

Understanding

Thyroid cancer

Caring for people with cancer

Understanding

Thyroid cancer

This booklet has information on:

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

Useful numbers

Specialist nurse

Family doctor (GP)

Endocrinologist

Medical physicist

Radiation oncologist

Medical social worker

Emergency

Hospital records number (MRN)



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Fast facts



Can my cancer be treated?

Page 31

All stages of thyroid cancer can be treated. Your doctor will discuss your treatment options with you.

What kind of treatment might I have? Page 45

Surgery: An operation to remove the cancer.

Radioactive iodine therapy: This treatment can destroy small amounts of cancer cells, if some remain after surgery.

Thyroid hormone therapy: If your thyroid gland is removed, you will need to take hormone replacement tablets every day.

See page 35 for advice about making a decision.

What is differentiated thyroid cancer?

Page 11

Differentiated thyroid cancer (DTC) is the most common type of thyroid cancer. This booklet is about DTC. When we refer to thyroid cancer in this booklet we are mainly talking about DTC.

Clinical trials

Page 66

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

We're here for you

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

Ways to get in touch

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

See page 100 for more about our services.

Support Line Freephone 1800 200 700

Reading this booklet



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

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

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

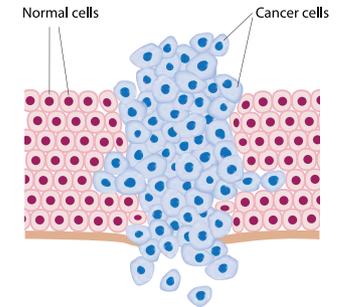
We cannot give advice about the best treatment for you. Talk to your hospital team about your treatment and care – they know your medical history and your individual circumstances.

About thyroid cancer

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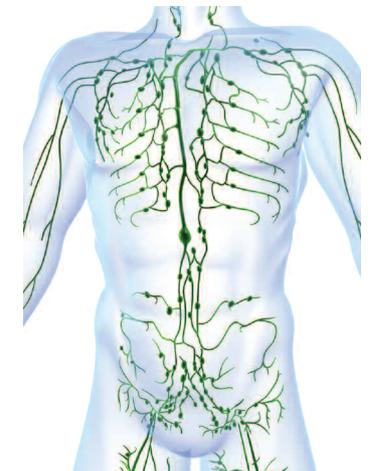
What is cancer?

- **Cancer is a disease of the body's cells**
Cancer cells are abnormal cells that grow without control. They can form a lump (tumour).
- **Cancers are named after the organ or cell where the cancer starts**
Thyroid cancer starts in cells in the thyroid.
- **Cancers sometimes spread**
If a tumour is cancerous (malignant), a cell or group of cells can be carried by your blood or lymph fluid to another part of your body, where it can form a new tumour. This is called metastasis. Sometimes cancer cells spread into nearby lymph nodes.



What is the lymphatic system?

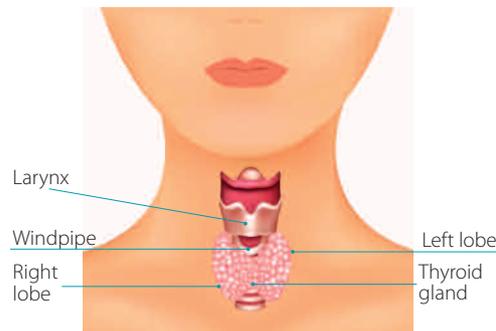
- The lymphatic system is part of our immune system. It protects us from infection and disease and removes extra fluid and waste from the body's tissues.
- It is made up of lymph nodes connected by tiny tubes called lymph vessels.
- Lymph nodes are found mainly in the neck, armpit, groin and tummy.
-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



What is the thyroid

The thyroid is a small gland at the front of your neck shaped like a butterfly. It sits at the base of your throat, on top of your windpipe and below your voicebox (larynx).

The gland has two halves called lobes that are linked by a thin piece of tissue called the isthmus. The thyroid is part of a network of glands that make up your endocrine system.



This system makes hormones that help to control various functions in your body. It is common to have lumps called nodules on your thyroid as you get older.

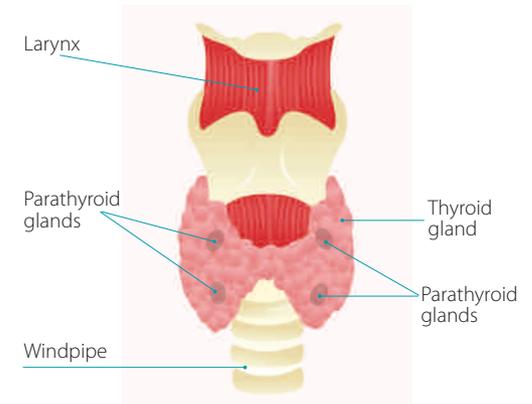
The thyroid makes two important hormones that are released into your bloodstream. These are thyroxine (T4) and triiodothyronine (T3). They affect your heart rate, blood pressure, body temperature, the speed at which food is changed into energy (metabolism) and your weight.

In fact, every cell in your body depends on these hormones to function normally. For the thyroid to work, it needs a regular supply of iodine. This is mainly found in fish, seafood and dairy products like milk, yogurt and cheese.

The thyroid also produced a hormone called calcitonin, which helps to regulate the amount of calcium in your blood.

Parathyroid glands

Attached to the back of the thyroid gland are four tiny glands. These are called the parathyroid glands and they make a hormone called the parathyroid hormone. Also involved in regulating your blood calcium levels, the parathyroid hormone helps to store and use calcium in your body.



What is thyroid cancer?

Thyroid cancer happens when cells in your thyroid change and start to grow quickly. They can form a tumour.

What are the types of thyroid cancer?

Your doctor will find out your type of thyroid cancer by taking a small sample of cells from your thyroid (biopsy).

Differentiated thyroid cancer

The most common type of thyroid cancer is called differentiated thyroid cancer (DTC). Caught early, most thyroid cancers are curable. There are two types of DTC: papillary and follicular cancer.

Papillary thyroid cancer: This is the most common type, accounting for about 4 out of 5 thyroid cancer diagnoses. It is more common in women and often occurs between the ages of 35 and 45. Even though the cancer cells grow slowly, they often spread to the lymph nodes in your neck.

Follicular thyroid cancer: About 1 in 5 people with thyroid cancer has follicular thyroid cancer. It is less common than papillary, grows slowly and is usually found in slightly older people. Follicular cancer can spread to lymph nodes in the neck first. It is also more likely to grow into blood vessels and then spread to distant areas, particularly your lungs and bones. Hürthle cell cancer is a type of follicular thyroid cancer.

Rarer types of thyroid cancer

Medullary thyroid cancer: This is a very rare type of thyroid cancer that often runs in families. It can be linked to faulty genes like RET. The cancer develops in the C cells of the thyroid, which make the hormone calcitonin. See 'Family history and inherited conditions' on the next page.

Anaplastic thyroid cancer: This is a very rare cancer, most often found in older people. The cancer cells look very different from normal thyroid cells. It grows quickly and can be difficult to treat.

Other rare types of thyroid cancer include thyroid lymphomas or thyroid sarcomas. They are treated in a different way.

This booklet is about differentiated thyroid cancer (DTC). When we refer to thyroid cancer in this booklet we are mainly talking about DTC.

If you have a rarer type of thyroid cancer, your doctor will explain it to you fully. For more information, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Support Line Freephone 1800 200 700

What caused my cancer?

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

Family history and inherited conditions

Your family may be at increased risk of thyroid cancer if there is a family history of the disease. Or you may be at risk if you inherit faulty genes. For example, the RET gene can cause medullary thyroid cancer. Also, the bowel condition familial adenomatous polyposis (FAP) can lead to thyroid cancer.

If a family member is concerned about their risk, they should talk to their family doctor (GP), who may refer them to a specialist or advise them on the best action to take.

An overactive or underactive thyroid does not increase your risk of thyroid cancer.

How common is thyroid cancer?

Even though thyroid cancer is rare, it is still the most common type of endocrine cancer. Endocrine means glands that release hormones directly into your bloodstream. About 250 people are diagnosed with thyroid cancer each year in Ireland; some 175 of these are women. The number of thyroid cancer being detected is higher now than it was 20 years ago. Doctors think this is due to new diagnostic tools that allow them to find small thyroid cancers much earlier.



Preparing for your hospital appointments

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Preparing for your hospital appointments

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



Before your appointment

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

What to take to your appointment

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

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

Before leaving the appointment

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

After the appointment

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

Note

If you have to cancel your appointment...

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

Email: supportline@irishcancer.ie



Diagnosis and further tests

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Being diagnosed with thyroid cancer

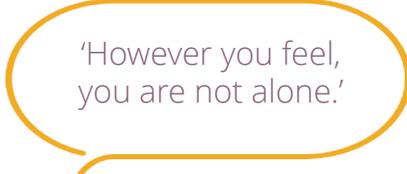
Hearing that you have thyroid cancer can be a huge shock. You may be feeling:

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

However you feel, you are not alone.

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

- **Ask to speak to the cancer (oncology) liaison nurse or the medical social worker at the hospital.** They can help you and your family to cope with your feelings and advise you about practical matters.
- **Talk to one of our cancer nurses in confidence** – visit a Daffodil Centre or call our Support Line on 1800 200 700. You can email the nurses at supportline@irishcancer.ie
- **Speak to an Irish Cancer Society Survivor Support volunteer** who has had a cancer diagnosis and really knows what you are going through. Our cancer nurses can put you in touch with a volunteer.
- **Talk to other people affected by cancer.** Join our online community at www.cancer.ie/community
- **Go to your local cancer support centre.** For more information, see page 106.



'However you feel,
you are not alone.'

Telling people about your diagnosis



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

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

What tests will I have after diagnosis?

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

The tests you have after diagnosis are done to help the doctor get more information about your illness and to stage the cancer. Staging means finding out the size of the cancer and if it has spread to other parts of your body. Staging is very important, as it helps your doctor to decide the best treatment for you.

Your doctors will tell you which of the following tests you may need.

Ultrasound scan of neck

This scan uses sound waves to look at your thyroid gland. This is the most important scan for diagnosing thyroid cancer and monitoring your response to treatment. The scan only takes a few minutes.

Some gel is first put on your neck and the area is then scanned with a hand-held device called a probe. The probe changes the sound waves into an image of your neck on the computer.



Laryngoscopy

This is a test to check your voice box (larynx). The doctor can see if the thyroid tumour is pressing on your vocal cords. This can be done with special mirrors or with a very thin, flexible tube called a laryngoscope that the doctor passes down your throat. The laryngoscope has light and a lens on it so they can examine your voice box closely.

CT scan (CAT scan)

This is a type of X-ray that gives a detailed 3D picture of the tissues inside your body. You may be asked to fast (not eat) for a few hours before the test. You may be given an injection or a special contrast drink to



help show up parts of your body on the scan. The injection may make you feel hot all over for a few minutes. During the scan you will lie on a table which passes through a large doughnut-shaped machine. The scan is painless and takes between 10 and 30 minutes. You'll probably be able to go home as soon as the scan is over.

MRI scan

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

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

You cannot wear metal jewellery during the scan. If you have a medical device implanted, like a pacemaker or metal pin, you may not be suitable for the test. Usually you can go home soon after the scan.

PET scan

A PET scan can also 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.

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

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

Waiting for test results

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

Staging thyroid cancer

- Staging cancer means finding out its size and if it has spread.
- Staging helps your doctor to decide the best treatment for you.

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

Knowing the stage helps your medical team to decide the best treatment for you.

Staging thyroid cancer and assessing your risk of recurrence

A cancer stage is a way to describe the extent of the cancer at the time you are first diagnosed. The staging system normally used in thyroid cancer is called TNM. This stands for:

Tumour (T): What is the size and extent of the main tumour? T1, for example, means the tumour is in the thyroid gland and is up to 2cm in size.

Nodes (N): Is there cancer in the lymph nodes? N1, for example, means the cancer is also in nearby lymph nodes.

Metastasis (M): Has the cancer spread to other parts of the body? M0, for example, means it has not spread to other parts of the body.

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

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

Thyroid cancer can be staged slightly differently in some cases. This may depend on the type of cancer and your age.

The TNM system does not fully predict the risk of the disease coming back (recurring). Your doctor will look at many other factors – including the biology of the tumour – to assess your risk of recurrence. This is called risk stratification and will help your doctor decide what further treatment is needed.

Medullary and anaplastic tumours are not staged in the same way. Speak to your doctor, nurse specialist or a cancer nurse on our Support Line 1800 200 700 for more information.

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



Asking about your prognosis

Your prognosis includes information about how your cancer is likely to progress, including average survival times or life expectancy. It's not always easy for doctors to answer a question about life expectancy. Everyone is different, so what happens to you might be quite different from what the doctor expects.

Should I ask about my prognosis?

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

If you decide you want information on your prognosis:

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

Treatment overview

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How is thyroid cancer treated?

- Most patients with differentiated thyroid cancer are treated with surgery, radioactive iodine therapy or both.
- A team of healthcare professionals will be looking after you (multidisciplinary team).

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



This booklet focuses on the treatment of differentiated thyroid cancer only. Medullary, anaplastic and lymphoma thyroid cancers will have different treatments – speak to your team about your type of cancer.

Treatment overview

The type of treatment you have will depend on:

- The size and type of the tumour
- If it has spread
- Your age
- Your general health

Most patients with differentiated thyroid cancer are treated successfully with surgery, radioactive iodine or both. Each patient is treated individually. You will have a different risk of the cancer returning than another patient. As a result, your doctor will balance your treatment with the risk of the cancer returning.



Surgery

The most important treatment for thyroid cancer is surgery. Surgery to remove all of your thyroid is known as a total thyroidectomy. Surgery to remove part of your thyroid is called a partial thyroidectomy or thyroid lobectomy. Usually this cures the cancer, especially when found early. After surgery, you may need thyroid hormone therapy or radioactive iodine therapy. See page 47 for more details on surgery.

Radioactive iodine therapy

Some patients might need radioactive iodine therapy after their surgery. This can destroy tiny amounts of normal thyroid tissue or cancer cells, if any are left behind after surgery.

As a result, it reduces the risk of the cancer recurring or spreading elsewhere. It is also called radioiodine or internal radiotherapy. See page 54 for more details.

Thyroid hormone therapy

Most patients receive thyroid hormone therapy after surgery. Once your thyroid gland is removed, you can no longer make thyroid hormones, so you will need to replace them by taking medication for the rest of your life. It is not a cancer treatment as such. See page 62 for more details.

Deciding on treatment

Multidisciplinary team

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

Understanding your treatment

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

Time to think

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

Accepting treatment

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

Who will be involved in my care?

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

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

Surgeon A doctor who specialises in surgery and who can remove a tumour from your body.

Endocrinologist A doctor who specialises in treating diseases of the thyroid and other glands in your body.

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

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

Medical physicist A person who manages the safe use of radiation and provides advice to people receiving radiation as part of their treatment.

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

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

Medical social worker A healthcare professional trained to help you and your family with all your social issues and practical needs. They can give counselling and emotional support. They can also give advice on benefits and financial matters and on practical supports and services available to you when you go home.

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



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

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

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

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

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

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

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

Community health services This includes 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.

Support Line Freephone 1800 200 700

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 it to be given. Before treatment, you should have been given full information about:

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

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

Waiting for treatment to start

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

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

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

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



How can I help myself?

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

Eat well

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

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



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

Stay active

Keeping active has many benefits. It can help to:

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



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

Support Line Freephone 1800 200 700

Quit smoking

If you are coping with a cancer diagnosis, you may find it stressful to quit smoking.

However, research tells us that:

- Non-smokers have fewer or less severe side-effects during cancer treatment. For example, it reduces the risk of chest problems such as chest infection.
- Smoking can reduce how well chemotherapy or radiotherapy work.
- Smoking increases risk of complications following surgery such as delayed wound healing and chest infections.



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

Other ways to help yourself

Get information about your cancer and treatment

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

Involve your family and close friends

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

Use your support network

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

Try relaxation and stress management techniques

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

Accept change in your life

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

Know that there will be ups and downs

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

Try to cope day by day

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

Email: supportline@irishcancer.ie

Types of treatment

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Surgery

- Surgery is one of the main treatments for thyroid cancer.
- A team of specialists will decide if surgery is the best option for you and the kind of approach that would suit you best.

Surgery is the most common treatment for thyroid cancer. The operation to remove the thyroid gland is called a thyroidectomy. All of the gland may need to be removed but often only one lobe needs to be removed. Surgery to remove nearby lymph glands may be done at the same time.



Types of surgery

Total thyroidectomy

A total thyroidectomy is the removal of the entire thyroid gland or as much of it as possible. This reduces the chances of the cancer coming back. A small cut is usually made in the centre of your neck to get directly at the gland. If any tissue is left behind after surgery, you might need radioiodine therapy later.

Lobectomy or partial thyroidectomy

When one lobe of the thyroid is removed, it is called a lobectomy. Sometimes it may be possible to remove just the affected lobe.

Lymph node removal

Your surgeon might remove some or all of the lymph nodes close to your thyroid gland. These can be examined under a microscope to see if cancer has spread to them. Removing the lymph nodes is called a lymphadenectomy or a neck dissection. As many as possible of the nodes are removed to prevent the cancer from coming back.

More surgery

Sometimes it is not possible to diagnose thyroid cancer before surgery. To make a diagnosis, your surgeon may need to remove the affected lobe so that it can be examined under a microscope. If the diagnosis of cancer is confirmed and depending on the staging of the tumour, the remaining lobe may need to be removed during a second operation.

Your surgeon might need to remove some of the tissues in the area around the thyroid gland if you have anaplastic thyroid cancer or if the cancer has begun to spread outside the gland.



Before surgery

Talk to your surgeon

Your surgeon will explain what to expect after surgery and any scarring that will happen. If you are worried about scarring, don't be afraid to talk to the surgeon and the team about the operation. It can help to make a list of questions before you go into hospital.

Tests before surgery

Thyroidectomy and lobectomy are operations that can take about 2-3 hours. You will need extra tests to make sure you are strong enough for surgery. These might include:

- A chest X-ray
- Blood tests
- Heart test (ECG)
- Breathing tests

Smoking

It's very important to stop smoking for at least one week before your surgery. Smoking can cause chronic irritation to your airways. This could lead to a lot of coughing with a risk of bleeding and pain after surgery. It can delay your wound healing as well.

If you would like help in quitting smoking, call the HSE Quit Team on Freephone 1800 201 203 or visit the website www.quit.ie

Exercises

A physiotherapist or nurse will show you how to do special exercises. These will involve deep breathing and leg exercises. They will help to prevent you getting a chest infection or a blood clot after your surgery.

Skin marks

The skin on your neck will be marked, especially if only one lobe is to be removed. The marks will show the doctors where the incisions are to be made.

Fasting

You will not be allowed to eat or drink anything from midnight before your surgery.

Preventing clots

Depending on your surgeon or the hospital, you may get an injection of an anti-clotting drug before surgery. For example, heparin. You might also get a course of it afterwards. This is to prevent a clot forming in your legs after surgery as you will be less mobile for a few days.

Rarely, if you have breathing difficulties, your surgeon might have to remove part of your windpipe (trachea) and make an opening in your throat to allow you to breathe. This surgery is called a tracheostomy.

You may have to avoid certain foods or supplements in the weeks before surgery – see page 55 for more information.

After surgery

Drips and drains

You will have a drip in your arm to replace any lost fluids. Once you can eat and drink well again, this will be removed. You may have one or two tubes in the wound. These are there to help drain fluid from your wound and are usually removed in a day or two after your surgery. Sometimes clips or glue are used instead of stitches to close the wound. If you have stitches, these will be removed before you go home.



Pain and discomfort

You will be given painkillers if you have any discomfort after your surgery. If your medicine isn't controlling your pain, tell your doctor or nurse. They can change your pain medication.

Mobility

To help you breathe easily and reduce any swelling, your nurses will make sure you are lying in a semi-upright position. You will also be encouraged to start moving about as soon as possible afterwards.

Keep doing your regular leg movements and deep breathing exercises even when in bed. The physiotherapist can help you with these and offer advice.

Eating and drinking

For a short while after your surgery you may find it difficult to swallow. A soft diet might be best for you at this time. Your nurses or hospital dietitian will discuss food and meal ideas with you before you go home. For more information and ideas about recipes, see the booklet *Diet and Cancer*. Call our Support Line on 1800 200 700 for a copy, visit a Daffodil Centre or download it from www.cancer.ie

What are the side-effects of surgery?

You may experience some of the following side-effects after thyroid surgery:

- Hoarse voice
- Change in calcium levels
- Tiredness
- Neck stiffness
- Scarring

Hoarse voice

Your voice can sound hoarse and weak at first after the surgery. Sometimes this can be from slight damage to the nerves to the voice box (larynx). In most cases it is a temporary problem, but it can be permanent for a very small number of people. Your doctor may do another check of your voice box after the operation. If the hoarseness continues they may refer you to a speech and language therapist.

Change in calcium levels

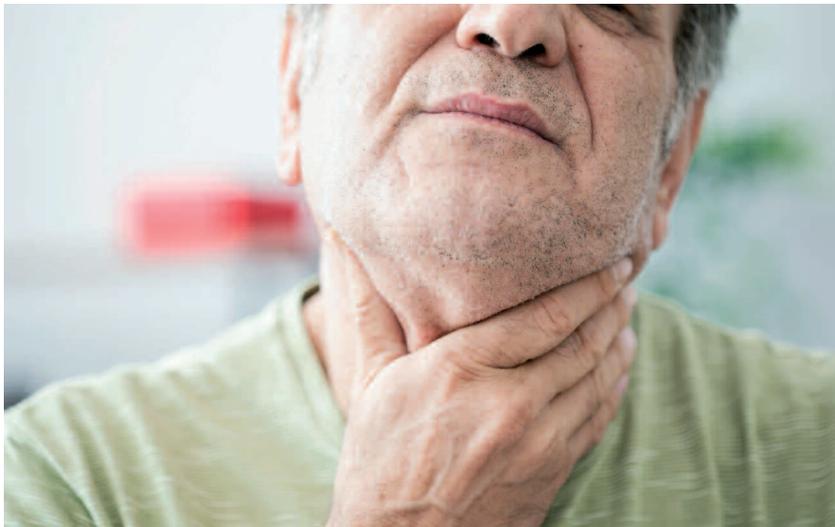
If there is damage to your parathyroid glands during surgery, the calcium levels in your blood may drop. This is called hypoparathyroidism. Signs of low calcium levels include tingling in your hands, feet or around your mouth. Or you may have unusual muscle movements, such as jerking or muscle cramps. Let your nurse or doctor know if you are experiencing any of these symptoms. You will also have regular blood tests to check your calcium levels. If needed, your doctor will prescribe calcium, and possibly vitamin D, until your levels are normal again.

Tiredness

It is common to feel tired or weak for a few weeks after your surgery. The time it takes to heal is different for everyone. For more information on dealing with tiredness or fatigue, see our booklet *Coping with Fatigue*. Call our Support Line on 1800 200 for a copy, visit a Daffodil Centre or download it from www.cancer.ie. See also page 75.

Neck stiffness

You may experience some neck stiffness for a few days to weeks after your surgery. Your doctor will prescribe painkillers to help with this.



Scarring

It is natural to be worried about scars after surgery. You will have a small scar across the front of your neck just above your collar bone. The scar will look red or dark at first but will fade with time. It is usually very neat and fades to a pale silver depending on your complexion.

Thyroid hormone replacement therapy

If you have a total thyroidectomy, you will no longer have a thyroid gland to make the hormones your body needs. As a result, you will need to take thyroxine tablets every day for the rest of your life. This is called thyroid hormone therapy. If you have a partial thyroidectomy you may also need to take these tablets. Regular blood tests will be done to make sure your thyroid hormone levels are correct. See page 62 for more details.

Going home

If all goes well after the surgery, you can usually go home after 1-2 days. If you live alone or have problems getting around the house, talk to the medical social worker or nurse as soon as you are admitted to the ward. That way, they can organise any community services you may need after you leave hospital. Your doctor will also advise you on when you can return to driving and to work. They can give you a letter or sick note for your employers if you need it.

On the day you go home, your doctor will tell you when they would like you to come back for a check-up.

If you have a worry or symptom that is causing you concern before your check-up date, contact your doctor, cancer nurse specialist or hospital ward for advice. See page 69 for more about follow-up.

Radioactive iodine therapy

- 
- Radioactive iodine therapy is sometimes given after surgery.
 - Radioactive iodine can kill off any cancer cells remaining after surgery.

What is radioactive iodine therapy?

Radioactive iodine therapy is a type of internal radiotherapy. It is also known as radioiodine therapy or thyroid remnant ablation.

The radioactive iodine, also called radioactive-iodine 131 (I-131), is usually given as a capsule.

Some people are given this therapy after thyroid surgery. Your doctor will let you know if you need it or not. This decision is based on international guidelines, and usually depends on the size of the cancer that was removed and the risk of it coming back.

You might also receive radioactive iodine therapy if some of the tumour could not be removed, or if this was a reoccurrence of thyroid cancer. This therapy can destroy tiny amounts of cancer cells, if any were left behind after surgery.

You may have to wait several weeks to recover after surgery before having this treatment. You will be referred to a specialist centre for this treatment.

How radioactive iodine works

The radioactive iodine is absorbed by thyroid cancer cells and destroys the cells – even if they have spread to other parts of the body.

Preparing for treatment

High TSH level

You will need a high level of thyroid-stimulating hormone (TSH) in your bloodstream for the treatment to be a success. This is done by giving an injection of TSH before treatment. TSH activates thyroid cells and encourages them to absorb the radioactive iodine.

Taking recombinant TSH: You will continue on your hormone therapy and be given recombinant human TSH (rhTSH). The drug is given over 2 days before the iodine capsule is taken. It will boost the level of TSH in your body to make sure the therapy works. It is rare to experience side-effects from rhTSH. If they do occur, you might have fatigue, nausea or headaches.

Low-iodine diet

Your doctor or nurse may advise you to limit the iodine in your diet for 2 weeks beforehand. A low-iodine diet may help your body to take up the radioactive iodine more effectively. Limiting iodine in your diet is usually not a problem in Ireland as most people have low levels anyway. Iodine is mainly found in fish, seafood, eggs, and dairy products like milk, yogurt and cheese. Just cut down on these rather than cutting them out. Your nurse can give you more advice.

Avoid certain foods and supplements

In the 2 weeks before you come into hospital, avoid the following:

- Cough medicine
- Iodised tablet salt
- Sea salt
- Pink Himalayan salt
- Canned and glacé cherries
- Salami, pastries and red-coloured sweets
- Vitamin supplements
- Mineral supplements

Once you have received your radioiodine treatment, you can return to your normal diet.

Pregnancy and breastfeeding



It is very important that you do not become pregnant or father a child during this treatment and for 6 months afterwards, or longer if advised by your doctor. Use a reliable method of contraception before you start treatment. If you are pregnant, you cannot be given radioiodine treatment. For this reason, you must tell your doctor if you are pregnant or think you might be. A pregnancy test will be done, even though it will not be accurate if you are in very early pregnancy (first 2 weeks).

If you are breastfeeding, you must stop a few days before your treatment. It is best if your child is weaned before treatment, or if you postpone treatment until your baby is weaned. You can discuss this with your doctor at the planning stage to make sure you and your baby are kept safe. It is not safe to start breastfeeding again after your treatment, but future pregnancies and breastfeeding will not be affected.

What to bring to hospital?

You can bring in old clothes, pyjamas and slippers, but they may have to be left behind when you leave because of the risk of contamination. You can also bring books and magazines or anything to help pass the time. It is best not to bring valuable items that might have to be left behind. Ask your nurse what is available in the room – such as a computer or DVD player. They can give you more information on what to bring.

What's involved?

Special care must be taken with this treatment. You will be admitted to a specialist centre to receive it. Before treatment you will be brought to a private room with an ensuite where you will stay for a few days. Usually this is a side room away from the main ward. All your meals will be brought to this room. You will be asked not to leave the room once you have been given the treatment and to stay there until you go home.

The treatment uses radioactive iodine called iodine-131. It is usually given as a small capsule to take with water. The radioiodine goes into your bloodstream and travels to thyroid cells in your body. The thyroid cells absorb the radioiodine and it kills them. This treatment does not hurt.

No harm comes to other cells in your body as they do not absorb the radioiodine. The treatment can be repeated if thyroid cells are still present.

Isolation

The therapy makes you radioactive for a few days. Because of this, you will need to be nursed in isolation for up to 5 days. You must stay in your room until the radioactivity has reduced to a safe level. It is gradually lost from your body in your urine, stools, blood, saliva and sweat. It is best to drink lots of fluids as this will help get rid of the radiation quicker.

The medical physicist will measure your radiation levels every day to make sure they have dropped to a safe level. Usually after 3 days you will be allowed home. A large amount of radiation will be gone from your body by then.

Usually a scan is done before you go home or the following week. You will be advised by the medical physicist on further precautions needed at home. These follow international guidelines.

Safety precautions

There is a chance that the hospital staff and your relatives and friends might be exposed to the radiation. Because of this, certain safety precautions are taken while the radioiodine is still in your body.

- No visitors are allowed for the first 24 hours. After that they are only allowed in your room for a short time each day, one at a time.
- Children under 14 and pregnant women will not be allowed to visit you. Some hospitals might have other precautions not listed here. These will be explained to you in more detail before your treatment.

Feeling isolated

It is natural to feel isolated, afraid or depressed at this time, especially when you want people around you. Let your nurses know if you are feeling this way. Voicing your worries can help a great deal. Ask about your treatment too, as it can reassure you to know what is happening next. There will be a telephone in the room so that you can ring family and friends and they can ring you.

Email: supportline@irishcancer.ie

Are there any side-effects?

As mentioned above, you will be radioactive but only for a few days.

Swelling

The radioiodine might cause a slight swelling under your jaw or salivary glands. This does not last long and can be eased by sucking on sharp-tasting sweets like lemon drops.

Other side-effects

Your doctor and nurse will let you know about any other rare side-effects that you might experience, such as a dry mouth or altered taste. Ask them for advice on coping with side-effects.

Going home

Usually you can go home after about 3-5 days. The nurses on the ward will let you know when your doctor wishes to see you again. You might have to return the following week for a whole body scan to check if all the thyroid cells are gone.



Hints & Tips – precautions at home during the first 2 weeks

- Avoid close and lengthy contact with people.
- Keep a distance of at least 6 feet (2 metres) from everyone. Double this amount for pregnant women and young children.
- Sleep in a separate bed.
- If you have a baby or young child, get your partner, relative or friend to care for them. Avoid bathing, changing or feeding them yourself.
- Breastfeeding must be completely stopped before and after treatment.
- Travel through an airport is not allowed during the first two weeks. Avoid long journeys on public transport.
- Avoid social functions or entertainment venues (cinema, theatre, stadiums, festivals, etc.) for at least a week.
- Do not return to work or school for at least a week, or longer if you work with children.
- Flush the toilet 2 or 3 times with the lid down after using it.
- Bathe or shower frequently.
- Rinse your toothbrush thoroughly.
- Do not share cutlery, crockery, towels and bed linen unless washed once.

Travelling abroad

Talk to your medical physicist before leaving hospital if you are planning to travel. You may face some restrictions. You will be given a letter for airport authorities in case the security scanners pick up any radioactivity.

If you would like more information on radioiodine therapy, call our Support Line on Freephone 1800 200 700 or visit a Daffodil Centre.



Individual treatment

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

Thyroid hormone therapy

- Thyroid hormone therapy replaces the natural thyroid hormones that can no longer be made after your surgery.
- It slows down the growth or recurrence of thyroid cancer.

Hormones help to control various functions in your body. After surgery to remove your thyroid gland, you will need thyroid hormone. This hormone is given for two reasons. First, you will need to replace the natural thyroid hormone now that your thyroid gland is gone or partially gone. Second, thyroid hormone therapy reduces the amount of thyroid-stimulating hormone (TSH) in your body. As a result, it stops or deactivates any surviving thyroid cells from working and cancer coming back.



What hormone is replaced?

The usual thyroid hormone replacement is thyroxine, which is also called T4. It is often started after surgery. You will be given this

replacement drug for life. Without these hormones you would develop signs and symptoms of an underactive thyroid (hypothyroidism). Symptoms include weight gain, tiredness, dry skin and hair, and physical and mental slowness. Most people only need to take the drug once a day but at the same time. It may take some months to find the correct dosage for you. As a result, you will have blood tests to check your hormone levels regularly.

Thyroid hormone preventing cancer

For many patients, an important part of treatment is keeping TSH levels low. TSH is made by the pituitary gland in your brain and it deactivates the thyroid cells. By keeping TSH levels low, it prevents thyroid cancer developing. By giving higher than normal doses of thyroid hormone, TSH levels can be kept very low. This is also known as TSH suppression. You may be given thyroid hormone if only part of your thyroid gland is removed. TSH will be kept low for at least 1 year after radioactive iodine therapy or until you complete the surveillance testing. For more information on surveillance, see page 70.

Side-effects of treatment

Although thyroid hormone therapy seldom causes side-effects, too much thyroid hormone may lead to weight loss, and feeling hot and sweaty. It may also cause a fast heart rate, chest pain, cramps and diarrhoea. In the long term, it can cause weak bones (osteoporosis). Too little thyroid hormone can cause weight gain, feeling cold and tired, and dry skin and hair. Tell your doctor or nurse if you have any side-effects. Your doctor can do a blood test to make sure you are getting the right dose of thyroid hormone.

More information

If you would like more information on thyroid hormone therapy, you can speak to our cancer nurses by calling our Support Line on 1800 200 700 or visiting a Daffodil Centre.

Treating metastatic (advanced) thyroid cancer

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

If it has spread, it can still be treated. Treatment in this case is to try to control the cancer rather than to cure it. There is a range of treatment options for metastatic cancers, and new treatments are being developed all the time. There may be treatments that you can have as part of a clinical trial (see page 66),

Metastatic thyroid cancer might be treated in the following ways:

External beam radiotherapy

This is the use of high-energy X-rays to destroy the cancer cells or slow their growth. The radiation comes from a machine called a linear accelerator. External radiotherapy might be given as a treatment for thyroid cancer that cannot be removed with surgery. It can also be given to shrink thyroid cancer that has come back after being treated, or not completely cured by surgery or radioactive iodine therapy. It can also be given for thyroid cancer that has spread to another part of your body.

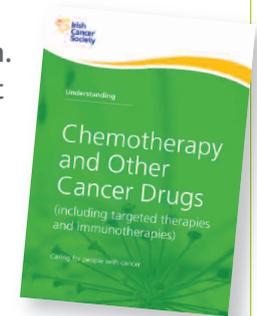
Chemotherapy

Chemotherapy is the use of drugs to cure or control cancer cells. It might be used if the cancer returns or has spread to other parts of your body.

Targeted therapies

These are drugs that work with your body to fight cancer. New targeted therapies are being developed all the time and existing therapies are being used in new ways. You may also be given a targeted therapy as part of a clinical trial (see page 66). Ask your doctor if there are any targeted therapies available to treat your cancer or if there are any trials that are suitable for you.

Your doctor and nurse will explain these treatments in more detail if you need them. For more information, you can also contact our Support Line on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of the booklets, *Understanding Radiotherapy* or *Understanding Chemotherapy and other cancer drugs*. You can also download them from www.cancer.ie



Clinical trials

Clinical trials are research studies that try to find new or better ways of treating cancer or reducing side-effects. Patients with cancer are sometimes asked to consider taking part in a clinical trial. This means that instead of the standard treatment you may get a new trial drug. Or you may be given existing treatments used in different ways. For example, giving a different dose of a drug or using two treatments together.

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

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

More information

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

After treatment

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What follow-up do I need?



After treatment, you will need to have regular check-ups. This is called follow-up or surveillance. Even though thyroid cancer has a very high cure rate, you will need follow-up for life. Your doctor will always be checking the risk of recurrence as the months and years go by. Any changes in your health can be noted at these check-ups and treated if needed.

At first these visits to your doctor will be quite often, but gradually become less frequent. If you receive radioiodine, you will see your doctor every 3 months. You may need yearly check-ups if the risk of cancer coming back is low, or every 6-12 months if the risk is higher.

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

It's important to attend your follow-up appointments as they will allow your doctor to check for signs of recurrence and to follow up on any ongoing side-effects that you may have. They can also check for signs of new side-effects that may develop after you have finished treatment. It is better to be aware of these as early as possible so that suitable treatment can be given.

Thyroid cancer surveillance

An important part of your follow-up is called thyroid cancer surveillance. This check-up takes place about 9 months to 1 year after your treatment. The aim of this check-up is to prove the absence of disease. You may have some or all of these tests:

- Blood tests, including thyroglobulin
- Ultrasound scan of your neck
- Injection of a human thyroid stimulating hormone (TSH)
- A full body scan using radioiodine

Thyroglobulin: A blood test to check your levels of thyroglobulin will be done regularly if you had papillary or follicular thyroid cancer. Thyroglobulin (Tg) is a protein made only by thyroid cells. So you should have little or none of it in your bloodstream after surgery and treatment. It usually takes 6-12 months after your surgery for it to become undetectable in your bloodstream. Once it becomes undetectable it should remain that way for the rest of your life. However, about 1 in 4 patients will have small detectable level of thyroid antibodies in their bloodstream which makes the test less reliable. Your doctor will use other ways and tests to manage your condition.

If the cancer comes back, the thyroglobulin becomes positive long before the cancer causes symptoms.

Problems or concerns

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

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

What if the cancer comes back?

Talk to your doctor or specialist nurse about the risk of your type of thyroid cancer coming back. If the thyroid cancer does return, it can be treated again.

Life after treatment

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

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

There is more about how to cope with these feelings and adjusting to life after cancer on our website www.cancer.ie. You can also call our Support Line or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 85 for other ways to get emotional support.

After-treatment workshops



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

Living a healthy lifestyle

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

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

A healthy lifestyle includes:

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

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

How will my lifestyle be affected?

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How can I cope with fatigue?

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

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

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

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



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

Hints and tips: Fatigue



- **Ask your doctor about exercising.** Being active can help with fatigue. Your doctor may also be able to recommend an exercise programme for you.
- **Get to know when your energy levels tend to be better.**
- **You may have to decide which tasks are important to finish and do them over the course of the day or when you have most energy.**
- **Ask for help at work or at home** with any jobs that you find tiring.
- **Try to eat a well-balanced diet.** Eat little and often if your appetite is poor. Our booklet *Diet and Cancer* has tips to help.
- **Try to avoid stress.** Talk to friends and family about any worries you have and take time to enjoy yourself. Counselling (see page 84) may help too.
- **If you are not sleeping well, have a good bedtime routine and try relaxation techniques.** Avoid stimulants like caffeine and alcohol in the evening and try not to use electronic devices for an hour before bedtime.
- **Short naps (less than an hour) and rest periods can be helpful,** as long as they don't stop you from sleeping at night.
- **Try complementary therapies** such as meditation, acupuncture or massage, if your doctor says they're safe for you.

Will treatment affect my sex life?

Sex and sexuality

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

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

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

There is no set time for you to be ready to have sex again. It varies from person to person. Your doctor can advise you about having sex again after treatment.

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

Email: supportline@irishcancer.ie

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. It is very important that you do not become pregnant or father a child during radioactive iodine therapy and for 6 months afterwards, unless a longer period is advised by your doctor.

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

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

Asking for advice

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

Will treatment affect my fertility?

The treatment for differentiated thyroid cancer is unlikely to affect your fertility in the long term. If you are a woman, your periods might stop or become irregular for several months after radioiodine therapy, but this is only temporary. Many people, especially younger patients, go on to have normal pregnancies and births.

For men, radioiodine may affect their sperm count and levels of testosterone briefly. But you will be able to father a child. It is best to wait at least 6 months after treatment before you go ahead. If you need repeated radioiodine therapies, you do have the option of sperm banking (storing sperm for later use).

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

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

Integrative care

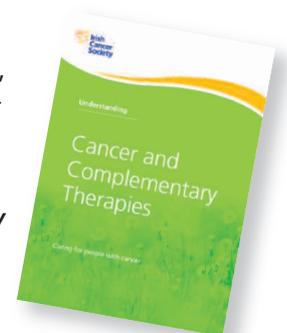
Integrative care means combining (integrating) your standard cancer treatment with complementary therapies to try to feel as well as possible and to cope better with your cancer.

What's the difference between complementary and alternative therapies?

Complementary therapies are used **together with** standard medical treatment. Alternative therapies are used **instead of** standard medical care. Modern medical treatments are very effective at curing cancer and keeping it under control. An unproven alternative therapy could harm your health, or you might miss out on a treatment that could really help you.

More information

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





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

Anxiety and depression

If you feel that anxiety or low moods are getting the better of you or you're finding it hard to cope, it's important to get help. Try to talk with someone you know who is a good listener, join a support group or tell your GP. Medical social workers can also offer support to you and your family. Your doctor may also suggest medication to help with anxiety or depression. Often a short course of medication can work well. Professional counselling can also be very helpful.

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.

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 many local cancer support centres. To find out more about counselling call our Support Line on Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at supportline@irishcancer.ie. A list of counsellors funded by the Irish Cancer Society is available at www.cancer.ie

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

Ways to get emotional support



Find out about cancer support services in your area: Most provide a range of helpful services like counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 106 for more about cancer support services.

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

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

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

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

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

If you need more information or help with finding support, call our Support Line on 1800 200 700 or drop into a Daffodil hospital or to one of our cancer nurses.

Survivor support

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

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

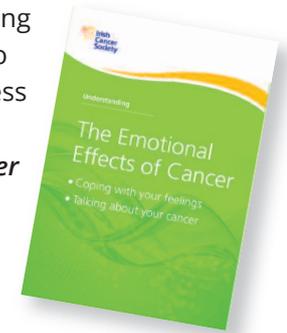
Positive feelings



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

You and your family

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



Further information and support

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

Changing relationships



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



Advice for carers

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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 Support Line for free copies of our cancer information booklets.

Support Line Freephone 1800 200 700

Share worries

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

Be kind to yourself

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



Try counselling

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

Find out about support for carers

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

Support for you



Our cancer nurses are there to support you. Call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie for confidential support, advice and information. Our booklet, *Caring for someone with cancer* has lots of information on:

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

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



How to talk to someone with cancer

When someone close to you has cancer it can be hard to know what to say. You may find it difficult to talk about their cancer. Or you may be afraid of saying the wrong thing. Often what people with cancer want most is someone to listen to them. If you want advice on how to support a friend or loved one with cancer, call our Support Line on 1800 200 700. Ask for a copy of our booklet *Caring for someone with cancer*. The booklet has a section 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 resources

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Money matters

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

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

Medical expenses

Medical expenses that you might have to pay include:

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

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

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

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

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

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

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

Benefits and allowances

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

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

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

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

If you have money problems

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

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice.

The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 103 for more details of our Volunteer Driver Service and the Travel2Care fund.

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



More information

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

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

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

Irish Cancer Society services

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

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

Support Line Freephone 1800 200 700

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

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



Email: supportline@irishcancer.ie

Daffodil Centres

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



Who can use the Daffodil Centres?

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

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

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

Survivor Support



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

Support in your area

We work with cancer support groups and centres and the National Cancer Control Programme to ensure patients and their families have access to high-quality confidential support in a location that's convenient to them. The Society funds professional one-to-one counselling (including telephone and video-call counselling) and group survivorship programmes in communities across the country.

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

Patient travel and financial support services



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

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

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

Irish Cancer Society Night Nursing



We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is a unique service in Ireland, providing palliative nursing care at night between 11pm and 7am to cancer patients.

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

Email: supportline@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 Support Line for free copies of our publications.

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

Local cancer support services

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

For example:

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of free one-to-one counselling through many local cancer support services)



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

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



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

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

Support Line Freephone 1800 200 700

What does that word mean?

Anaplastic A very rare form of thyroid cancer. It grows quickly and can be hard to treat.

Benign Not cancer. A tumour that does not spread.

Biopsy Removing a small amount of cells or tissue from your body to examine under a microscope. It can tell if cancer cells are present or not.

Calcitonin A hormone made in your thyroid gland. It helps keep a healthy level of calcium in your blood. When the calcium level is too high, calcitonin lowers it.

Cells The building blocks that make up your body. They are tiny and can only be seen under a microscope.

Chemotherapy The use of drugs to cure or control cancer.

Differentiated This refers to the most common types of thyroid cancer – papillary and follicular thyroid cancers.

Endocrinologist A doctor who specialises in treating diseases of the thyroid and other glands in your body.

Fatigue Ongoing tiredness often not eased by rest.

Follicular The second most common type of thyroid cancer. It grows slowly and is usually found in slightly older people.

Lobectomy Surgery to remove one lobe of your thyroid gland.

Malignant Cancer. A tumour that spreads.

Medullary A rare type of thyroid cancer.

Radioactive iodine A radioactive form of iodine. It is often used for tests or to treat a thyroid cancer. It is usually given as a capsule and kills cancer cells.

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

Papillary The most common type of thyroid cancer. It often affects women more than men.

Parathyroid A gland behind your thyroid gland. It makes parathyroid hormone that stores and controls calcium in your body.

Targeted therapies Drugs that use your body's immune system to fight cancer.

Thyroglobulin A protein made by thyroid cells. It is the form that thyroid hormone takes when stored in the cells of your thyroid. If your thyroid has been removed, thyroglobulin should not show up on a blood test.

Thyroid The gland above your windpipe that makes hormones that control various functions in your body. These include your heart rate, blood pressure, body temperature, speed of changing food into energy, and your weight.

Thyroidectomy Surgery to remove all or part of your thyroid gland.

Thyroid-stimulating hormone (TSH) A hormone made by your pituitary gland. It helps the release of thyroid hormone from thyroglobulin. It also helps the growth of thyroid follicular cells.

Thyroxine A hormone made by the thyroid gland.

Staging Tests that measure the size and extent of cancer.

Questions to ask your doctor

Here are some questions you might like to ask your doctor. Never be shy about asking questions. It is always better to ask than to worry.

What stage is my cancer at?

Will surgery cure the cancer?

Are there other treatment options? Why is this one best for me?

Would I be suitable for a clinical trial?

How long will my treatment take?

Do I have to stay in hospital for my treatment?

What side-effects or after-effects will I get?

Is there anything I can do to help myself during treatment?

How often will I need check-ups?

About this booklet

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

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

Support people affected by cancer

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

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

Share your experiences

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

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

Raise money

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

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

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

Did you like this booklet?

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

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