

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 29

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.

Will I be OK?

Page 26

What is likely to happen to you (your prognosis) is hard to predict. It depends on a lot of things – for example, if the cancer has been found early and your general health. Everyone's prognosis is different. Your doctor can talk to you about what is likely to happen in your situation.

What kind of treatment might I have?

Page 43

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 45).

External radiotherapy: Using high-energy rays to kill cancer cells (see page 55)

Chemotherapy: Drugs to slow down and control the growth of cancer (see page 70)

Targeted therapies: Drugs to stop the cancer growing (see page 75)

How will treatment affect me?

Page 43

Some treatments can cause side-effects, but they usually go away after you finish treatment. 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.

Clinical trials

Page 78

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

We're here for you

Page 122

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

Ways to get in touch

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

See page 122 for more about our services.

Reading this booklet



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

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

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

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



Cancer Nurseline Freephone 1800 200 700

About head and neck cancers

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What is cancer?

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

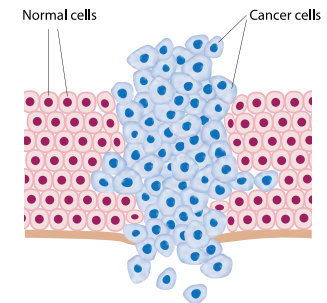
Cancer cells are abnormal cells that grow without control. They can form a lump (tumour).

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

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.



What is the lymphatic system?

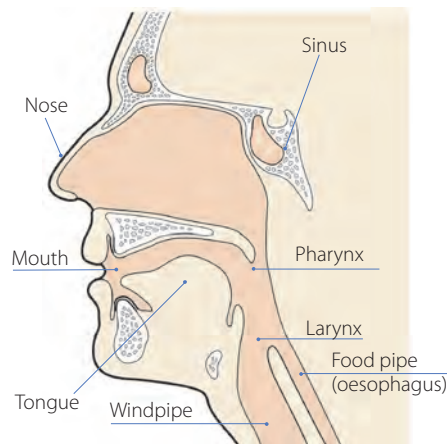
- The lymphatic system protects us from infection and disease and removes extra fluid and waste from the body's tissues.
- It is made up of lymph nodes connected by tiny tubes called lymph vessels
- Lymph nodes are found mainly in the neck, armpit, groin and tummy.
- If cancer cells spread into lymph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



What caused my cancer?

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

What are head and neck cancers?



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

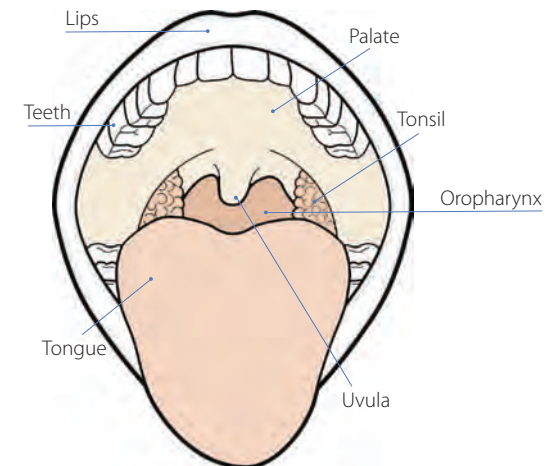
- **The pharynx.** This is the area behind the nose and mouth that leads to the oesophagus and larynx. It is divided into areas called the nasopharynx, hypopharynx and oropharynx.
- **The larynx** (voice box)
- **The thyroid gland**
- **The food pipe** (oesophagus/gullet)
- **The wind pipe** (trachea).

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. For oropharyngeal cancers (e.g. tonsil and tongue base), chemoradiation (radiotherapy and chemotherapy together) is often

the first treatment. Early cancers may be treated with laser surgery using a tube passed into your mouth which has a laser on the end (transoral endoscopic surgery). See page 45 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 47).

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 70), **chemoradiation** (chemotherapy and radiotherapy together) or **targeted therapies** (see page 75). There's more about the different treatments on page 43.

Mouth cancer side-effects

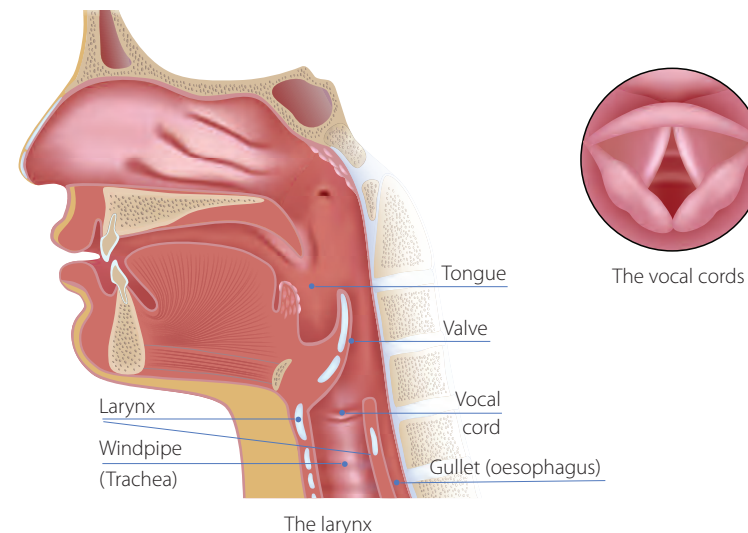
Treatment for mouth and oropharyngeal cancer might affect how you look, eat, speak or breathe. It can take time to get used to these changes. See page 81 for information and tips to help you with these changes.



Cancer of the larynx (laryngeal cancer)

The larynx is also called the voice box. It is a tube in your throat that contains the vocal cords, found at the front of your throat.

It is a rare cancer, but it is the second most common cancer in the head and neck area.



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 pages 70-77). How much tissue will be removed and what other treatments you might need will depend on the stage of the cancer (see page 24).

Laryngeal cancer side-effects

Treatment for laryngeal cancer might affect how you eat, speak or breathe. See page 81 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 89).

Cancer of the thyroid

Thyroid cancer affects the thyroid gland at front of your neck above your voice box. See our booklet *Understanding cancer of the thyroid* if you want more information on thyroid cancer.

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 43 for more about the different treatment types. 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 you can talk to one of our cancer nurses by visiting a Daffodil Centre or calling our Cancer Nurseline 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 this type.

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.

How common are head and neck cancers?

In general, head and neck cancers are not common. About 400 people are diagnosed with them in Ireland each year.





Diagnosis and tests

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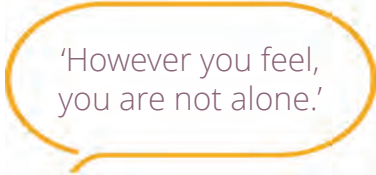
Being diagnosed with cancer

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

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

- Ask to speak to the cancer liaison nurse or medical social worker at the hospital. They can help you and your family to cope with your feelings and advise you about practical matters
- Talk to one of our cancer nurses in confidence – visit a Daffodil Centre or call our Cancer Nurseline on 1800 200 700. You can email the nurses at cancernurseline@irishcancer.ie
- Speak to an Irish Cancer Society Survivor Support volunteer who has had a cancer diagnosis and really knows what you are going through. Our cancer nurses can put you in touch with a volunteer.
- Talk to other people going through the same thing. Join our online community at www.cancer.ie/community
- Go to your local cancer support centre. For more information, see page 128.



'However you feel,
you are not alone.'

Telling people about your diagnosis



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

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

What tests will I have?



- Tests you may have after 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 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.

CT scan (CAT scan)

This is a special type of X-ray that builds up a detailed 3D picture of the tissues inside your body. You might be asked to fast (not eat) for a few hours before the test. You may be given a special drink or injection to help show up parts of your body on the scan.

This is called a contrast. Tell the doctor if you're allergic to iodine or have asthma before you have the contrast.

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 safe and painless and takes between 10 and 30 minutes. You'll probably be able to go home as soon as the scan is over.



MRI scan

This is a scan that uses magnetic energy to build up a picture of the tissues inside your body. Because it uses magnetic energy, MRI may not be suitable for you if you have any metal in your body – for example metal plates, pacemakers or if you've had an accident or a job where some metal may have entered your body. Your radiation therapist will ask you some questions about this. You will also have to take off any metal jewellery.

During the scan you will lie inside a tunnel-like machine. Some people are afraid they may feel claustrophobic during the MRI scan. Tell the radiation therapist if you're feeling anxious.

An MRI can also be noisy, but you will be given earplugs or headphones to wear during it. You might get an injection before the scan to show up certain parts of your body, called a contrast. Usually you can go home soon after the scan. You shouldn't need to stay in hospital.

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.

PET scan

A PET scan can show if the cancer has spread to other tissues and organs. A low dose of radioactive sugar is injected into your arm. An hour or so later you will have a scan. The radioactivity can highlight cancer cells in your body. During the scan, you will lie on a table which moves through a scanning ring. The scan can last up to an hour. Before the scan, you may have to fast (not eat) for a few hours. PET is safe to use and there are no side-effects.

You may have to travel to a specialist centre to have a PET scan, as not every hospital has these scanners.

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.

Chest X-ray

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

Testing for viruses



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

HPV test for mouth cancers

You doctors may do a test (called p16) on a sample of cancer cells removed during a biopsy to see if your cancer is caused by the HPV virus.

Nasopharyngeal cancer and the Epstein Barr virus (EBV)

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

Waiting for results

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

Cancer Nurseline Freephone 1800 200 700

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.
- Staging and grading help your doctor to decide the best treatment for you.
- 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 — how big it is and if it has spread

Grading describes **the cancer cells** — what they look like 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): The size of the tumour. Doctors put a number next to the T to describe the size and spread of the cancer. T1 is a small tumour and T4 is a large cancer.

Nodes (N): If there is cancer in your lymph nodes and how many nodes are affected. N0 means no lymph nodes are affected. If cancer has spread to the lymph nodes (positive nodes) the N will have a number to describe how many lymph nodes are affected.

Metastasis (M): If the cancer has spread to other parts of your body this is called metastatic cancer. M1 means the cancer has spread to other organs such as liver or lungs and M0 means it hasn't.

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

Number staging system

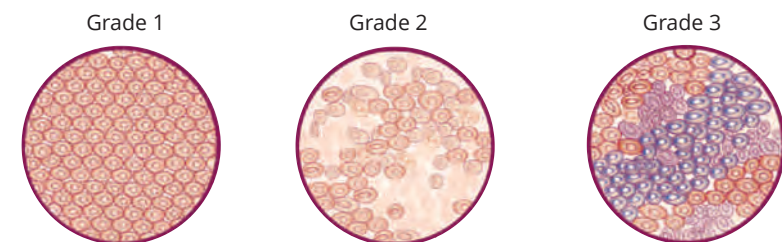
Early cancer: Stage 1 or 2 cancers are small (less than 4cm in size) and have not spread.

Advanced cancer: Stage 3 or 4 cancers are bigger (more than 4cm), have grown into nearby tissue, spread to lymph nodes, or 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.

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.



Lower grades are usually slower growing and less likely to spread. Higher grades tend to grow more quickly and be 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 is information about how your disease is likely to progress, including average survival times for your type of cancer (life expectancy). Many people with cancer have questions about their prognosis.

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



Should I ask about my prognosis?

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

If you decide you want information on your prognosis:

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



How are head and neck cancers treated?

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Treatment overview



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

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 cancer. 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 45 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 55 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 70 for more about chemotherapy.

Other cancer drugs

Targeted therapy 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 page 75 for more details.

Specialist centres

Head and neck cancers are treated in specialist cancer centres in Ireland. The staff at these centres have expertise and 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, oncologist (cancer doctor), 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 treatment

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

Ask as many questions as you need to. It can help to have a friend or family member with you to help you. If you forget to ask a question or would like more explanations, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre and talk to one of our cancer nurses.



Time to think

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

Second opinion

You might find it reassuring to have another medical opinion to help you decide about your treatment. But it may delay you starting treatment, so discuss it with your doctor.

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 so you understand what this will mean for you. It may help to talk to your GP as well. The important thing is that you are fully aware of the benefits and risks.

Giving consent for treatment

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

'Ask plenty of questions so you know how a treatment might affect you and possible side-effects.'

Individual treatment

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

Waiting for treatment to start

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

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

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

You might like to make some lifestyle changes while you're waiting for treatment. This can help you prepare for your treatment and feel more in control. For more information, see pages 38-41.

Who will be involved in my care?

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

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.

Ear, nose and throat (ENT) specialist

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 from your body.

Medical oncologist

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

Radiation oncologist

A doctor who specialises in treating cancer patients using radiotherapy.

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.

Oncology liaison nurse/Clinical nurse specialist

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

Radiation therapist

A specially trained person who delivers the 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.

Speech and language therapist

A therapist who treats speech and swallowing defects and disorders if they are affected by 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 specialises in helping people who are ill or disabled learn to manage their daily activities.

Medical social worker

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

Palliative care team

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

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

Psycho-oncology team

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

Psychologist

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

Counsellor

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

GP (family doctor)

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

Community health services

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

Before treatment

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

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 small operation to have a PEG feeding tube fitted. A PEG tube is a small tube inserted through your tummy into the stomach. Liquid food can go straight into your stomach through the tube. The tube will be removed when your swallowing improves.

Speech and language therapist

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 better.

Lifestyle changes

Eat well

Eating a balanced diet can help you feel better. It can help you to:

- Maintain a healthy weight and keep muscle mass
- Cope better with the side-effects of treatment
- Reduce your risk of infection
- Recover

It's also important to drink plenty of fluids (around 8 cups) every day. Ask to see the dietitian at the hospital. They can give you advice about the best diet for you. You can also read our booklet ***Diet and Cancer***. To get a copy call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. Or download it from our website www.cancer.ie



Be active

Being 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, but build up gradually.

Quit smoking

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

- Non-smokers have fewer or less severe side-effects during cancer treatment
- Smoking can reduce how well chemotherapy or radiotherapy works
- Not smoking or drinking reduces the risk of cancer and other illnesses

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

Alcohol

You will probably be advised to avoid alcohol during treatment, as it can make some side-effects worse, such as mouth sores, and may interact with certain drugs. Your doctor will talk to you about this and about support, if you need it.

Other ways to help yourself

Get information about your cancer and treatment

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

Involve your family and close friends

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



Use your support network

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



Try relaxation and stress management techniques

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

Accept change in your life

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

Know that there will be ups and downs

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

Try to cope day by day

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



Types of treatment and side-effects

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Surgery

- Surgery is one of the main treatments for head, neck and mouth cancers.
- If the cancer is found early, surgery can often cure it.
- Your surgeon may also need to remove skin, muscle, bone or lymph nodes in your neck.
- Another surgeon might work with your surgeon to reconstruct the affected area. You might need a prosthesis to replace any bone or muscle removed.
- You will have several tubes and drains in after surgery. For example, a drip, catheter, feeding tube.
- Most patients go home within a couple of weeks.



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.

Keyhole surgery

This is also known as laparoscopic surgery. It is where the cancer is removed through one or more very small cuts (incisions) instead of a large cut. Your surgeon will put a tube with a tiny telescope and light inside your body through the small cut. Special instruments are then used to remove the tumour. With keyhole surgery, you usually recover quicker and need to spend less time in hospital than for open surgery.

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 a bigger 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 your cancer. This can be replaced by a skin or muscle flap or a prosthesis (see the next page).

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'. E.g. 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 lab 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 surgeon (plastic/maxillofacial) might also 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).

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

To make sure you are fit for surgery you will have some extra tests. 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. Depending on where you're having surgery you might 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 81.

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 or high dependency unit or special ward. It is normal to be attached to tubes and drips after your surgery. For example:

IV fluids/drip

You will need to fast (not eat) before your surgery and for some time afterwards. A drip giving fluids into your vein (IV) can prevent you from becoming dehydrated.

Urinary catheter

A catheter is a small tube placed in your bladder which drains urine into a bag. It is used to save you having to get out of bed to go to the toilet. The tube is usually removed a few days after surgery.

Wound drain

Plastic tubes may be placed at your wound and stitched into place. These collect any excess blood or oozing from your wound to let your wound heal. Drains are normally removed a few days after surgery.

Clips/stitches

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

Feeding tubes

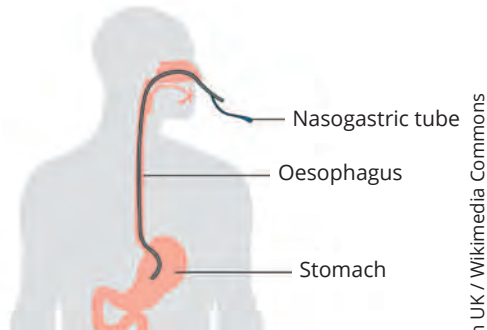
You may have a tube in your nose or stomach to allow you to heal and give you nutrition until you can eat through your mouth again.

Tube feeding can start the day after surgery and continues for as long as needed. The feeding tube will be removed after your check-up if your doctor is satisfied with your weight and food intake.

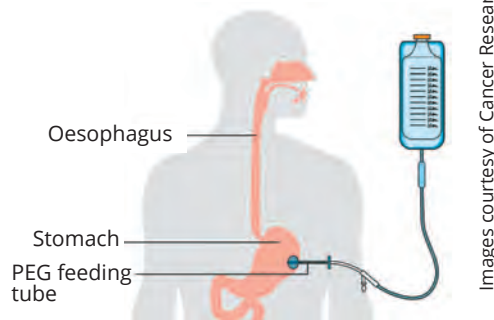
Your dietitians will help to make sure you get enough nutrition after surgery. They will discuss your nutritional needs with you and your doctors and prescribe supplements if needed.

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

Pain

It is normal to have pain or discomfort after your surgery. Pain can be controlled, but your doctors need to know about it. You may be given painkilling medicine or tablets, or you may have a patient controlled analgesia pump (PCA). This sends pain medication into your blood when you press a button. A nurse will show you how to use it.

If you cannot eat properly, you will be given painkillers by injection, through a drip or in liquid form through your nasogastric or PEG tube.

If your 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

A physiotherapist will visit you regularly after surgery. These visits are to help you with breathing and leg exercises. Even when you are in bed you will be encouraged to move your legs and do deep breathing exercises at least once an hour to help prevent clots and chest infections. On the day after surgery the physio or nurse will help you get out of bed and take you for a short walk. These walks will become more frequent and longer as you get better.

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 83.

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 you have your larynx removed you will not be able to speak in the normal way any more. See page 87 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. Radiotherapy to the neck can also cause it.

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

Shoulder stiffness and arm weakness

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 you have your accessory nerve removed – for example during surgery to remove lymph nodes in your neck – the damage is permanent.

Tracheostomy

Sometimes your surgeon may decide to make an opening (stoma) into your windpipe, held open by a tube. This is called a tracheostomy (“track-ee-ost-oh-mee”). A tracheostomy can help you to breathe more easily if swelling or bruising around your mouth or throat is making it difficult to breathe. A tracheostomy allows air to go directly into your lungs without having to pass through your mouth and nose.



Usually the tube will be removed after a few days. The opening (stoma) will usually close over by itself. You will have a dressing over the wound until it heals. If you have your larynx removed, the stoma will be permanent.

Tubes

A small plastic tube will keep the stoma open. Your nurses and physiotherapists will help you to care for your stoma and do breathing exercises after your surgery. For most patients the tracheostomy is temporary.

Speaking

More than likely, you won't be able to talk for a time after a tracheostomy because you are not using your voice box (larynx) in the normal way. Air cannot pass through your larynx to produce your voice. Your doctors, nurses and speech and language therapist will help you to communicate. You might find it easier to write down what you want to say on a notepad or tablet or send text messages on your mobile phone.

Going home with a tracheostomy

If you still have a tracheostomy when you leave hospital, you will be trained on how to look after your tube at home.

Caring for your tracheostomy



For a few days after surgery, your nurse will look after your tracheostomy 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 an entire team of experts available to you, including dietitians, medical social workers, speech and language therapists and physiotherapists. Remember they are there to help you.

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. They include sore mouth and throat, dry mouth, dental problems, mouth stiffness, difficulty with eating and drinking, fatigue and skin reactions.
- Side-effects normally go soon after treatment ends, but some can be long-lasting.

Why is radiotherapy given?

Radiotherapy uses high-energy rays to kill cancer cells. The aim of radiotherapy is to destroy the cancer cells with as little damage as possible to normal cells.

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.

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 (3-D) computer image of your tumour and nearby tissues.

The radiation beams are precisely focused 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 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 (usually in the Dublin dental hospital). He or she will:

- Give you advice on how to care for your mouth (oral hygiene), on your diet and any physiotherapy exercises that you may need during or after radiotherapy.
- Check that your mouth and teeth are healthy and plan for any treatment you might need after radiotherapy. You may need to have any cavities filled or some teeth removed before treatment starts, as usually you will need to avoid having dental work 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.

Side-effects often happen because a patient's mouth is not healthy. 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 make a mould of your upper teeth. The radiation therapist will then attach a small frame to your mould. Your radiation therapist 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 actually 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.

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

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 the Cancer Nurseline 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 a longer time 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.

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 57)



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

- Ask your nurse or doctor for advice about products to help keep your mouth and lips moist. Artificial saliva, enzyme gels, mouthwashes, lozenges, pastilles and lubricants are all available.
- Try sipping cool drinks during the day. Carry a bottle of water with you. Avoid sugary, alcoholic or acidic drinks.
- Avoid very dry food like crackers and use sauces or gravy to make food moist and easier to swallow.
- Smoking can make a dry mouth worse, so try to give up or cut down.
- A humidifier at home can keep the air moister and help you to feel more comfortable.
- Use lip balm to keep your lips moist.

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. He or she 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. It's best to talk to the hospital dietitian if you're finding it hard to eat, as they can help you get the nutrition you need. 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. The soreness should get better within a few weeks of finishing your radiotherapy.



Tips

- 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.
- Keeping your teeth, gums and mouth very clean will help to control the soreness and reduce the risk of a mouth or throat infection.
- If your mouth is sore, choose soup (not too hot), smoothies and yogurts.
- Avoid eating hot, spicy or very cold food and drink.
- Avoid alcohol (especially spirits) and tobacco as they can irritate the lining of your mouth and throat. They can also make side-effects more severe.

Dental problems

A lack of saliva can make teeth problems more likely, 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 66 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 using of 1 level teaspoon of salt or baking soda (sodium bicarbonate) dissolved in half a litre of warm water.
- 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 (see tips below) and tell you dentist or medical team if you notice anything.
- Go to your dentist for regular check-ups – at least every 6 months.

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 with eating and drinking

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.

NUTRITIOUS SNACKS

🍴 Cereals – hot or cold

🍴 Beans on toast

🍴 Cheese and crackers

🍴 Custards

🍴 Hot chocolate
(make with milk)

🍴 Milk puddings

🍴 Milkshakes

🍴 Creamy soups

🍴 Yoghurt or fromage frais

🍴 Smoothies

🍴 Mousses



🍴 Sandwiches

🍴 Nuts

🍴 Omelettes

🍴 Quiche

🍴 Muffins or scones

🍴 Scrambled eggs

🍴 Baked potatoes with
beans, cheese, tuna

🍴 Dips made with
cheese or yoghurt



LIQUIDS



CLEAR LIQUIDS



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



FULL LIQUIDS

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



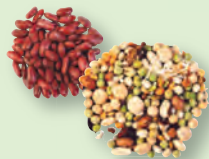
SOFT DIET

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



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

HOW TO INCREASE CALORIES



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

HOW TO INCREASE PROTEIN

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

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



Taste changes

Radiotherapy can affect your sense of taste – you may not taste as well as before or 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 to 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 50).

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, and refer you to a dietitian or speech and language therapist, if necessary.

There's more about eating difficulties on page 85. You might also like to look at the eating suggestions in the centre of this booklet or read our booklet *Diet and Cancer*.

Cancer Nurseline Freephone 1800 200 700

Mouth 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 91.

Skin reactions

Any skin reactions usually happen after 3 to 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 to 4 weeks after treatment has finished. The skin may remain a little darker than the surrounding skin.

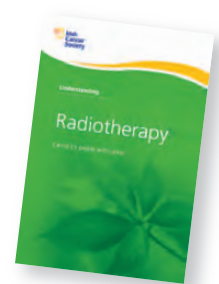
Tips

- 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, call our Cancer Nurseline on 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



Chemotherapy

- Chemotherapy uses drugs to cure or control cancer. It can be used on its own or with radiotherapy.
- It may also help to prevent the cancer coming back or to control advanced cancer.
- Any side-effects depend on the drug used and the dose. They usually go away after treatment ends.
- Possible side-effects include sore mouth, taste changes, loss of appetite, nausea and vomiting, diarrhoea, infection, fatigue, hair loss, and numbness or tingling in hands or feet.

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

How is chemotherapy given?

Chemotherapy 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.

What kinds of drugs are used?

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

Understanding your drug treatment



It's important that you understand any drugs you're having. Don't be afraid to ask your doctor or specialist nurse for more information about your drug treatment and any possible side-effects. They may be able to give you a printed sheet to take home with you.

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

What are the side-effects of chemotherapy?

The side-effects of chemotherapy vary from person to person and depend on the drugs used and the amount of chemotherapy given.

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

Mouth and throat problems

Some drugs can cause mouth and throat problems including a dry mouth, ulcers and gum infections. Try to keep your teeth, gums and mouth very clean. If you have dentures, remove them if your gums are sore. 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.

Diarrhoea

Passing more than three watery bowel motions a day is known as diarrhoea. You may also have cramping or abdominal pain. If this happens, drink lots of clear fluids to replace the fluid you are losing. Tell your doctor or nurse if you get diarrhoea, as there is medication to stop this side-effect.

Infection

Chemotherapy can increase your risk of infection. You will be asked to watch out for signs of infection at all times. These signs include feeling shivery and unwell, having a high temperature, having a cough, or pain passing urine.

Tiredness (fatigue)

Fatigue is where you feel tired and weak and rest does not seem to help. For more information see page 91.

Hair loss (alopecia)

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

Bleeding and bruising

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

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.

Numbness or tingling in hands or feet

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. Tell your doctor if you have these symptoms.

Changes in kidney function

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

Other side-effects

For the effects of chemotherapy on fertility and advice on contraception, see page 93. Other possible side-effects include aching joints and muscles, hearing changes (e.g. ringing in your ears, difficulty hearing high-pitched sounds), an itchy rash and headaches. Your doctor can prescribe medication to help prevent or treat any of these problems.

If you have any symptoms that are troubling you or you feel unwell, tell your doctor or nurse straight away. He or she will tell you what to do.

For tips to help you cope with the side-effects of chemotherapy see our website, www.cancer.ie, or our booklet *Understanding chemotherapy and other drug treatments*. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for advice and support from a cancer nurse.



Targeted therapies and immunotherapy

- Targeted therapies are drugs that target certain parts of the cancer cells that make them different from other cells.
- Immunotherapy changes parts of your immune system to work better to fight cancer cells.
- You may have these drugs alone or with other treatments such as radiotherapy or chemotherapy.
- Side-effects depend on the drugs being used and vary from person to person.

Different drugs 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 the cells die
- Stop making new blood vessels to feed the cancer cells
- Carry toxins to the cancer cells to kill them
- Help your immune system to fight cancer

Examples of drugs used for some types of head and neck cancer include cetuximab and nivolumab. Cetuximab blocks proteins on cancer cells so that they can't help the cells to grow. It's usually given for mouth, oropharyngeal, laryngeal, tongue and tonsil cancer that has spread to nearby areas (locally advanced), metastatic cancer or cancer that has come back after treatment (recurrent cancer). Nivolumab is usually used after chemotherapy.

Often cancer drugs are given through a drip into a vein. Some drugs are given in tablet form or as an injection.

New developments

New cancer drugs are being developed all 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 page 78). 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.

Side-effects

Side-effects depend on the drugs being used and vary from person to person. Some of the more common side-effects include:

Flu-like symptoms

These include fever and chills, weakness, nausea, vomiting, cough diarrhoea and headache. These are often worse just 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 cancer drugs. 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 or nail 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.

Fatigue

This is extreme tiredness. See page 91 for more on coping with fatigue.

Inflammation

You may have some inflammation in the lining of the intestine, mouth and nose or eye. This may cause nose bleeds or irritation and redness in the eye (conjunctivitis).

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



Clinical trials

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

Drugs that are used in a clinical trial have been carefully tested before they're given to patients. Because the drugs are still in trial, you'll be very closely monitored and may have extra tests and appointments. Trials often investigate very specific features of a particular cancer or treatment, so you may not be suitable for a trial, even if it is researching your particular cancer. Your doctor can advise you about this.

More information

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



Treatment for cancer that has spread (metastatic cancer)

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

If your cancer has spread it can still be treated. Treatment is usually to try to control the cancer rather than to cure it. There is a range of treatment options for most advanced cancers, and new treatments are being developed all the time.

Often metastatic cancer is treated with chemotherapy or targeted therapies, but you may also have surgery in some cases. There may also be treatments that you can have as part of a clinical trial (see page 78).

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

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

Cancer Nurseline Freephone 1800 200 700

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?

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Treatment for head, neck and mouth cancers can sometimes bring big changes to how you look, eat, breathe, speak or hear. 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 health professionals ready to help you and your family to cope.

Changes to appearance



Treatments such as radiotherapy or surgery can change the way you look. For example, you may have scarring or more significant changes to your appearance which can be difficult to adjust to.

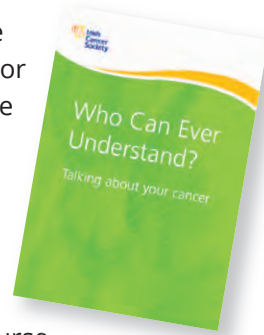
If you have a stoma in your throat you may feel self-conscious about this, but most people adjust well to having a stoma in time.

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. It can help to get some support:

- Don't be afraid to ask for help from the medical 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 ***Who Can Ever Understand: Talking about Your Cancer*** has advice if you find it hard to share your feelings.
- It may help to talk to someone who has been through a similar surgery. Ask your specialist nurse or speech and language therapist about this. You can also call our Cancer Nurseline 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 at our affiliated cancer support centres. See page 106 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 programmes 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 50). 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 look at the eating suggestions in the centre of this booklet or 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 with any changes to your speech and 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 medical 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

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 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 Cancer Nurseline 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 53 for advice on managing with a **tracheostomy**.

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 hearing aids available.



How can I cope with fatigue?

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

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

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



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

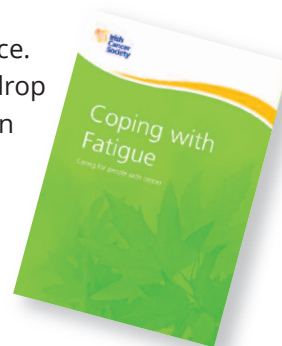
Finding out what is causing your fatigue makes it easier to treat, although sometimes it can be hard to find the cause. If you have a low red blood cell count, a transfusion can make you feel better. If you are not eating well a dietitian may be able to give you some advice to help you.

Hints and tips: Fatigue



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

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



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 83 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 can enjoy other forms of closeness, such as touching, caressing and holding each other.

You may find that talking about your feelings eases any worries you have. If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. He or she may refer you for specialist relationships counselling or sex therapy. This can help you and your partner deal with a change in your sexual relationship and find ways of being close again.

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

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

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 there's no need to feel embarrassed. You can also call our Cancer Nurseline 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 cancernurseline@irishcancer.ie

Will treatment affect my fertility?

Your fertility may be affected by some of the treatments so that you may not be able to have a child in the future. Discuss any worries you have about infertility with your doctor before treatment starts. 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 may not be easy, depending on your age and if you have already had children. It can bring feelings of sadness, anger and loss of identity. It can help to talk through your concerns with someone who is a good listener or with a professional counsellor. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for information and support from a cancer nurse.

Cancer and complementary therapies

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

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

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



Integrative care



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

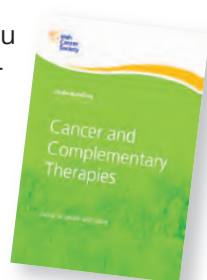
What's the difference between complementary and alternative therapies?

- **Complementary therapies** are used **together with** standard medical treatment.
- **Alternative therapies** are used **instead of** standard medical care.

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

More information

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



After treatment

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What follow-up will I need?

After your cancer treatment has ended you will still need to go back to the hospital for regular check-ups. This is called follow-up. The follow-up may involve having a physical exam, blood tests and scans. At first you will see your consultant every 3–6 months but these check-ups will become less frequent over time.

Tell your doctor or nurse how you have been since your last appointment. Remember to tell them about any new symptoms or problems you're having, or if you're finding it hard to cope.



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

It's important to attend your follow-up appointments as they will allow your doctor to check for signs of the cancer coming back (recurrence) and to help with any side-effects that you may have. It's best to be aware of these as early as possible so that suitable treatment can be given.

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

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

Life after cancer treatment

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

Feelings you may have include:

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

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

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

Healthy lifestyle changes

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

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

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

A healthy lifestyle includes:

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



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

What if the cancer comes back?

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



Coping and emotions

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How can I cope with my feelings?

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

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

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

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

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

Anxiety and depression

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

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

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

Counselling

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

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

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



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

Ways to get emotional support



Find out about cancer support services in your area: Most provide a range of helpful services like counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 128 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 the same challenges. Many cancer support centres have activities and groups where you can meet other people affected by cancer.

Ask about psycho-oncology services at the hospital: Hospital psycho-oncology services give cancer patients emotional and psychological support to help them cope. Your doctor, specialist nurse or medical social worker can refer you to psycho-oncology support services.

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

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

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

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

Survivor Support



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

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

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

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

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

You and your family

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

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

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.

Further information and support

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



Supporting someone with cancer

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Supporting someone with cancer

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

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

Learn about cancer

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

Share worries

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

Be kind to yourself

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

Try counselling

You might find it helpful to talk to a counsellor. Free one-to-one counselling is available to friends and family members at our affiliated cancer support centres. Talk to your GP or see page 128.

Find out about support for carers

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

How to talk to someone with cancer



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

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



Support for you



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

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

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

Free copies are available from our Daffodil Centres and our Cancer Nurseline, or download it from our website www.cancer.ie





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Coping with the financial impact of cancer



- If you have cancer you may not be able to work for a time. You may also have extra expenses.
- 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 treatment to check you're covered.

Benefits and allowances

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

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

- **The medical social worker** in the hospital you are attending
- **Citizens Information** – Tel: 0761 074 000
- **Department of Employment Affairs and Social Protection** – Tel: 1890 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

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

If you have money problems

If you 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 0761 07 2000 for information.

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 125 for more details of our Volunteer Driver Service and the Travel2Care fund.

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

More information

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

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



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



Irish Cancer Society services

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

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

Cancer Nurseline Freephone 1800 200 700

Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information. It's open Monday–Friday, 9am to 5pm.

You can also email us on cancernurseline@irishcancer.ie or visit our Online Community at www.cancer.ie

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



Daffodil Centres

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



Who can use the Daffodil Centres?

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

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

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

Survivor Support



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

Support in your area

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

Cancer Nurseline Freephone 1800 200 700

Patient travel and financial support services



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

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

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

Irish Cancer Society Night Nursing

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



Email cancernurseline@irishcancer.ie

Publications and website information

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



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

Local cancer support services

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

For example:

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of free one-to-one counselling in many affiliated support services)
- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- **Special exercise programmes**, like the Irish Cancer Society's *Strides for Life* walking group programme
- **Stress management and relaxation techniques**, such as mindfulness and meditation
- **Complementary therapies** like massage, reflexology and acupuncture



- **Specialist services** such as prosthesis or wig fitting and manual lymph drainage
- **Mind and body sessions**, for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics



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

You can call our Cancer Nurseline on Freephone 1800 200 700 to find your nearest cancer support centre. Or see our online directory at <http://www.cancer.ie/support/support-in-your-area/directory>

Questions to ask your doctor

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

What tests will I need?

Will I have to stay in hospital for the tests?

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

At what stage is my cancer?

What type of treatment do I need?

What 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?

Acknowledgments

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

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- *Cancer in Ireland 1994-2016 with estimates for 2016-2018*: Annual report of the National Cancer Registry (2018)
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- *The Chemotherapy Source Book*, M Perry, Lippincott Williams and Wilkins, 5th Ed (2012).

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Join the Irish Cancer Society team

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

Support people affected by cancer

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

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

Share your experiences

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

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

Raise money

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

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

Contact our Cancer Nurseline on Freephone 1800 200 700 if you want to get involved!

Did you like this booklet?

We would love to hear your comments or suggestions.

Please email reviewers@irishcancer.ie

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