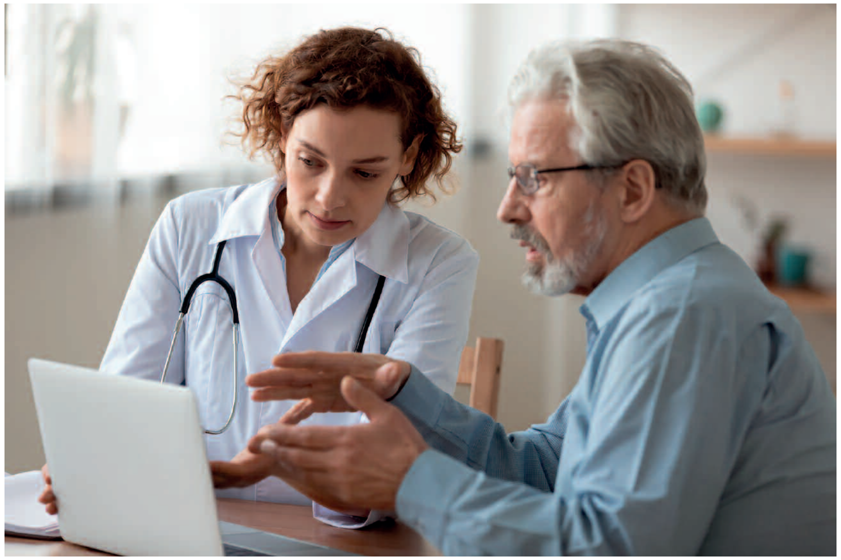
For more information on the side-effects of radiotherapy, talk to a cancer nurse on our Support Line 1800 200 700 or visit a Daffodil Centre. Ask for a free copy of our booklet ***Understanding Radiotherapy*** or read it on our website, **www.cancer.ie**

Drug therapies

You may be given one type of drug therapy at a time or or you may have a combination of therapies. The three main categories of drug therapies are: chemotherapy, targeted therapies and immunotherapy.

Your doctor will prescribe the drug therapy most suitable for your type of cancer. This will depend on:

- **Where the cancer is**
- **Whether the drugs are being given alone or at the same time as radiotherapy**
- **Whether the cancer has spread to nearby areas** (locally advanced)
- **Whether it has come back after treatment** (recurrent cancer)
- **Whether it has spread to other organs in the body** (metastatic cancer)



Chemotherapy

- Chemotherapy is used to destroy cancer cells or to control cancer growth. It can be used on its own or together with radiotherapy, targeted therapy or immunotherapy.
- Chemotherapy can cause a range of side-effects.
- Side-effects normally go or lessen after treatment finishes.

Chemotherapy uses drugs to kill or control cancer. The doctor who specialises in prescribing chemotherapy and other drugs is called a medical oncologist. Chemotherapy drugs may be given at different times and for different reasons:

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

How often will I have chemotherapy?

Chemotherapy is given in cycles with a rest period in between treatments. This will vary according to the chemotherapy drugs being administered and whether they are being given alone or at the same time as radiotherapy. For example, you might have chemotherapy treatment on day one and then have 20 days rest before your next chemotherapy treatment is due on day 21. The rest period allows your body time to recover from the side-effects of treatment. The number of cycles can vary, depending on the cancer type and how well it is responding to treatment.

How is chemotherapy given?

Chemotherapy may be given directly into a vein as an injection and/or through an intravenous infusion (by drip or pump). It may also be given in tablet form. Usually your treatment will be given in the chemotherapy day care unit.

If you are having chemotherapy intravenously (into a vein), you may have a central venous access device fitted. This is a thin tube (line) which goes directly into a vein and stays in place until your treatment is over. This saves you having repeated injections. There are different types of central venous access devices, such as ports, Hickman lines and PICC lines. Your doctor or nurse will advise you on what is most suitable for you and will provide you with information.

What kinds of drugs are used?

Platinum-based chemotherapy drug cisplatin is often used to treat head and neck cancers and is sometimes given in conjunction with radiotherapy.

Understanding your drug treatment

It’s important that you understand the drugs you have been given. Ask your doctor or specialist nurse for more information about your drug treatment and any possible side-effects. They should give you a printed sheet to take home with you. If you know the name of your chemotherapy drug, visit the Health Product Regulatory Authority's website at **www.hpra.ie** for more information about the drug and possible side-effects.

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

What are the side-effects of chemotherapy?

The side-effects of chemotherapy vary from person to person and depend on the drugs used and the amount of chemotherapy given. Side-effects happen because chemotherapy can affect both healthy cells and cancer cells. Most side-effects can be helped with medication. In most cases the side-effects go away when the treatment ends or soon after.

Side-effects may include:

Mouth and throat problems

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

Anaemia

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

Nausea and vomiting

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

Infection

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

Constipation and diarrhoea

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

Fatigue

Fatigue is where you feel tired and weak and rest does not seem to help. Sometimes exercise can help. See more about fatigue on page 100.

Hair loss (alopecia)

Some chemotherapy drugs can cause hair loss or hair thinning. Your hair will grow back after you finish chemotherapy.

Bleeding and bruising

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

Loss of appetite

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

Taste changes

You may notice that your food tastes different. Normal taste usually returns once treatment is over.

Skin and nail changes

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

Peripheral neuropathy

Some drugs can affect your nerve endings. They may cause numbness or a tingling or burning sensation in your hands and feet. This is known as peripheral neuropathy. It is important to report altered sensation in your hands and feet to your chemotherapy nurse or doctor, as early treatment and intervention can prevent longer term damage.

Changes in kidney or liver function

Some drugs can irritate or damage kidney cells. Talk to your doctor if you have decreased urination, swelling of the hands or feet (oedema) or headaches, as these can be a sign of kidney damage. Yellowing of the skin or eyes (jaundice) can be a sign of liver problems. Blood tests before your chemotherapy treatments will check your kidney and liver function.

Changes to hearing

Some drugs can affect your hearing. A hearing test is often done before treatment starts – but let your doctor or nurse know if you notice any changes to your hearing.

Other side-effects

If you notice side-effects or you are feeling unwell, tell your doctor or nurse straight away. They will tell you what to do. For more information on the side-effects of chemotherapy or to ask for a copy of the booklet ***Understanding chemotherapy and other cancer drugs***, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also look at our website, **www.cancer.ie** for tips on coping with side-effects.

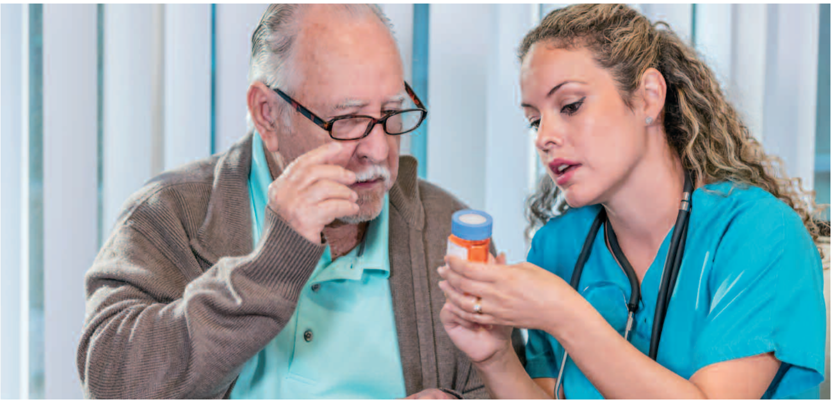
Targeted therapies

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

Different targeted therapies work in different ways. For example, they can:

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

Targeted therapies can be given alone or together with other treatments such as chemotherapy or radiotherapy. How often and how many treatments you have will depend on the type of cancer it is and the drugs that are being used. Targeted therapies are usually given in a course of treatments. This course can last weeks, months or years.



How are targeted therapies given?

Some drugs are given as an injection under the skin or into a vein through a drip. Other drugs are given in tablet form.

Side-effects of targeted therapies

Side-effects depend on the drugs being used and vary from person to person. Your doctor and nurse will explain your treatment to you in more detail and tell you about any likely side-effects. Some possible side-effects include:

Flu-like symptoms

These include fever and chills, weakness, nausea, vomiting, cough, diarrhoea and headache. They are often worse after the first dose. You may be given medication to try to stop these side-effects.

Skin changes

Rashes and skin dryness are common side-effects of targeted therapies. Your skin may be itchy, sore or scaly, or you may get an acne-like rash. Skin changes usually go away after treatment ends. Let your doctor or nurse know if you have any skin changes. They can recommend creams that won’t irritate your skin if it is dry or itchy and advise you about any medication that can help.

Diarrhoea

It is important to tell your doctor or nurse if diarrhoea is severe or if it continues after taking anti-diarrhoea medication.

Feeling tired (fatigue)

Fatigue is a common side-effect. It is important to pace yourself and sometimes exercise can help. See page 100 for more on coping with fatigue.

Hair changes

You might notice that your hair changes. It may become finer, curlier or more brittle. These changes are usually temporary and improve once treatment stops.

Nail changes

Nails may become weak and brittle. Your doctor or nurse will recommend creams that won’t irritate your skin.

Immunotherapy

Immunotherapy treatment is designed to boost your own immune system to fight cancer.

Cancer cells often disguise themselves in your body so that the immune system doesn’t recognise them as bad cells.

Immunotherapy works by helping the immune system to recognise and attack the bad cells caused by cancer. It can help to control the cancer and stop it from spreading.

How is immunotherapy given

Different forms of immunotherapy may be given in different ways. Most immunotherapy drugs for head and neck cancers are given into a vein (intravenously) through a drip. Sometimes two immunotherapy drugs are given together. They can also be given along with chemotherapy and targeted therapies.

Side-effects of immunotherapy

Immunotherapy boosts your natural immune system and you may feel quite well and experience minimal side-effects during treatment.

The immune system, when stimulated by immunotherapy, can attack healthy organs resulting in inflammation in any part of the body.

Side-effects can occur at any time during or even after treatment is finished. You may be more likely to experience side-effects if you are having more than one immunotherapy drug.

If you do experience side-effects, it is important to tell your doctor or nurse straight away.

Depending on the drugs being given, side-effects can include:

Pneumonitis

Inflammation of the lung – you might experience shortness of breath or a cough

Colitis

Inflammation of the bowel – you might experience diarrhoea or abdominal discomfort or pain

Skin rash

A skin rash or dryness. The rash may look like acne

Fatigue

This is extreme tiredness. See page 100 for more on coping with fatigue

Joint or muscle problems

Pain or weakness in the joints or muscles

Nerve problems

Numbness or tingling in the hands or feet

Eye problems

Red or sore eyes. Blurred vision or other changes to your eyesight

Liver problems

Yellowing of the skin or the whites of the eyes. Pain to the right side of the stomach. Passing dark urine

Kidney problems

Passing less urine, passing blood in the urine

Inflammation of the heart muscle

Chest pain, fast or irregular heartbeat

Brain inflammation

Headache, confusion, changes in mood or behaviour, seizures or neck stiffness

Immunotherapy can affect the glands that produce hormones especially the thyroid, pituitary, adrenal glands and pancreas.

It is important to contact your doctor or nurse if you experience:

- Changes in mood or behaviour, headache or confusion
- Changes to your heartbeat: If you feel that your heart is beating faster or slower.
- Unusual bowel habits
- Weight gain or weight loss
- Changes to the amount of urine that you pass

It is also important to read the information leaflet that comes with the medication so you are aware of more specific side-effects.

Allergic reaction

Occasionally you can have a severe allergic reaction to a cancer drug. Signs include breathing difficulties, fainting, fever, sensitivity to light, blood pressure changes, rashes, blistering or itchy or peeling skin. Let your medical team know immediately if you have any of these symptoms.

Other possible side-effects

There are many other possible side-effects of cancer drugs. Your doctor and nurse will explain your treatment to you and tell you about any possible side-effects and things to watch out for. Always tell your doctor or nurse if you don't feel well or if you are having any symptoms that are troubling you. For more information on cancer drugs and their side-effects or a copy of the booklet ***Understanding chemotherapy and other cancer drugs***, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

New developments

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

Clinical trials

Clinical trials are research studies that try to find new or better ways of treating cancer or reducing side-effects. Patients with cancer are sometimes asked to consider taking part in a clinical trial. This means that instead of the standard treatment you may 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.

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

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

More information

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

Treatment for cancer that has spread (metastatic cancer)

If the cancer spreads to another part of your body, it is called metastatic or secondary cancer. Your cancer may be in more than one part of your body when it is first diagnosed.

If it has spread, it can still be treated. Treatment at this point is usually to try to control the cancer rather than to cure it. There is a range of treatment options for most metastatic cancers, and new treatments are being developed all the time. Often metastatic cancer is treated with chemotherapy, targeted therapies or immunotherapy, or sometimes surgery. You may also be offered treatments as part of a clinical trial (see previous page).

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.

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

Palliative care

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

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

How will my lifestyle be affected?

Changes to appearance

Treatment for head, neck and mouth cancers – such as radiotherapy or surgery – can sometimes bring big changes to how you look, eat, breathe, speak or hear. For example, you may have scarring or other significant changes to your appearance which can be difficult to adjust to. If you have a stoma in your throat you may feel self-conscious about this, but most people adjust well to having a stoma in time.

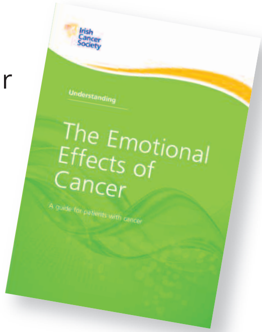
There is no set time for adjusting to these changes, but there are many people and services to help you. You will be seen regularly for follow-up appointments and there will be a team of healthcare professionals ready to help you and your family to cope.

Any scarring, swelling or bruising should improve over time.

Getting support

Even a small change in your appearance can affect your confidence and your body image, which is how you see yourself. Accept that it will take time to get used to these changes. But in the meantime, don't be afraid to ask for help.

- **Tell your healthcare team or support services if you're finding it hard to cope.**
- **Tell your partner, family and friends how you're feeling** and talk through any particular worries or difficult feelings you have. For example, if you're worried about going out and about. Our booklet ***Understanding the emotional effects of cancer*** has advice if you find it hard to share your feelings.



Irish Cancer Society

Understanding

The Emotional Effects of Cancer

A guide for patients with cancer

- **It may help to talk to someone who has been through similar surgery.** Ask your specialist nurse or speech and language therapist about this. You can also call our Support Line or visit a Daffodil Centre for information on support groups and our Survivor Support programme.
- **Talking to a counsellor may help you to work through your feelings about what has happened.** Free counselling is available through many cancer support centres. See page 138 for more.
- **If you're meeting new people, it might help to explain that you have had treatment for cancer.** There are also practical things you can do to feel better, such as using camouflage make up or dressing to make the most of your appearance. There are special workshops and classes to help with this, such as ***Look Good Feel Better*** and programmes run by cancer support centres.

Changes to eating

Not being able to eat normally is a common problem after treatment for head, neck and mouth cancers. It can be hard to chew, eat or swallow. For most people these difficulties don't last long, but for some people there can be longer-term or permanent changes.

Checking your swallowing – videofluoroscopy

You may need to have a test called a videofluoroscopy done. This is a type of X-ray that looks at the way your swallowing works. If the results show that food or liquid is getting into your lungs, you may need to have your food through a tube in your stomach (see page 53). Sometimes this tube can be permanent but usually it is temporary. Your speech and language therapist will teach you exercises to improve your swallow too.

Your speech and language therapist and dietitian will carefully work out the cause of your eating problems and help you to manage them. You may lose weight if you're finding it hard to eat. Your dietitian will help you with this too.

Tips

- It is best to put small amounts of food into your mouth and chew them properly before you try to swallow.
- Eat little and often if you find it hard to eat or your appetite is poor. Eating high-protein and high-calorie foods will help you to get the most nutrition from the food you eat. The dietitian can advise you on the best foods to eat.
- Try eating foods combined with liquid, such as thick soups or stews.
- If fluids go down the wrong way, there is a powder available which, when added to your drink, makes it thicker and easier to swallow.

There's lots of advice on managing side-effects, including eating difficulties, weight loss and nausea, on our website, **www.cancer.ie.** You might also like to read our booklet ***Diet and Cancer***.

> 'If you're having difficulties with eating when you get home, ask to see the dietitian at the hospital.'

Changes to speech

You might find it hard to make certain sounds or say certain words. Your voice may sound hoarse or be weaker or quieter. These changes can make it harder to communicate, which can be frustrating or upsetting. Your speech might get back to normal in time, once you have recovered from treatment. Or there may be permanent changes in how you speak.

- Keep a notepad, tablet or mobile phone with you, so that you can write down what you want to say.
- You may feel self-conscious about your speech, but in time most people find ways to manage and feel more comfortable.

Speech therapy

Speech therapy can help you to communicate as well as you can. You will start speech therapy soon after surgery and it may carry on for a number of months. Depending on what speech changes you have, you may be given mouth or tongue exercises to help you to speak. You may also be taught how to use special communication devices.

Speech after laryngeal cancer surgery

If you have your larynx removed, you won't be able to speak in the normal way. It may be quite a shock when you realise you have no voice, but you will have lots of support from the multidisciplinary team. You should feel better once you get used to communicating in a different way.

Talking by covering the opening with a thumb

Your speech and language therapist will help you to adjust and give you information on new ways of speaking. For example:

- Tracheoesophageal speech
- Oesophageal speech
- Electrolarynx (a battery-operated machine that produces sound for you to create a voice)

There's more information on these new ways of speaking on our website **www.cancer.ie**

It might also help you to meet someone who has been through this type of surgery. Ask your specialist nurse or speech and language therapist about this. Or ask one of our cancer nurses about our Survivor Support programme. Talk to a nurse at a Daffodil Centre, or call our Support Line on 1800 200 700.

Breathing changes

With some surgeries your surgeon may make a stoma (hole) in your throat for you to breathe through. This is called a tracheostomy. Usually this is temporary. If you have your larynx removed, the stoma will be permanent and you will breathe through this. See page 57 for advice on managing with a stoma.

Changes to hearing

If your hearing is affected after treatment, you will need a hearing/ENT assessment. Your doctor will discuss if you need drainage or if an implant (digital hearing aid) is suitable for you. There are also prostheses and other hearing aids available.

How can I cope with fatigue?

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

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

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

Usually fatigue starts to improve once treatment is over, but it can carry on for some people. Tell your doctor or nurse if fatigue is affecting you, so that they can help you. Finding out what is causing your fatigue makes it easier to treat. For example, if you have a low red blood cell count, a transfusion can make you feel better. If you are not eating well, a dietitian may be able to give you some advice to help you.

Hints and tips: Fatigue

- **Ask your doctor about exercising.** Being active can help with fatigue. Your doctor may also be able to recommend an exercise programme for you.
- **Get to know when your energy levels tend to be better.** You may have to decide which tasks are important to finish and do them over the course of the day or when you have most energy.
- **Ask for help at work or at home** with any jobs that you find tiring.
- **Try to eat a well-balanced diet.** Eat little and often if your appetite is poor. Our booklet ***Diet and Cancer*** has tips to help.
- **Try to avoid stress.** Talk to friends and family about any worries you have and take time to enjoy yourself. Counselling (see page 116) may help too.
- **If you are not sleeping well, try changing your bedtime routine and try relaxation techniques.** Avoid stimulants like caffeine and alcohol in the evening and try not to use electronic devices for an hour before bedtime.
- **Short naps (less than an hour) and rest periods can be helpful,** as long as they don't stop you from sleeping at night.
- **Try complementary therapies** such as meditation, acupuncture or massage, if your doctor says they're safe for you.

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

Will treatment affect my sex life?

Sex and sexuality

Cancer can affect how you feel about sex and your relationships. Coming to terms with the fact that you have cancer can take quite a while. It can be hard to relax as well when you have a lot of worries on your mind. You may also be feeling tired from the effects of treatment and lose interest in sex as a result. Or you may be coming to terms with changes in your appearance after surgery. See page 93 for information on coping with physical changes.

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

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. Our Support Line 1800 200 700 and our Daffodil Centres can help you to find accredited therapists and supportive information if you would like to talk to someone. Therapy can help you and your partner deal with a change in your sexual relationship and find ways of being close again.

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

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

Contraception

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

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

Ask your doctor's advice about contraception 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. Your doctor and nurse are well used to talking about these matters, so try not to feel embarrassed. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre to discuss any worries you might have with a cancer nurse. Or email the nurses at supportline@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. They 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 clinic if this is an option for you.

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

Cancer and complementary therapies

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

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

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

Integrative care

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

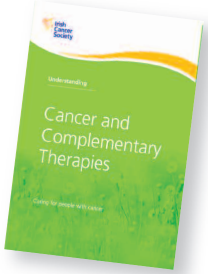
What's the difference between complementary and alternative therapies?

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

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

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

More information



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

After treatment

What follow-up will I need?

After your cancer treatment has ended you will still need regular check-ups. This is called follow-up. The follow-up may involve having a physical exam, blood tests and scans. The follow-up for head and neck cancers usually entails visits:

- Every 3 months for 2 years
- Every 6 months for another 3 years
- After 5 years – follow-up is decided on an individual basis

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

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

Tell your doctor or nurse how you have been since your last appointment. Remember to tell them about any new symptoms, aches or pains you have, or if you are finding it hard to cope. It can help to write down what you want to say before you see the doctor, so you don't forget anything.

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

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

What if the cancer comes back?

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

Life after treatment

It can take some time to adjust to life after cancer treatment. It's normal to feel quite low and lost after your treatment has ended, especially during the first few months. Feelings you may have include:

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

There is more about how to cope with these feelings and adjusting to life after cancer on our website **www.cancer.ie**. You can also call our Support Line or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 117 for other ways to get emotional support.

After-treatment workshops

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

Living a healthy lifestyle

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

- Feel better
- Heal and recover faster
- Keep up your energy and strength
- Reduce your risk of further illness

A healthy lifestyle includes:

- Exercising
- Eating well
- Trying to stay at a healthy weight
- Not smoking
- Avoiding alcohol
- Protecting yourself from the sun
- Getting any vaccinations recommended for you

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

Planning ahead

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.
- **Sorting financial affairs.**

Who can help me plan?

Think Ahead is a planning pack with different sections and easy-to-read forms. You can fill in your personal, medical, financial and legal information and preferences.

It’s available from the Irish Hospice Foundation at **www.hospicefoundation.ie**

Coping and emotions

How can I cope with my feelings?

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 Support Line on 1800 200 700 or visit a Daffodil Centre for a free copy.

Anxiety and depression

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

Your doctor may also suggest medication to help with anxiety or depression. Often a short course of 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 can help you to express your feelings, worries and fears and make sense of them.

Counselling can also give you emotional support, help you to make decisions and learn ways to cope better. Free one-to-one counselling is available through many local cancer support centres. To find out more about counselling call our Support Line on Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at supportline@irishcancer.ie. A list of counsellors funded by the Irish Cancer Society is available at **www.cancer.ie**.

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

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 138 for more about cancer support services.

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

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

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

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

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

If you need more information or help with finding support, call our Support Line 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.

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

Positive feelings

In time, some people say they can find positive things in their cancer experience. They say that cancer brought them closer to the people around them or made them appreciate what's important in life. Or it opened up new experiences and relationships. Getting support, such as counselling, may help you to come to terms with your diagnosis and feel more positive.

> '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 ***Understanding the Emotional Effects of Cancer*** can help you to find ways to talk about your cancer and to ask for the help and support you need.

Further information and support

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

Changing relationships

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

Advice for carers

Supporting someone with cancer

Finding out someone you love has cancer and trying to care for them can be difficult. You might be unsure about how best to support them, practically or emotionally. You might also be struggling with your own feelings and responsibilities. Here are some things that can help to make life a little easier:

Learn about cancer

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

Share worries

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

Be kind to yourself

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

Try counselling

You might find it helpful to talk to a counsellor. Free one-to-one counselling is available to friends and family members through many cancer support centres. Talk to your GP or see page 138.

Find out about support for carers

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

Support for you

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

Our booklet, ***Caring for someone with cancer,*** has lots of information on:

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

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

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.

The booklet *Caring for someone with cancer* has a section on how to talk to someone with cancer. It also has tips to help you to feel more confident about supporting your friend or relative. You can pick up a copy at your local Daffodil Centre.

Support resources

Money matters

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

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

Medical expenses

Medical expenses that you might have to pay include:

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

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

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

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

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

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

If you have health insurance the insurance company will pay some of the costs, but the amount will depend on your insurance plan. It's important to contact your insurance company before starting tests and 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: 0818 074 000
- **Department of Employment Affairs and Social Protection (DSP)** – Tel: 0818 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

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

If you have money problems

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

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 135 for more details of our Volunteer Driver Service and the Travel2Care fund.

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

More information

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

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

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

Irish Cancer Society services

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

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

Support Line Freephone 1800 200 700

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

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

Email: supportline@irishcancer.ie

Daffodil Centres

Visit our Daffodil Centres, located in 13 hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide free 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 diagnosis similar to yours. 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 and the National Cancer Control Programme to ensure patients and their families have access to high-quality confidential support in a location that's convenient to them. The Society funds professional one-to-one counselling (including telephone and video-call counselling) and group survivorship programmes in communities across the country.

For information about what's available near you, call our Support Line on 1800 200 700 or go to **www.cancer.ie** and search 'Find support'.

Patient travel and financial support services

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

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

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 a unique service in Ireland, providing palliative nursing care at night between 11pm and 7am to cancer patients.

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

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 Support Line for free copies of our publications.

If you would like more information on any of our services, call our Support Line 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 through many local cancer support services)

- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- **Special exercise programmes**
- **Stress management and relaxation techniques**, such as mindfulness and meditation

- **Complementary therapies** like massage and reflexology
- **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 Support Line on Freephone 1800 200 700 to find your nearest cancer support centre. Or go to **www.cancer.ie** and search 'Find support'.

What does that word mean?

Adjuvant treatment Treatment for cancer that is given soon after surgery.

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

Anti-emetic A tablet, injection or suppository to stop you feeling sick or vomiting.

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.

Fatigue Ongoing tiredness often not helped by rest.

Grading Tests that look at the structure of cancer cells under the microscope.

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

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

Neo-adjuvant Treatment that is given before surgery to shrink a tumour.

Oncology The study of cancer.

Palliative care team A team of doctors and nurses who are trained in managing pain and other symptoms caused by cancer. They can also help you cope with any emotional distress.

Prognosis The expected outcome of a disease.

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

Staging Tests that measure the size and extent of cancer.

Targeted therapies Drugs or other substances that block the growth and spread of cancer by interfering with specific molecules involved in tumour growth.

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?

What stage is my cancer at?

What type of treatment do I need?

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?

Do I have to eat special foods?

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

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

Notes

About this booklet

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 from diagnosis and throughout treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible. We would particularly like to acknowledge the contribution of the many consultants, nurses and other healthcare professionals who so kindly gave up their time and expertise to contribute to previous editions of this booklet.

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

- *National Cancer Strategy 2017-2026,* National Cancer Control Programme
- *Cancer in Ireland 1994-2019:* Annual report of the National Cancer Registry (2021)
- *The Chemotherapy Source Book,* M Perry, Lippincott Williams and Wilkins, 5th Ed (2012)
- National Comprehensive Cancer Network 2020
- National Cancer Control Programme: Chemotherapy regimens (last edited 2022)

Published in Ireland by the Irish Cancer Society.

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

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

Did you like this booklet?

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

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