Understanding

Cancer of the Thyroid

Caring for people with cancer
Understanding

Cancer of the thyroid

This booklet has been written to help you understand about thyroid cancer. It has been prepared and checked by surgeons, cancer doctors, nurses, medical physicists and patients. The information in this booklet is an agreed view on thyroid cancer, its treatment and how it may affect you.

If you are a patient, your doctor or nurse may go through the booklet with you and mark sections that are important for you. You can also list below any contact names and information you may need.

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<td>Specialist nurse</td>
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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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- National Cancer Strategy 2017-2026, National Cancer Control Programme
- Thyroid Cancer: ESMO Clinical Practice Guidelines for Diagnosis, Treatment and Follow-up. European Society for Medical Oncology, 2010.
- Revised American Thyroid Association Management Guidelines for Patients with Thyroid Nodules and Differentiated Thyroid Cancer. Thyroid 19(11), 2009.

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Quick facts

Can my cancer be treated? Page 21
Yes. All stages of thyroid cancer can be treated. Your doctor will discuss with you what treatments will be of most benefit to you.

Will I be OK? Page 20
What is likely to happen to you (your prognosis) is hard to predict. It depends on a lot of things, and everyone's prognosis is different. The prognosis for thyroid cancer is very good for most people. Your doctor will advise you on what is likely to happen in your situation.

What kind of treatment will I have? Page 21

**Surgery:** An operation to remove the cancer.

**Radioactive iodine therapy:** Radiotherapy to treat thyroid cancer is usually given as radioactive iodine (a radioactive substance given as a drink or capsule).

**Thyroid hormone therapy:** If you have had your thyroid gland removed you will need to take thyroid hormone replacement tablets every day.

See page 24 for advice about making a decision.

Are there side-effects from treatment? Page 45
Your doctor and the team caring for you will talk to you about possible side-effects. Read about each of the treatments to learn more about their side-effects.

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

Clinical trials Page 43
Clinical trials are when cancer patients get a new type of treatment to see if it works better than existing treatments. Ask your consultant if there are any trials suitable for you.

We’re here for you Page 72
If you or your family have any questions of worries, want to know where to get support, or if you just need to talk, you can talk to one of our cancer nurses.

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

This booklet has been written to help you to learn more about cancer of the thyroid.

We hope the booklet answers some of your questions and encourages you to discuss them with your doctors and nurses. Talk to your doctor about your treatment and care. The best choice for you will depend on your particular cancer and your individual circumstances.

Reading this booklet

Remember you do not need to know everything about cancer of the thyroid straight away. Read a section that you are interested in. Then read another section when you want to know more. If you do not understand something that has been written, discuss it with your doctor or nurse.

You can also call our Cancer Nurseline on Freephone 1800 200 700 or email the nurses at cancernurseline@irishcancer.ie. You can also visit a Daffodil Centre. See page 72 for more about Daffodil Centres. You can email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.

About thyroid cancer

What is cancer? 8

What is the thyroid? 9

What is thyroid cancer? 10

What are the types of thyroid cancer? 10

How common is thyroid cancer? 11

What increases my risk of thyroid cancer? 11
What is cancer?

Cancer is a word used to describe a group of diseases, not just one. There are more than 200 different types of cancer. Each is named after the organ or type of cell in which the cancer first grows. For example, thyroid cancer starts in the cells in the thyroid.

All cancers are a disease of the body’s cells, which are the building blocks of your body. Normally, cells grow and divide in a controlled way and replace old cells to keep the body healthy. But with cancer, the abnormal cells grow without control. Groups of abnormal cells can form a growth or tumour.

Tumours can be either benign or malignant. Benign tumours are not cancerous and do not spread to other parts of your body. Malignant tumours are cancerous and can spread to other parts of your body. This happens when a cell or group of cells breaks away and is carried by your bloodstream or lymph vessels to other tissues and organs in your body, where they can form a secondary tumour. This is also called metastasis.

To sum up

- Cancer is a disease of the cells of the body.
- With cancer, the cells do not behave as normal. They keep on growing even when there is no need.
- If a tumour is malignant, cells can break away and be carried by the bloodstream or lymph to form a tumour somewhere else. This is called a metastasis or secondary tumour.

What is the lymphatic system?

The lymphatic system protects us from infection and disease. The lymph vessels are tiny tubes, which usually lie just under the skin. They transport lymph fluid, which carries extra fluid and waste from body tissues.

Lymph nodes, pouches where the fluid collects, are found mainly in the neck, armpit, groin and tummy. Lymph nodes are connected by a network of lymph vessels. Sometimes cancer cells spread into lymph nodes or start in the lymph nodes themselves. If this happens the lymph nodes 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, 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.
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. This helps to store and use calcium in your body. Parathyroid hormone is especially important in controlling the amount of calcium in your bloodstream.

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). The most common thyroid cancers are called differentiated.

Differentiated thyroid cancer
This means that the cancer cells have some features of normal thyroid cells. The two most common types, papillary and follicular, together are called differentiated thyroid cancer.

- **Papillary thyroid:** This is the most common type, affecting about 4 in 5 people with thyroid cancer. 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:** This affects about 1 in 5 people with thyroid cancer. It is less common, 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. Hürtthle cell cancer is a type of follicular thyroid cancer.

Less common types
- **Medullary thyroid:** 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. If it occurs in your family, you and your family members should get checked out regularly by your GP.

- **Anaplastic thyroid:** This is a very rare cancer, most commonly found in older people. The cancer cells look very different from normal thyroid cells. It grows quickly and can be difficult to treat. There are other more rare types too, such as thyroid lymphomas or thyroid sarcomas. They are treated in a different way. This booklet deals mainly with differentiated thyroid cancer.

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

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 275 people are diagnosed with thyroid cancer each year in Ireland: 200 women and 75 men. The rate of thyroid cancer is rising. Doctors think this is due to new diagnostic tools that allow them to find small thyroid cancers much earlier.

What increases my risk of thyroid cancer?
The exact cause of thyroid cancer is unknown. But there are certain risk factors that can affect your chances of getting the disease.

Having a risk factor doesn’t mean you will definitely get cancer.
Sometimes people without any known risk factors develop cancer.

Some things that can increase your risk of thyroid cancer are:

- **Age**: Thyroid cancer can develop at any age. But most cases occur in people over 40 years.
- **Gender**: Women are more at risk than men.
- **Family history of thyroid cancer**: You are more at risk if a family member has had thyroid cancer.
- **Exposure to radiation**: If you had radiotherapy as a child, you may be more at risk in later life of developing thyroid cancer. If you have been exposed to radiation from a nuclear plant, you can develop thyroid cancer many years later. One example is the people who lived near the Chernobyl reactor in Ukraine after it exploded in 1986.
- **Inherited faulty gene**: You may be at risk if you inherit faulty genes. For example, the RET gene may cause medullary thyroid cancer. Also, the bowel condition called familial adenomatous polyposis (FAP) may lead to thyroid cancer.

Remember an overactive or underactive thyroid does not increase your risk of thyroid cancer. If you think you may be at risk, first talk to your family doctor (GP) about your concerns. They may advise you to visit a specialist. If you or a family member is found to have a faulty gene, your doctor might advise surgery to remove your thyroid gland as a precaution.

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**To sum up**

- Thyroid cancer is rare but is the most common type of endocrine cancer.
- The most common thyroid cancers are called differentiated.
- They include papillary and follicular thyroid cancers.
- Most thyroid cancer patients are diagnosed with papillary cancer.
- The cause of thyroid cancer is unknown in most cases. Exposure to radiation and inherited faulty genes can increase your risk of developing it.

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**Diagnosis and tests**

- **Being diagnosed with thyroid cancer**
- **What tests will I have?**
- **Staging thyroid cancer**
- **Asking about your prognosis**
Understanding cancer of the thyroid

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
- Scared about the future

Everyone reacts differently to a cancer diagnosis. However, you feel, you are not alone. There are many people who can help and support you at this time.

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

- Ask to speak to the medical social worker or cancer liaison nurse at the hospital. They can help you and your family to cope with your feelings and advise you about practical matters
- Talk to one of our cancer nurses in confidence – call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre
- Email our cancer nurses at cancernurseline@irishcancer.ie
- Talk to other people going through the same thing. Join our online community at www.cancer.ie/community

Take it a day at a time. Don’t make assumptions. Trust the specialists.

What tests will I have?

The tests you have after diagnosis are usually done to help the doctor to stage your 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.

Often it is not possible to fully stage your cancer until after your surgery. Depending on your diagnosis, your doctor might arrange for these tests listed on the next page. These tests may also be used to see how you are responding to treatment:

Telling people about your diagnosis

It can be hard to tell other people the news that you have been diagnosed with cancer.

You may want to talk about your diagnosis, or you may prefer not to tell people straight away. Talking can help you to get support from friends and family. On the other hand, you may find it hard to cope with other people’s reactions when they hear the news. For example, they may fuss over you or be upset. Remember, thyroid cancer is not infectious and cannot be passed on to other people.

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

It was all a bit scary telling friends, family and work about it, but once you get your head around it, it’s OK.

We hope this booklet will help you too. It has information on what to expect when you have been diagnosed with cancer. It also has tips on how to cope – practically, emotionally and financially. More helpful information is available on our website www.cancer.ie
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.

CT scan: This is a special type of X-ray that gives a detailed picture of the tissues inside your body. During the scan you will lie on a table which passes through a large doughnut-shaped machine. The scan is painless and takes between 10 and 30 minutes. You might be asked to fast (not eat) for a few hours before the test. You may also be given an injection or a special drink to help show up parts of your body on the scan. Before you take the drink, let the radiographer know if you are allergic to iodine or have asthma. The injection may make you feel hot all over for a few minutes. Preparations for a CT scan can vary. The doctor or nurse in your hospital will tell you what to do. This test is usually done as an outpatient, so you should not need to stay in hospital.

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 may feel claustrophobic during the MRI scan. If you are anxious, contact the radiographer the day before. They may be able to give you medication to relax you on the day.

PET scan: PET stands for positron emission tomography. PET uses a low dose of radioactive sugar to measure the activity of your cells. This sugar is first injected into your arm and travels to all the cells in your body. Because cancer cells absorb large amounts of the sugar, there will be more radioactivity where the cancer cells are found. An hour after the injection, the scan is taken and can show if the cancer has spread to other tissues and organs. During the scan, you will lie on a table which moves through a scanning ring. Before the scan, you may have to fast (not eat) for a few hours.

Waiting for test results
It usually takes 2 to 4 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 Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

Staging thyroid cancer
There are different ways to describe the stages of cancer. The staging system normally refers to the size of the tumour (T), if there is cancer in your lymph nodes (N), and if the cancer has spread to other parts of your body (M for metastasis).

An MRI can also be noisy, but you will be given earplugs to wear during it. You might get an injection before the scan to show up certain parts of your body. During the scan you cannot wear metal jewellery. If you have any medical device in your body, like a pacemaker or pin, you may not be suitable for the test. Usually you can go home soon after the scan. You shouldn’t need to stay in hospital.

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

Your doctor often uses this information to give your cancer a stage number – from 0 to 4. A higher number, such as stage 4, means a more serious cancer. Some stages are further divided into stage A and B. The different types of thyroid cancer can have different stage numbers, depending on your age, or they may omit certain stages. For example, there is no stage 3 or 4 for papillary or follicular cancer in people under 45.

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

What are the stages of thyroid cancer?

Unlike most cancers, papillary and follicular thyroid cancer are also staged according to the age of the person.

Papillary or follicular thyroid cancer in people aged under 45

Stage 1: The cancer is any size and may or may not have spread to the lymph nodes. It has not spread to other parts of the body.

Stage 2: The cancer has spread to other parts of the body.

There is no stage 3 or 4 thyroid cancer for people in this age group.

Papillary or follicular thyroid cancer in people aged 45 or over

Stage 1: The cancer is no bigger than 2cm and hasn’t grown outside the thyroid gland.

Stage 2: The tumour is between 2 and 4 centimetres but hasn’t grown outside the thyroid gland.

Stage 3: The tumour has spread just outside the thyroid gland into nearby lymph nodes in the neck.

Stage 4A: The tumour has spread beyond the lymph nodes and into other tissues of the neck such as muscles or the lymph nodes of the upper chest. It has not spread to other parts of the body.

Stage 4B: The tumour has spread to the tissues near the spine but not to other parts of the body.

Stage 4C: The tumour has spread to other parts of the body, such as distant lymph nodes, the lung or bones.

This staging system is not used for anaplastic thyroid cancer. All anaplastic thyroid cancers are considered stage 4 at diagnosis.

To sum up

- You may need to have tests such as a CT scan or PET scan.
- These tests can help to stage the cancer.
- Staging cancer means finding out its size and how far it has spread in the body.
Understanding cancer of the thyroid

20

Asking about your prognosis

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

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.

It’s not always easy for doctors to answer a question about life expectancy, as the answer is based on a ‘typical’ experience. In reality, experiences can vary a lot from person to person. What happens to you might be quite different from what the doctor expects.

If you decide you want information on your prognosis:

■ Think carefully about how you will cope with the information before asking for your prognosis.

■ Get information on prognosis from your doctor. They know your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.

■ Avoid looking online. It can be hard to understand the information you find online without an expert like a doctor to help. The information may not really apply to your situation or to your particular cancer type.

■ Accept that you will need some time to think about what you have been told. You may forget some things or there may be things you didn’t understand. You may need to talk to your doctor again after you have thought about everything.

■ Get emotional support if you need it. If you feel upset or anxious about your prognosis you can get support from friends, family or your hospital team. You can also call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or email cancernurseline@irishcancer.ie. Our cancer nurses can give you support, information and advice. They can also tell you about free counselling and other services that can help you.

Treating thyroid cancer

How is thyroid cancer treated? 22

Types of treatment 22

Deciding on treatment 24

Giving consent for treatment 25

Who will be involved in my care? 26
How is thyroid cancer treated?

This booklet focuses on the treatment of differentiated thyroid cancer only. Medullary, anaplastic and lymphoma thyroid cancers are treated differently. In Ireland, thyroid cancer is treated at specialist cancer centres. There, a team of doctors will decide the best treatment for you once all your test results are available. The type of treatment you receive will depend on:

- The type of thyroid cancer
- The size of the cancer
- If it has spread or not
- Your age and general state of health

Types of treatment

More than likely you will receive more than one type of treatment. The following treatments can be used for thyroid cancer:

- Surgery
- Radioactive iodine therapy
- Thyroid hormone therapy

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 the risk of the cancer returning and giving you suitable treatment.

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 30 for more details on surgery.

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

As a result, it reduces the risk of the cancer recurring or spreading elsewhere. It is also called radiiodine or internal radiotherapy. See page 35 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 41 for more details.

Treatment of less common or advanced thyroid cancers

Less common or advanced thyroid cancers 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 43). 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 the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of the booklets, Understanding Radiotherapy or Understanding Chemotherapy. You can also download them from www.cancer.ie
Giving consent for treatment

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

- What the treatment is for
- The type and amount of treatment you will have
- The benefits and risks of the treatment
- 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. They can explain it to you again. Some treatments can be hard to understand and may need to be explained more than once. You can still change your mind after you have started treatment. Talk to your doctor or nurse if you have any worries about your treatment plan.

Individual treatment

You may notice that other people with 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.

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. This also gives you time to talk about all your treatment options with your doctors, family, and friends.

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

### Who will be involved in my care?

Usually a team of health professionals will be involved in your treatment and care. It varies who will lead the team and co-ordinate the management of your care. For example, your endocrinologist may lead the team at one stage or your surgeon at another time.

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<th>Role</th>
<th>Description</th>
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<tr>
<td><strong>Surgeon</strong></td>
<td>A doctor who specialises in surgery and who can remove a tumour from your body.</td>
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<tr>
<td><strong>Endocrinologist</strong></td>
<td>A doctor who specialises in treating diseases of the thyroid and other glands in your body.</td>
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<tr>
<td><strong>Radiation oncologist</strong></td>
<td>A doctor who specialises in treating cancer patients using radiotherapy.</td>
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<td><strong>Radiation therapist</strong></td>
<td>A specially trained person who delivers the radiotherapy and gives advice to cancer patients about their radiation treatment.</td>
</tr>
<tr>
<td><strong>Medical physicist</strong></td>
<td>A person who manages the safe use of radiation and provides advice to people receiving radiation as part of their treatment.</td>
</tr>
<tr>
<td><strong>Medical oncologist</strong></td>
<td>A doctor who specialises in treating cancer patients using chemotherapy and other drugs.</td>
</tr>
<tr>
<td><strong>Oncology liaison nurse / clinical nurse specialist</strong></td>
<td>A specially trained nurse who works in a special cancer care unit. They give information and reassurance to you and your family from diagnosis and throughout treatment.</td>
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### Medical social worker

A person trained to help you and your family with your social issues and practical needs. They can give counselling and emotional support. They can 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 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.

### Palliative care team

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

### Physiotherapist

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

### Dietitian

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

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

Surgery 30
Radioactive iodine therapy 35
Thyroid hormone therapy 41
Clinical trials 43
**Understanding cancer of the thyroid**

**Surgery**

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

**Total thyroidectomy:** A total thyroidectomy removes the entire thyroid gland or as much of it as possible. This reduces the chances of the cancer coming back. A small cut in the centre of your neck is usually made to get directly at your 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.

**New methods of thyroid surgery**

With advances in technology new methods of thyroid surgery are developing. It is possible to remove your thyroid using keyhole surgery, where a much smaller cut is made in your neck than in regular surgery. Special surgical instruments and a small video camera can be placed in the wound to guide your surgeon when removing the gland. This is called an endoscopic thyroidectomy.

The thyroid can also be removed using robotic surgery. In a robotic thyroidectomy a cut is made in your chest, armpit or high in your neck. This means you will not have a scar in the centre of your neck. These two new methods are available in specialist centres only and may not yet be available in Ireland.

**Before surgery**

**Discussions with your surgeon:** Your surgeon will explain what to expect after surgery and any scarring that will happen. If you are worried about scarring, do talk to your surgeon. Your scar is likely to be in the middle of your neck but will be neat and hardly noticeable. Do discuss your surgery fully with your surgical team. It can help to make a list of your questions before you go into hospital.

**Tests:** You will need extra tests to make sure you are strong enough for surgery. Thyroidectomy and lobectomy are operations that can last several hours and need long anaesthetics. The tests beforehand may include a chest X-ray, heart tracing (ECG) and blood tests. An anaesthetist will also examine you to make sure you are fit for surgery.

**Smoking:** It’s 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](http://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.

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.

After surgery

Drips and drains: You will have a drip for about a day or so to replace any lost fluids. Once you can eat and drink again, this will be removed. One or two tubes will drain fluid from your wound as well. These are usually removed after about 2 days. Sometimes clips or glue are used instead of stitches to close the wound. These will be removed before you go home.

Pain and discomfort: You will be given painkillers if you have any discomfort after your surgery. Let your nurse know if they are working well enough or not. They can be changed to something a little stronger if needed.

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. It is best to try a soft purée diet at this time. Your nurses or hospital dietitian will discuss this with you before you go home. Make sure you have a balanced diet. For more information and ideas about recipes, see the booklet *Diet and Cancer*. Call Cancer Nurseline on 1800 200 700 for a copy, visit a Daffodil Centre or download it from [www.cancer.ie](http://www.cancer.ie)

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What are the side-effects of surgery?

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

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

Hoarse voice: Your voice can sound hoarse and weak at first after the surgery. Sometimes there may be slight damage to the nerves to the voicebox (larynx). This can make your voice sound hoarse and weak. In most cases it is a temporary problem, but it can be permanent for a very small number of people.

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My voice took quite a long time to recover. I still can’t shout loud without it being sore.”
Radioactive iodine therapy
You might receive radioactive iodine therapy after your thyroid surgery. This is also known as radioiodine therapy or thyroid remnant ablation. Your doctor will let you know if you need it or not, based on international guidelines. It usually depends on the size of the cancer that was removed and the risk of it coming back.

This therapy can destroy tiny amounts of normal thyroid tissue or cancer cells, if any, left behind after surgery. It is used after surgery in some cases of papillary and follicular thyroid cancer. You may have to wait several weeks to recover after surgery. You will be referred to a specialist centre for this treatment. Remember not all patients need radioactive iodine therapy.

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 hormone activates thyroid cells and encourages them to absorb the radioactive iodine. There are two ways to do this, either by stopping your hormone therapy or by giving you injections of TSH before treatment.
**Understanding cancer of the thyroid**

**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, unless advised longer by your doctor. Do 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. This issue can be discussed 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 or be collected at a later date. 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. Usually there is a TV, radio, CD player, DVD player, and computer in the special room where you will be staying. Your nurse will 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 but it does not hurt. It is usually given as a small capsule to take with a glass of 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.

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- **Stopping hormone therapy:** Your doctor might ask you to stop taking your levothyroxine about 4–6 weeks before the therapy. This is because these hormones stop TSH from being made. Stopping the hormone therapy can make you feel more tired, but this will ease once the medication is resumed. Usually only a small number of patients are asked to stop taking their hormone therapy.

- **Taking recombinant TSH:** More than likely 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 of 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. Do not stop eating these foods but reduce them instead. Your nurse can give you more advice.

“In preparation for my treatment I went on a low-iodine diet. I focused on this and it helped me to remain “in control” and to feel I was doing something to help.”

**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.
Feeling isolated: It is natural to feel isolated, afraid or depressed at this time, especially when you want people around you. Do let your nurses know if you are feeling this way. By voicing your worries, it can help a great deal. Do ask questions 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.

Are there any side-effects?
As mentioned above, you will be radioactive but only for a few days.

Tiredness: You might also feel tired, especially if your thyroid hormone therapy has been stopped. See page 46 for more about coping with fatigue.

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. Do ask your doctor or nurse for more advice.

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.

- Protective screens may be placed on either side of your bed to block radiation.
- 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. Your own hospital might have other precautions not listed here. These will be explained to you in more detail before your treatment.

Cancer Nurseline Freephone 1800 200 700
Understanding cancer of the thyroid

Thyroid hormone therapy

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.

To sum up

- The thyroid cancer cells pick up the radioactive iodine in your bloodstream to make sure there are no thyroid cells remaining after surgery.
- The treatment uses a radioactive form of iodine called iodine-131.
- It is given as an inpatient.
- There are some safety precautions to be followed with this treatment after you go home.
- You will only be radioactive for a period of time.

Thyroid hormone replacement

The usual thyroid hormone replacement is thyroxine, which is also called T4. It is often started after surgery or radioiodine therapy. You will be given this replacement drug for life. Without these hormones you would develop signs and symptoms of an underactive thyroid. This is called hypothyroidism. Signs of it 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.

Tips & Hints – 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 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 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

Do 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 the Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre.
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. In that way, 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 52.

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. If you have any side-effects, do tell your doctor or nurse. Your doctor can do a blood test to make sure you are getting the right dose of thyroid hormone.

To sum up

- Thyroid hormone therapy is usually given for two reasons.
- It replaces the natural thyroid hormones that can no longer be made after surgery to remove your thyroid gland.
- It slows down the growth or recurrence of thyroid cancer.
- Without thyroid hormones, you would develop signs and symptoms of an underactive thyroid.
- Signs of an underactive thyroid are weight gain, tiredness, dry skin and hair, and physical and mental slowness.
- More than likely you will need to take hormone therapy for life.

Clinical trials

Clinical trials are research studies that try to find new or better ways of treating or diagnosing cancer.

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

Drugs that are used in a clinical trial have been carefully tested to make sure they are safe to use in a clinical trial.

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.

More information

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

Email: cancernurseline@irishcancer.ie
It’s available to read or download on our website, [www.cancer.ie](http://www.cancer.ie). You can also get a free copy by calling our Cancer Nurseline on 1800 200 700 or by dropping into a Daffodil Centre.

You can see a list of current cancer trials at [www.cancertrials.ie](http://www.cancertrials.ie).

It's best to talk to your doctor if you're interested in taking part in a clinical trial. 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 thyroid cancer. Your doctor can advise you about this.

Managing side-effects and symptoms

How can I cope with fatigue? 46

Will treatment affect my sex life? 47

Will treatment affect my fertility? 48

Cancer and complementary therapies 49
Understand cancer of the thyroid

Will treatment affect my sex life?

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

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

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

Once you return to your usual routine your interest in sex should return too. You can also enjoy other forms of closeness, such as touching, caressing and holding each other.

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

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 advised longer by your doctor.

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

Ask your doctor’s advice about contraception or if you 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 taking about these matters, so there’s no need to feel embarrassed. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with a cancer nurse in confidence. Or email the nurses at cancernurseline@irishcancer.ie

Will treatment affect my fertility?
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.

Chemotherapy can affect fertility, but this treatment is rarely used for thyroid cancer. It may be possible to freeze your eggs or sperm before treatment begins. For more information, talk to your doctor and nurse.

You can also contact our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

Cancer and complementary therapies
Some people with cancer find it helpful to try complementary therapies as well as their standard treatment.

Complementary therapies: Complementary therapies are treatments that can be given in addition to standard medical treatment. Examples of complementary therapies are yoga, meditation, acupuncture, aromatherapy and massage.

Standard treatment: Standard or conventional cancer treatments include chemotherapy, radiotherapy and surgery. The effects and the side-effects of standard treatments have been scientifically tested.

Alternative therapies: Alternative therapies are generally treatments that are used instead of standard treatments. For example, diet therapy, megavitamin therapy and herbalism. Alternative therapies have not been scientifically proven. Some alternative therapies may even harm your health.

If you decide to have complementary or alternative treatments...
Before you decide to change your treatment or add any methods of your own, talk to your doctor or nurse. Some methods can be safely used along with standard medical treatment. But others can interfere with standard treatment or cause serious side-effects.

More information
To find out more about the different complementary and alternative therapies, read our booklet Understanding Cancer and Complementary Therapies: A Guide for Cancer Patients. To get a copy call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also read or download the booklet on our website www.cancer.ie
After treatment

What follow-up do I need? 52
Leading a healthy lifestyle 54
Life after cancer 54
What follow-up do I need?

After treatment, you will need to come back for 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. But if the thyroid cancer comes back, it can be treated successfully again. Your doctor will always be checking the risk of recurrence in your case, as the months and years go by. Any changes in your health can be noted at these check-ups and treated if needed.

How often? 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 after 6 weeks and then every 3 months. You may need yearly check-ups if the risk of cancer coming back is low, and 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 what you wanted to say.

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. Giving a replacement hormone (rhTSH) encourages your thyroid cells to make thyroglobulin. So this test can measure if you are reaching the target levels of TSH. Thyroglobulin only becomes accurate 3 months after surgery or treatment and can be measured then.

If the cancer comes back, the thyroglobulin becomes positive long before the cancer causes symptoms. Before a thyroglobulin test or whole body scan, you might need a dose of TSH or need to stop taking your thyroid hormones for about 6 weeks. Your doctor and nurse will give you more information and advice. About 1 in 5 patients will have thyroid antibodies in their bloodstream which makes the test less reliable as a result. Even so, your doctor will use other ways to manage your condition.

Once the tests are over, an appointment will be made for your next visit to your doctor.

Problems or concerns: By having regular follow-up, your doctor can check for any signs of recurrence. If you are between check-ups and have a symptom that is worrying you, tell your doctor or nurse. Make an appointment to see them as soon as possible.

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.
Leading a healthy lifestyle

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

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

- Heal and recover faster
- Cope better with the side-effects of treatment
- Keep up your energy and strength
- Feel better

A healthy lifestyle includes:

- Exercising
- Eating healthy foods
- Staying at a healthy weight
- Not smoking
- Protecting yourself from the sun

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

Life after cancer

Being told your treatment has been successful is wonderful news. But it can take some time to adjust to life after cancer treatment. It isn’t unusual to feel quite low and lost after your treatment has ended, especially during the first few months.

Feelings you may have include:

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

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

You can also call our Cancer Nurseline or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 59 for other ways to get support.
Coping and emotions

How can I cope with my feelings? 58
Ways to get emotional support 59
How can I help myself? 60
You and your family 62
How can I cope with my feelings?

Being told you have thyroid cancer can naturally come as a shock. But remember it has a very high cure rate. Often the biggest challenge is living without your thyroid gland. Even so, it is natural to worry if the cancer will return.

There are many reactions when you hear you have cancer. Reactions differ from person to person. There is no right or wrong way to feel and there is no set time to have one particular emotion or not.

**Common reactions include:**

- Shock and disbelief
- Sorrow and sadness
- Fear and uncertainty
- Denial
- Loss of control
- Anger
- Resentment
- Blame and guilt
- Withdrawal and isolation

**Anxiety and depression**

Sometimes a cancer diagnosis can cause anxiety and depression. If you feel that your low moods are getting the better of you or you are finding it hard to cope, it’s important to get help. It’s not a sign of failure to ask for help or to feel unable to cope on your own. Try to talk with someone you know who is a good listener or tell your GP. Medical social workers can also offer support to you and your family.

If you are finding it difficult to get over a period of depression, your doctor may suggest a treatment. Often a short course of antidepressants can work well. Professional counselling can also be very helpful.

**Counselling**

Sometimes it can be hard to talk to the people closest to you if you are feeling very distressed or finding it hard to cope. You may worry about upsetting or worrying your friends or family. 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 make decisions and learn ways to cope better.
Learning to cope

Everyone experiences cancer in a different way. And how each person copes with cancer varies too. There is no right or wrong way to cope with cancer, only your way.

It can take some time to come to terms with your emotions after a cancer diagnosis. Coping with the physical effects of treatment can also add to the burden of dealing with cancer.

While it’s true that some treatments can have some unpleasant side-effects, most people are able to adjust to life during treatment.

How can I help myself?

Here is a list of things to help make you feel more involved and more in control of your illness. They can help to boost your self-esteem and well-being, making it easier to deal with cancer.

Use your support network: Doing things for yourself can help to make you feel more in control, but be realistic about what you can manage by yourself. Don’t be afraid to ask for help from those who want to support you or to use the support services available. Telling people what you need and how they can help means you will get the right amount of support to suit you.

Involving your family and close friends: Don’t keep your worries or any physical problems secret from the people closest to you. Ask someone close to you to come with you when you are visiting the doctor and when treatments will be discussed. If you’re feeling alone, you can also talk in confidence to one of our cancer nurses by calling our Cancer Nurseline or visiting a Daffodil Centre.

Gather information about your cancer and treatment: Understanding cancer and its treatment and knowing what to expect can help to relieve anxiety and stress for some people.

Eat well: Try to eat as well as you can. Have lots of different types of foods with plenty of fresh fruit and vegetables.

Get some exercise: Exercising is a great way to boost your mood and sense of well-being. Exercise can also improve your energy levels if you are feeling very tired. Talk to your doctor or nurse about which activity will suit you best.

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.

Try complementary therapies: Complementary therapies are treatments like acupuncture, yoga and aromatherapy that are given in addition to your standard treatment. They may help to relieve the side-effects of cancer and its treatment. They can also help you to feel better emotionally. See page 49 for more information on complementary therapies.

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.

Keep busy: Try to keep busy and make plans for the things you would like to do. This can mean taking trips, visiting loved ones or doing certain activities.

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.

Express yourself: Keep a diary or journal if you need to express yourself without holding back. It can help you to make sense of what you are going through. Other forms of creative expression, such as music and art, may help too.

Practical planning: It’s very understandable that you might feel anxious or reluctant to talk to your family or friends about how you might like to be looked after if your cancer progresses, for fear of upsetting yourself or them. However, it can give you the chance to plan and deal with any practical concerns or worries you may have in your personal life. If your cancer is advanced, you can look at our advanced cancer web pages on our website www.cancer.ie for more help with planning ahead. You can also call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for advice, information and support.
You and your family

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

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

Talking to children and teenagers

Every family deals with cancer in its own way. You may feel that you don’t want your illness to upset family life, or feel guilty that you can’t do activities with your children, or that you’re letting them down. You may also worry about the emotional impact your illness will have on your children, especially older children, who may already be struggling with the difficult changes that adolescence can bring. These are all natural feelings to have at this time.

Saying nothing

You may feel it’s best not to tell your children anything. You may be worried about what to say or how they will react. But children and teenagers can often sense that there is a problem. If no one explains to them why things have changed, they may imagine something worse or blame themselves. By talking openly you can answer their questions and help them to cope with their emotions.

How to tell your children

It’s best that you or your partner tell your children about your cancer diagnosis. How you discuss your cancer and treatment with them will depend on their age and character. A useful booklet called *Talking to Children about Cancer. A Guide for Parents* gives practical advice for talking to children about cancer, with specific advice for different age groups. It also has information on supporting children and teenagers and helping them to deal with their emotions.

The booklet is available free of charge from Daffodil Centres or by calling the Cancer Nurseline. It’s also available on our website [www.cancer.ie](http://www.cancer.ie).

Further information and support

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

How can my family and friends help?

Your family and friends can support you in different ways. Some family members and friends can offer a listening ear and give you advice if needed. Some may gather up-to-date information on cancer to know what you can expect and what you are going through. Others may prefer to help you in a practical way with travelling to and from the hospital, with childcare, cooking, shopping or housework. It may take time to know which way suits you and your family or friend best.

**Positive emotions**

A cancer experience can also bring positive emotions. However, it may be some time before you are ready to accept these emotions as positive. You may experience great love, affection and closeness by those around you, not only family and friends but also neighbours and even the healthcare team. With that can come a sense of gratitude too. The experience of cancer can also bring personal growth and knowledge – it can make you realise where your strength lies and what’s important in life for you. You may also get the chance to do and enjoy different things that you would never have done otherwise.
Advice for carers

Caring for someone with cancer  66
Looking after yourself  67
Caring for someone with cancer

Caring for someone who has had treatment for thyroid cancer can be difficult at times. Some patients manage well and need little practical support from family and friends. Others may need more support and care.

Coping with both the practical and emotional issues of treatment can be hard. Here are some things that can help to make life a little easier.

Learn about cancer: Learn more about thyroid cancer, any possible side-effects and the emotional effects it can cause. This will help you to understand how you can support your partner, relative or friend. Visit our website www.cancer.ie or call our Cancer Nurseline for a free copy of our publications.

Plan as much as you can ahead of the discharge date: Ask to speak to a medical social worker about the community services that are available. Tell your GP and local public health nurse that your loved one will be coming home. If dressings or other medical supplies are needed, make sure you have some at home before the discharge date. Ask for a contact name and telephone number at the hospital so that you can talk to somebody if you have a problem.

Talk to the dietitian: If your relative or friend has had major surgery, talk to the diettitian before the discharge date. He or she will give you useful advice on the best foods and how to prepare them so that they can be easily swallowed.

Encourage your relative or friend: At first your relative or friend may feel very tired after treatment. As soon as they are feeling stronger, encourage them to do things for themselves. The more involved they are in their own care, the quicker they will adapt to a new way of life.

Looking after yourself

Share worries: You may feel tired with all the worry and extra work. It can also be very difficult as you try to adapt to a new way of life. Make sure you share your worries with someone else. Call our Cancer Nurseline on 1800 200 700 or drop into a Daffodil Centre if you want to chat to a cancer nurse in confidence. Stay in touch with your own friends and get out when you can, even if you don’t always feel like it.

Take regular breaks: If your partner or friend is anxious or depressed, try to take a break each day, even if it’s just a walk to the shops. Ideally, try to organise a longer break as well, such as an evening out with friends or a trip to the cinema each week. If you have young children, organise for your family or a babysitter to mind them for an hour or two, if possible.

Have little treats: If you don’t want to take a break, then at least give yourself little treats to keep yourself going. Order your favourite magazine each week and give yourself an hour to sit down with a cup of tea or coffee to read it. Or make sure that you can watch your favourite TV programme, have a long soak in the bath after a difficult day, or an early night with a good book.

If you find it difficult to cope, get help: Talk through your feelings and frustrations with a friend or your GP. Your GP can suggest other services and sources of help.

Look after your own health: See your GP sooner rather than later if you have any health concerns of your own.

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

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

Support resources

Coping with the financial impact of cancer 70
Irish Cancer Society services 72
Local cancer support services 74
Helpful books 75
What does that word mean? 76
Questions to ask your doctor 78
Coping with the financial impact of cancer

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

Medical expenses
Medical expenses that you might have to pay include:
- Visits to your family doctor (GP)
- Visits to hospital
- Overnight stays in hospital
- Medicines
- Appliances, like wigs

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

If you have a medical card, you will probably have very little to pay for hospital and GP (family doctor) care or your medication. If you are over 70 years old, 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 do not 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.

Benefits and allowances
There are benefits available from the Department of Social Protection that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer’s Allowance, Carer’s Benefit, Carer’s Leave.

If you want more information on benefits and allowances, contact:
- The medical social worker in the hospital you are attending
- Citizens Information – Tel: 0761 074 000
- Department of Social Protection (DSP) – Tel: 1890 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

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

If you have financial difficulties
If you are getting into debt or you are in debt, the Money Advice and Budgeting Service (MABS) can help you. MABS can look at your situation, work out your budget, help you to deal with your debts and manage your payments. The service is free and confidential. Call the MABS Helpline 0761 07 2000 for information.

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 73 for more details of our Volunteer Driver Service and the Travel2Care fund.

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

More information
For more information go to www.cancer.ie/publications and check out our booklet, Managing the Financial Impact of Cancer – A Guide for Patients and their Families. This explains:
- Medical costs and help available
- Benefits and allowances that you or your family may qualify for
- Travel services
- Ways to cope with the cost of cancer
Patient travel and financial support services. We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:

- **Travel2Care** is a limited fund, made available by the National Cancer Control Programme, for patients who are having difficulty getting to and from their treatments while attending one of the national centres of excellence or their approved satellite centres.

- **Irish Cancer Society Volunteer Driver Service** is for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments in our partner hospitals.

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

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

Our 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](http://www.cancer.ie) or call our Cancer Nurseline for a free copy of our publications.

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

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

- **Professional counselling** the Irish Cancer Society funds up to 8 sessions of free counselling in many affiliated support services
- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- **Special exercise programmes**, like the Irish Cancer Society’s *Strides for Life* walking group programme
- **Stress management and relaxation techniques**, such as mindfulness and meditation
- **Complementary therapies** like massage, reflexology and acupuncture
- **Specialist services** such as prosthesis- or wig-fitting and manual lymph drainage
- **Mind and body sessions**, for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics

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

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

Helpful books

The Irish Cancer Society has a wide range of information on reducing your risk of cancer, different types of cancer, treatments, and coping. For free copies call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download or order the booklets on our website: [www.cancer.ie](http://www.cancer.ie).

You may find the following helpful:

**Treatment and side-effects**

- *Understanding Chemotherapy*
- *Understanding Radiotherapy*
- *Understanding Cancer and Complementary Therapies*
- *Diet and Cancer*
- *Coping with Fatigue*

**Coping and emotions**

- *Understanding the Emotional Effects of Cancer*
- *Lost for Words: How to Talk to Someone with Cancer*
- *Who Can Ever Understand? Taking About Your Cancer*
- *Talking to Children about Cancer: A Guide for Parents*
- *Caring for someone with cancer*
- *A Time to Care: Caring for Someone Seriously Ill at Home*
# Understanding cancer of the thyroid

## What does that word mean?

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td><strong>Anaplastic</strong></td>
<td>A very rare form of thyroid cancer. It grows quickly and can be hard to treat.</td>
</tr>
<tr>
<td><strong>Benign</strong></td>
<td>Not cancer. A tumour that does not spread.</td>
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<tr>
<td><strong>Targeted therapies</strong></td>
<td>Drugs that use your body's immune system to fight cancer. Also called targeted therapies.</td>
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<tr>
<td><strong>Biopsy</strong></td>
<td>Removing a small amount of cells or tissue from your body to examine under a microscope. <strong>It can tell if cancer cells are present or not.</strong></td>
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<tr>
<td><strong>Calcitonin</strong></td>
<td>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.</td>
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<tr>
<td><strong>Cells</strong></td>
<td>The building blocks that make up your body. They are tiny and can only be seen under a microscope.</td>
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<tr>
<td><strong>Chemotherapy</strong></td>
<td>The use of drugs to cure or control cancer.</td>
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<tr>
<td><strong>Differentiated</strong></td>
<td>Cancer cells that have some features of normal thyroid cells. It refers to papillary and follicular thyroid cancers. These are the most common types of thyroid cancer.</td>
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<tr>
<td><strong>Endocrinologist</strong></td>
<td>A doctor who specialises in treating diseases of the thyroid and other glands in your body.</td>
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<tr>
<td><strong>Fatigue</strong></td>
<td>Ongoing tiredness often not eased by rest.</td>
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<tr>
<td><strong>Follicular</strong></td>
<td>The second most common type of thyroid cancer. It grows slowly and is usually found in slightly older people.</td>
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<tr>
<td><strong>Lobectomy</strong></td>
<td>Surgery to remove one lobe of your thyroid gland.</td>
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<tr>
<td><strong>Malignant</strong></td>
<td>Cancer. A tumour that spreads.</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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</thead>
<tbody>
<tr>
<td><strong>Medullary</strong></td>
<td>A rare type of thyroid cancer.</td>
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<tr>
<td><strong>Radioactive iodine</strong></td>
<td>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.</td>
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<tr>
<td><strong>Radiotherapy</strong></td>
<td>The treatment of cancer using high-energy X-rays.</td>
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<tr>
<td><strong>Papillary</strong></td>
<td>The most common type of thyroid cancer. It often affects women more than men.</td>
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<tr>
<td><strong>Parathyroid</strong></td>
<td>A gland behind your thyroid gland. It makes a hormone called the parathyroid hormone that stores and controls calcium in your body.</td>
</tr>
<tr>
<td><strong>Thyroglobulin</strong></td>
<td>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.</td>
</tr>
<tr>
<td><strong>Thyroid</strong></td>
<td>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.</td>
</tr>
<tr>
<td><strong>Thyroidectomy</strong></td>
<td>Surgery to remove all or part of your thyroid gland.</td>
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<tr>
<td><strong>Thyroid-stimulating hormone (TSH)</strong></td>
<td>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.</td>
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<tr>
<td><strong>Thyroxine</strong></td>
<td>A hormone made by the thyroid gland.</td>
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<tr>
<td><strong>Staging</strong></td>
<td>Tests that measure the size and extent of cancer.</td>
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</table>
Questions to ask your doctor

Here is a list of questions that you might like to ask your doctor. There is also some space for you to write down your own questions if you wish. Never be shy about asking questions. It is always better to ask than to worry.

- How long will it take to get the test results?
- What type of thyroid cancer do I have?
- What stage is my cancer at?
- Will surgery cure the cancer?
- Do I need any lymph nodes removed?
- Will the parathyroid glands or other tissues be removed?
- 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?
- What will my scar look like?
- Will I need to take hormone tablets for the rest of my life?
- Is there anything I can do to help myself during treatment?
- How often will I need check-ups?
- When can I get back to my normal activities?
- What if the cancer comes back?

Your own questions

1

Answer

2

Answer

3

Answer

4

Answer

5

Answer
Join the Irish Cancer Society team

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

Support people affected by cancer
Reaching out directly to people with cancer is one of the most rewarding ways to help:
- Help people needing lifts to hospital by becoming a volunteer driver
- Give one-on-one support to someone newly diagnosed with cancer as part of our Survivor Support programme
- Give information and support to people concerned about or affected by cancer at one of our hospital-based Daffodil Centres

Share your experiences
Use your voice to bring reassurance to cancer patients and their families, help people to connect with our services or inspire them to get involved as a volunteer:
- Share your cancer story
- Tell people about our services
- Describe what it's like to organise or take part in a fundraising event

Raise money
All our services are funded by the public’s generosity:
- Donate direct
- Take part in one of our fundraising events or challenges
- Organise your own event

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

Did you like this booklet?
We would love to hear your comments or suggestions.
Please email reviewers@irishcancer.ie

More information and support
If you would like more information or someone to talk to, now or at any time in the future, please call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.