



Understanding Thyroid Cancer

A guide for people with cancer,
their families and friends

Cancer
information

Cancer Council Helpline

13 11 20

www.cancercouncil.com.au

Understanding Thyroid Cancer

A guide for people with cancer, their families and friends

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Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain appropriate independent professional advice relevant to your specific situation and you may wish to discuss issues raised in this book with them.

All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

Cancer Council NSW

Cancer Council is the leading cancer charity in NSW. It plays a unique and important role in the fight against cancer through undertaking high-quality research, advocating on cancer issues, providing information and services to the public and people with cancer, and raising funds for cancer programs. This booklet is funded through the generosity of the people of NSW. To make a donation to help defeat cancer, visit Cancer Council's website at www.cancerCouncil.com.au or call 1300 780 113.



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Introduction

This booklet has been prepared to help you understand more about thyroid cancer.

Many people feel understandably shocked and upset when told they have thyroid cancer. We hope this booklet will help you understand how thyroid cancer is diagnosed and treated. We also include information about support services.

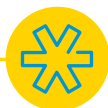
We cannot advise you about the best treatment for you. You need to discuss this with your doctors. However, we hope this information will answer some of your questions and help you think about questions you want to ask your doctors or other health carers.

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary. You may also like to pass this booklet on to your family and friends.

How this booklet was developed

This booklet was developed with help from health professionals and people who have been diagnosed with thyroid cancer. It is based on clinical practice guidelines.

Cancer Council Helpline **13 11 20** can arrange telephone support in different languages for non-English speakers. You can also call the Translating and Interpreting Service (TIS) direct on **13 14 50**.



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What is cancer?

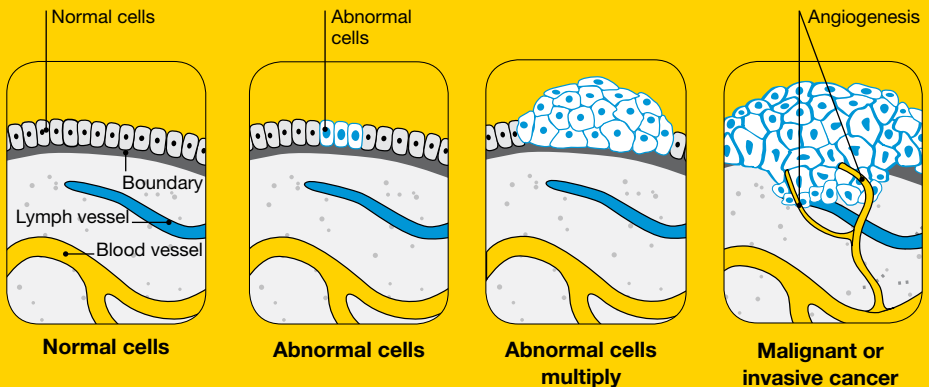
Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

Sometimes cells don't grow, divide and die in the usual way. This may cause blood or lymph fluid in the body to become abnormal, or form a lump called a tumour. A tumour can be benign or malignant.

Benign tumour – Cells are confined to one area and are not able to spread to other parts of the body. This is not cancer.

Malignant tumour – This is made up of cancerous cells, which have the ability to spread by travelling through the bloodstream or lymphatic system (lymph fluid).

How cancer starts



The cancer that first develops in a tissue or organ is called the primary cancer. A malignant tumour is usually named after the organ or type of cell affected.

A malignant tumour that has not spread to other parts of the body is called localised cancer. A tumour may invade deeper into surrounding tissue and can grow its own blood vessels (angiogenesis).

If cancerous cells grow and form another tumour at a new site, it is called a secondary cancer or metastasis. A metastasis keeps the name of the original cancer. For example, thyroid cancer that has spread to the lungs is called metastatic thyroid cancer, even though the person may be experiencing symptoms caused by problems in the lungs.

How cancer spreads

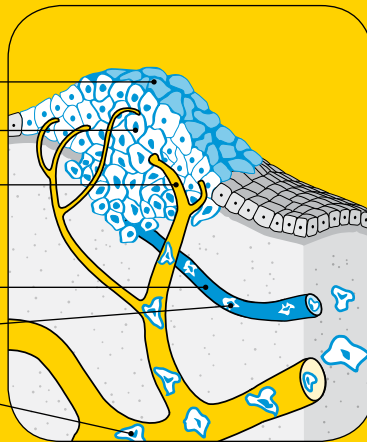
Primary cancer

Local invasion

Angiogenesis –
tumours grow their
own blood vessels

Lymph vessel

Metastasis –
cells invade other
parts of the body via
blood vessels and
lymph vessels





The thyroid gland

The thyroid is a butterfly-shaped gland in the front of the neck. It is found below the voice box (larynx or Adam's apple) and is made up of two halves, called lobes, which lie on either side of the windpipe (trachea). The lobes are connected in the middle by a small band of thyroid tissue known as the isthmus.

The thyroid gland is part of the endocrine system, which consists of a collection of glands responsible for producing the body's hormones. Hormones are the chemical messengers that communicate with the body and bring about changes. The thyroid gland makes hormones that help control the speed of the body's processes, such as heart rate, blood pressure, body temperature and weight – this is known as your metabolic rate.

What the thyroid gland does

The thyroid produces three hormones that are released into the bloodstream:

Thyroxine (T4) – This controls the body's metabolism. T4 is converted into another hormone, called T3.

Tri-iodothyronine (T3) – Also helps control metabolism. The thyroid produces only small amounts of T3. The majority of this hormone is created when

the liver and kidney convert T4 into T3. The active form of the thyroid hormone is T3.

Calcitonin – A hormone involved in controlling calcium levels in the body.

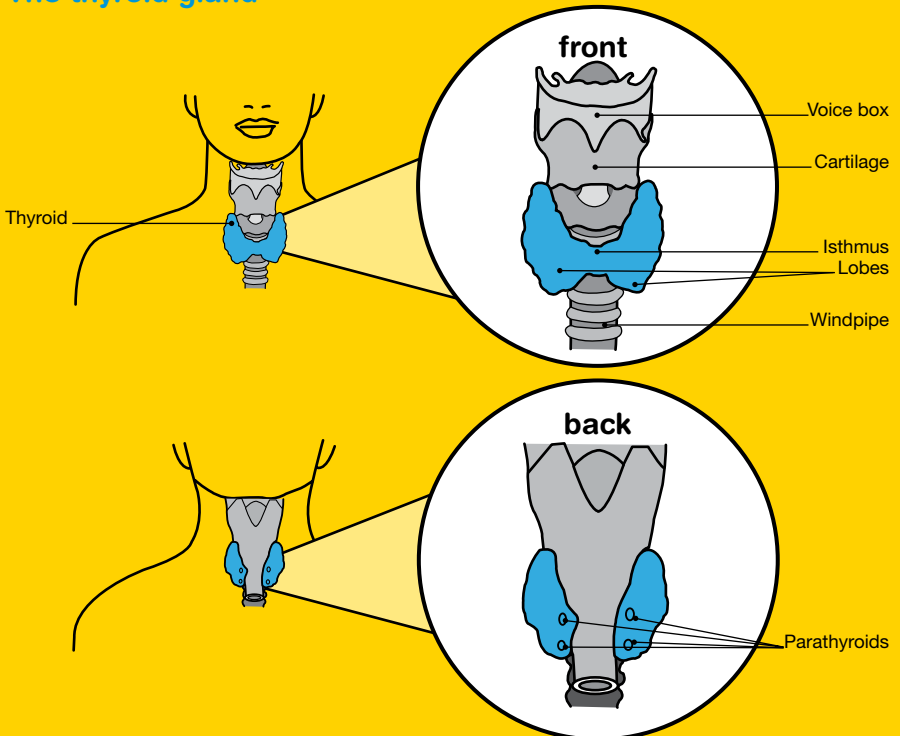
The thyroid gland needs iodine – found in foods such as seafood, iodised table salt, some mineral supplements and dairy products – to make T4 and T3.

The thyroid gland is made up of two main types of cells:

- **follicular cells** – make a protein called thyroglobulin (Tg) and produce and store T4 and T3
- **parafollicular cells (C-cells)** – produce calcitonin.

Behind the thyroid glands are the parathyroid glands. These four glands produce hormones that control the amount of calcium and phosphorus in the blood.

The thyroid gland



Thyroid hormones

The thyroid gland is controlled by the pituitary gland, which is found in the brain. The pituitary gland is regulated by another gland found in the brain called the hypothalamus.

When your body needs more hormones (T4 and T3), the pituitary gland produces thyroid-stimulating hormone (TSH), which prompts the thyroid gland to produce and release more T4 and T3.

The change in thyroid hormone levels can cause changes to how your cells respond (metabolism):

- **Underactive thyroid (hypothyroidism)** – The thyroid gland produces too few hormones causing the metabolism to slow down. You may feel tired and lethargic and gain weight easily.
- **Overactive thyroid (hyperthyroidism)** – The thyroid gland produces too many hormones causing the metabolism to speed up. You may lose weight, have an increased appetite, feel shaky and anxious, or have rapid, strong heartbeats (palpitations).



Key questions

Q: What is thyroid cancer?

A: Thyroid cancer develops when the cells of the thyroid gland grow and divide in a disorderly (abnormal) way.

Q: What types are there?

A: There are several types of thyroid cancer.

Types of thyroid cancer

| | |
|------------------------------------|--|
| papillary thyroid cancer | <ul style="list-style-type: none">• most common type (about 70–80% of all cases)• develops from the follicular cells• tends to grow slowly |
| follicular thyroid cancer | <ul style="list-style-type: none">• about 25% of thyroid cancer cases• develops from the follicular cells• includes Hürthle cell carcinoma, a rare subtype |
| medullary thyroid cancer | <ul style="list-style-type: none">• about 4% of all thyroid cancers• develops from the parafollicular cells (C-cells)• can run in families |
| anaplastic thyroid cancer | <ul style="list-style-type: none">• a rare thyroid cancer (1% of cases)• may develop from undiagnosed papillary or follicular thyroid cancer• usually grows quickly and affects elderly people |
| thyroid sarcoma or lymphoma | <ul style="list-style-type: none">• these rare types of cancer are not covered in this booklet – talk to your medical team or call Cancer Council Helpline 13 11 20 for information |

Q: What are the signs and symptoms?

- A:** Thyroid cancer usually develops slowly, without many obvious signs or symptoms. However, some people experience one or more of the following:
- a painless lump in the neck or throat, which may gradually get bigger
 - difficulty swallowing or breathing
 - a hoarse voice
 - swollen lymph glands in the neck, which may slowly grow in size over months or years
 - gastrointestinal changes, such as diarrhoea and constipation.

Having a painless lump in the neck is the most common sign. However, thyroid lumps, known as nodules, are relatively common and most are benign. In about 90% of cases, a thyroid nodule is a symptom of a goitre (a benign enlarged thyroid gland) or another condition affecting the head or neck.

If you notice any of these symptoms, you should see your general practitioner (GP) as soon as possible.



A cancerous thyroid usually continues to produce hormones. However, an underactive or overactive thyroid (hypothyroidism or hyperthyroidism) is not typically a symptom of cancer.

Q: What are the risk factors?

A: The exact cause of thyroid cancer is unknown, but several factors are known to increase the risk of developing it.

Exposure to radiation

A small number of thyroid cancer cases are due to having radiotherapy treatment as a child, or living in an area with high levels of radiation in the environment, such as a nuclear accident site. Thyroid cancer usually takes 10–20 years to develop after radiation exposure.

The most common source of radiation for the average person is an x-ray scan, however the risk of developing thyroid cancer after an x-ray is minimal.

Family history

Some people inherit a faulty gene called the RET gene, which increases their risk of developing thyroid cancer. This may occur in familial medullary thyroid cancer (FMTC) or multiple endocrine neoplasia (MEN).

If you have a family history of thyroid cancer, talk to your doctor who may refer you to a genetic counsellor or a family cancer clinic.

Benign thyroid diseases

Having a thyroid condition, such as thyroid nodules, an enlarged thyroid (goitre) or inflammation of the thyroid, may increase your chance of developing thyroid cancer.



The thyroid needs iodine to make hormones. Iodine is found in iodised salt, dairy products, seafood and eggs. Since 2009, iodine has been added to bread in Australia to help reduce the rate of iodine deficiency.

Q: How common is it?

A: About 2400 people are diagnosed with thyroid cancer each year in Australia. Thyroid cancer is much more common in females – it is the seventh most common cancer affecting Australian women.

The average age of a woman diagnosed with thyroid cancer is 49; the average age of a man diagnosed with thyroid cancer is 54.

Thyroid cancer cases have increased over the years. Between 1991 and 2009, cases of thyroid cancer increased by 250%[†] (see inside front cover for reference). Research is being done to determine the cause of this increase. The number may have increased because there are better ways to earlier detect small cancers that previously went undiagnosed.



Key points

- Thyroid cancer develops when the cells of the thyroid gland grow and divide in an abnormal way.
- There are four main types of thyroid cancer. The most common type is papillary thyroid cancer – it affects 70–80% of patients with thyroid cancer.
- Thyroid cancer often develops slowly, without obvious signs or symptoms. However, the most common sign is a painless lump in the neck. This is also called a nodule.
- In many cases, thyroid nodules are a symptom of a goitre. This is when the thyroid becomes enlarged, and it is a benign condition (not cancer).
- An underactive or overactive thyroid (hypothyroidism or hyperthyroidism) isn't usually a sign that you have thyroid cancer.
- The cause of thyroid cancer is usually unknown, but it may be caused by exposure to radiation, family history or a benign thyroid disease.
- About 2400 people are diagnosed with thyroid cancer each year. It's more common in women.



Diagnosis

If your doctor suspects you have thyroid cancer, you will have one or more of the following tests. It's unlikely you will have all of the tests listed in this chapter. Some of these tests can also show if the cancer has spread to other parts of your body.

Blood test

Your doctor may do a blood test to check the levels of hormones (such as T3 and T4) and thyroid-stimulating hormone (TSH). A cancerous thyroid can continue to function normally so a blood test may help rule out benign thyroid conditions, such as hypothyroidism or hyperthyroidism. If the blood test results show evidence of hyperthyroidism, you may have a radioisotope scan (see page 16).

The levels of calcitonin and a protein called thyroglobulin (Tg) may also be checked. High calcitonin levels in the blood can indicate medullary thyroid cancer.

Ultrasound

An ultrasound is a type of scan that uses soundwaves to produce a picture of internal organs. If you have a lump in your thyroid, the ultrasound can help the doctor determine if it is solid or fluid-filled.

The doctor will also check if the lump is the size and shape of a typical cancer. The scan can also show if the lymph nodes (small, bean-shaped structures) in your neck are affected.

The ultrasound scan is painless and takes about 15–20 minutes. A gel is spread over your neck, then a handheld device called a transducer is moved over the area. The device sends out soundwaves that echo when they meet something dense, like an organ or tumour. A computer changes these echoes into a picture.

Biopsy

If the doctor feels a nodule or sees it during an ultrasound, you may have a biopsy. This is when some thyroid tissue is removed and sent for examination under a microscope.

A fine needle aspiration is the most common type of biopsy. This is when a thin needle is inserted into your neck and a very small tissue sample is removed from the thyroid. You may be given local anaesthesia (pain relief) and an ultrasound may be used to guide the needle. The doctor usually has to do a few passes with the needle to get an adequate tissue sample.

It's not always possible to determine the type of nodule with a fine needle aspiration. If the results aren't clear, the doctor may do a biopsy during a hemi-thyroidectomy procedure (see page 24).

If thyroid cancer is found, you may need further surgery to remove the rest of your thyroid and possibly some lymph nodes in the neck.

“ My initial fine needle biopsy results were inconclusive so I had half of my thyroid removed. ” Jenny

Radioisotope scan

If the blood test shows evidence of an overactive thyroid (hyperthyroidism), you may have a radioisotope scan.

In this test, a small amount of radioactive liquid (such as iodine or technetium) is injected into a vein in your arm. After about 20 minutes, you will be asked to lie under a machine called a gamma camera. The camera measures the amount of radioactive liquid taken up by the thyroid gland.

Normal thyroid cells absorb iodine more quickly than cancer cells. Cells that take up more or a lot of the fluid may be called hyperfunctioning or 'hot' nodules and are usually benign. Cells that don't take up much radioactive fluid are called 'cold' nodules – these also usually indicate a benign thyroid condition, but a small number may be cancerous.



A radioisotope scan may be used to detect papillary or follicular thyroid cancer. It isn't used to find medullary thyroid cancer, as C-cells do not absorb iodine.

A radioisotope scan is painless and causes few side effects. After a diagnostic scan you will not be radioactive and it is safe for you to be with others. If you have the scan after radioactive iodine treatment, you will be slightly radioactive, and you will need to take some precautions to minimise the risk of exposing other people to radiation. Your medical team will talk to you about this.



The radioisotope scan may also be used as a follow-up test to check if there are any cancer cells remaining in your body after surgery or radioactive iodine treatment (see pages 30–32), or to see if the cancer has come back.

Further scans

The following scans are used to see if the cancer has spread to other parts of your body. These scans may also be used after a surgical procedure, such as a thyroidectomy (see page 24).

The scans are painless and are done as a day procedure. Most people are able to go home as soon as the procedure is over.

CT scan

A CT (computerised tomography) scan uses x-ray beams to form a more detailed picture of the inside of the body. You may have a CT scan if your thyroid is enlarged, so your doctor can make sure your windpipe (trachea) is not compressed.

Before the scan, dye may be injected into one of your veins to help create clearer pictures. This may make you feel flushed or hot for a few minutes and may also leave a strange taste in your mouth.

The CT scanner is large and round like a doughnut. You will lie on a table that moves in and out of the scanner. Some people feel afraid of confined spaces (claustrophobic), but the scan usually only takes a few minutes. See page 18 for some ways to cope with this.



The dye used for a CT or MRI scan is called a contrast solution and may contain iodine. If you are allergic to iodine, fish or dyes, let the person performing the scan know in advance.

MRI scan

The MRI (magnetic resonance imaging) scan uses both magnetism and radio waves to build up detailed cross-sectional pictures of the body. You will lie on a table that slides into a metal cylinder – a large magnet – that is open at both ends.

As with a CT scan, a dye may be injected into your veins before the scan.

Some people find lying in the narrow metal cylinder noisy and confining. Let your health care team know if you are uncomfortable or claustrophobic during the scan. They may help you to relax by allowing you to use headphones to listen to music, wear an eye mask or take a mild sedative.

People who have a pacemaker, joint replacement or certain other metallic objects in their body cannot have an MRI due to the potentially damaging effect of the magnet.

PET scan

The PET (positron emission tomography) scan may be used after a thyroidectomy to work out if the cancer has come back. It's only used occasionally, if the doctor thinks the cancer needs to be viewed in a different way.

Before the scan, you will be asked not to eat or drink for a period of time (fast). During this scan you will be injected with a small amount of radioactive glucose solution. It takes 30–90 minutes for the solution to flow throughout your body.

Your body will then be scanned for concentrated levels of radioactive glucose. Cancer cells show up brighter on the scan because they take up more of the glucose solution than normal cells. The PET scan is usually done on an outpatient basis, however it takes several hours to prepare for and have the scan.

Staging thyroid cancer

The tests described on pages 14–18 help determine whether you have thyroid cancer.

Some tests also show if the cancer has spread to other parts of the body. This is called staging. It helps your doctors recommend the best treatment for you. Most cancers follow a general international staging system known as TNM.

TNM system

| TNM system | |
|-----------------------|--|
| T (Tumour) | indicates the tumour size |
| N (Nodes) | indicates whether the lymph nodes are affected |
| M (Metastasis) | indicates whether the cancer has spread to other parts of the body |

Numbers or letters may be used after the T, N and M to provide more details. For example, a T1 tumour is smaller than a T2 tumour. The cancer may be grouped into further stages, based on your age and cancer type.

Doctors will usually explain cancer staging in plain English. If you are confused, ask your doctor or nurse to give you more information. You can also call Cancer Council Helpline 13 11 20 for more information.

Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis and treatment options with your doctor, but it is not possible for any doctor to predict the exact course of the disease. Instead, your doctor can give you an idea of what may happen, based on statistics and common issues that affect people with thyroid cancer.

The type of thyroid cancer you have, test results, the rate of tumour growth, how well you respond to treatment are all important factors in assessing your prognosis. Your doctor will also consider your age, fitness and medical history.

The most common types of thyroid cancer (papillary and follicular) have a very good long-term prognosis, especially if the cancer is found only in the thyroid or is confined to the nearby lymph nodes in the neck. Even if it has spread (metastasised), the outcome can still be very good.

Five-year survival rates

Most research studies monitor patients up to five years after treatment, so the most common way to measure average survival is the five-year survival rate. This statistic can predict longer-term survival – it does not mean you will only survive for five years.

Thyroid cancer has the highest five-year survival rate of all cancers (96%).

Women diagnosed with thyroid cancer generally have a slightly better prognosis than men (98% five-year survival rate).

“ Sometimes I felt people were a little dismissive because thyroid cancer has a good outlook. They would say, ‘If you’re going to get cancer, that’s the best type to get.’ But I didn’t find this very helpful. Hearing the word ‘cancer’ made me feel gutted and afraid. ” *Jenny*

Which health professionals will I see?

Your GP will arrange the first tests to assess your symptoms. This can be a worrying and tiring time, especially if you need several tests. If these tests do not rule out cancer, you will usually be referred to an endocrinologist or endocrine surgeon who will arrange further tests and advise you about treatment options.

You will be cared for by a range of health professionals who specialise in different aspects of your treatment (see page 22). This multidisciplinary team (MDT) will depend on the stage of the cancer.

Health professionals for early thyroid cancer

| | |
|------------------------------------|--|
| endocrinologist | specialises in diagnosing and treating disorders of the endocrine system |
| endocrine surgeon | operates on the thyroid gland, parathyroid glands, adrenal glands and the endocrine pancreas |
| ENT surgeon | treats the ears, nose and throat, including lymph nodes in the neck, and checks the vocal cords before and after surgery |
| head and neck surgeon | operates on cancer in the head and neck area |
| nuclear medicine specialist | coordinates the delivery of radioactive iodine treatment and nuclear scans |
| nurses | support patients and families throughout treatment and liaise with other staff |

Additional health professionals you may see

| | |
|---|--|
| medical oncologist | prescribes and coordinates the course of chemotherapy |
| radiation oncologist | prescribes and coordinates the course of radiotherapy |
| other allied health professionals, e.g. counsellors, physiotherapists, dietitians and social workers | links you to support and rehabilitation services and helps with emotional, physical and practical issues |



Key points

- Thyroid cancer often doesn't cause any symptoms, but you may feel a painless lump in your neck or throat.
- There are many different types of tests to diagnose thyroid cancer.
- You may have a blood test to check the level of thyroid hormones in your blood.
- Most people have an ultrasound and a fine needle biopsy to check for cancer in the thyroid tissue.
- Other tests used to diagnose thyroid cancer include a CT scan, MRI scan or, occasionally, a PET scan.
- A radioisotope scan is when radioactive fluid is injected into your body. Thyroid cells may not take up much fluid ('cold' nodules), or they may take up a lot of fluid ('hot' nodules). Knowing if the nodules are 'cold' or 'hot' may help detect cancer.
- The doctor will tell you the size of the cancer and if it has spread (its stage). The TNM system is often used for staging. This stands for Tumour, Nodes, Metastasis.
- Thyroid cancer has the highest five-year survival rate of all cancers (96%). Most thyroid cancers are treatable, and the cure rate is highest for papillary and follicular thyroid cancers.
- You will see a doctor who specialises in treating disorders of the endocrine system. You may see other health professionals who work together as a multidisciplinary team (MDT) to diagnose and treat you. You will probably see more professionals if you have advanced thyroid cancer or need extra support.



Treatment

Treatment for thyroid cancer usually includes surgery, thyroid hormone replacement therapy and radioactive iodine treatment. Some people also need external radiotherapy or chemotherapy. Most people receive a combination of treatments.

The type of treatments your doctor recommends will depend on the type and stage of thyroid cancer that you have. Discuss any preferences or concerns about treatment with your medical team.

Surgery

Surgery is the most common treatment for thyroid cancer. There are two main types of thyroid surgery.

Total thyroidectomy – The whole thyroid gland, including the isthmus, is removed. When the biopsy confirms the cells are cancer, surgeons often suggest patients have a total thyroidectomy to remove undetected cancer cells in other parts of the thyroid gland. A few lymph nodes may also be removed at this time.

Partial or hemi-thyroidectomy – In this operation, only the affected lobe or section of the thyroid is removed. This procedure is often used if the biopsy is inconclusive and the doctor needs to look at more tissue to determine if you have cancer.

With either type of operation, the surgeon may remove nearby lymph nodes. This is called a neck dissection. It is performed as a preventive measure or if the lymph nodes are enlarged due to the cancer spreading (metastatising).

In very rare cases, the surgeon removes other tissue (for example, the thymus gland and vascular tissues) near the thyroid that has been affected by the cancer.

Further treatment after surgery

After surgery it is common to have further treatment. This may include:

- **thyroid hormone replacement therapy** – surgery for thyroid cancer removes the cells that make the thyroid hormones. After surgery, you will need to replace the natural thyroid hormone with medication. See page 28.
- **radioactive iodine treatment** – may be used to destroy any remaining cancerous tissue left behind after surgery. It is usually scheduled at least 4–5 weeks after surgery, to allow your surgical wound time to heal. See page 30.
- **external radiotherapy** – not always required. See page 34.
- **chemotherapy** – not always required. See page 35.

After the operation

You will probably stay in hospital overnight or for a few days to recover from surgery. You will have a tube put into your vein (intravenous drip) to replace your body's fluids until you are able to eat and drink again. This is removed within a few days.

Your neck wound will be sealed with stitches, adhesive strips or small clips. Your nursing team will talk to you about caring for your surgical wound site.

See the table on pages 26–27 for tips on managing side effects.

Managing the side effects of thyroid surgery



Neck discomfort

You will probably feel some pain or discomfort where the incision was made.

The position you are placed in for surgery can sometimes give you a stiff neck and back. This is temporary, and neck massage and physiotherapy may help loosen the muscles in your neck. You can also try using a triangle-shaped pillow to support your neck after surgery and/or ask for pain-relieving medication.



Eating and drinking

Most patients are able to eat or drink normally within about 12–24 hours after surgery. To help your body recover from surgery, it needs to be well nourished. Try to continue gently swallowing and eating as much as possible.

If you find it painful to swallow, you may be referred to a speech pathologist and/or dietitian. For more information, call 13 11 20 for a free copy of *Nutrition and Cancer*.



Mood changes

Sometimes changes in hormone levels can affect your mood. If you feel anxious or have panic attacks, tell your doctor or nurse how you are feeling.



Breathing

Most people who have thyroid surgery do not have any breathing difficulties after the operation. If you have problems, tell your nurse or doctor immediately.



Scar

You will have a horizontal scar on your neck above your collarbone. In most cases, the scar is about 5cm long. At first, this scar will look red, but it should fade and become less noticeable with time. Your doctor may recommend using tape on the scar to help it heal.

Keep the area moisturised to reduce the appearance of the scar over time – ask your pharmacist or doctor to recommend a cream you can use.



Hoarse voice

Sometimes thyroid surgery affects the nerves to the voice box, which can make your voice sound hoarse or weak. This is often temporary and improves with time.



Low calcium levels

If surgery affected the parathyroid glands, it can reduce your calcium levels. This may cause you to have headaches and feel tingling in your hands, feet and lips.

Your doctor will do blood tests to check your calcium levels, and you may be prescribed vitamin D and/or calcium supplements until your parathyroid glands recover. Some people need to take supplements for the long term.



Feeling tired

Most people return to their usual activities soon after their operation, but some people need more time to rest.

Thyroid hormone replacement therapy

Once the thyroid is removed, you will no longer produce the hormones that maintain your metabolism and keep your body functioning at a normal, healthy rate.

After surgery, you will be prescribed an oral hormone tablet every day to replace thyroxine (T4). You'll have to take this hormone replacement for the rest of your life. This is part of the treatment plan for most people with thyroid cancer.

Without this hormone medication, you would develop the symptoms of hypothyroidism, such as weight gain, constipation, brittle and dry hair and skin, sluggishness and fatigue. In severe cases, heart problems could occur.

Taking the T4 hormone in tablet form also stops your pituitary glands from producing another hormone called thyroid-stimulating hormone (TSH). It is thought that high levels of TSH may cause cancer cells to grow in other parts of the body.

For this reason, your doctor may recommend you take a high dose of T4, with the goal of reducing the level of TSH. This may be known as TSH suppression.

“ I would recommend seeing an endocrinologist who specialises in thyroid cancer, who can help to get your TSH levels under control. ” *Jenny*

Finding the right dose

You will have regular blood tests to help your doctor work out the right T4 dosage for you. Finding the correct dosage may take weeks or months, but it usually remains stable after that. You'll be carefully monitored when you start taking the medication.

Until you are taking the right dose of T4, you may feel unwell and experience symptoms of hypothyroidism or hyperthyroidism. However, once you are taking the correct dose, you should not experience side effects.

Some people feel distressed or upset about taking medication daily for the rest of their life. Talking to someone about how you feel may help. See page 53 for information about support services.

tips

- Store your medication in the fridge. This helps maintain the T4 level in the tablets.
- Take your medication at the same time every day to get into a routine. First thing in the morning on an empty stomach is often best. Take with water only and wait half an hour before eating.
- Tell your doctor if you are also taking other medications or supplements, to confirm it is safe.
- If you miss a T4 dose, take the missed dose as soon as you remember.
- Don't stop taking your medication without discussing it with your doctor.
- Tell your doctor if you are pregnant. Women who are pregnant often need an increased hormone dosage.

Radioactive iodine treatment

Radioactive iodine (RAI) treatment is a type of internal radiotherapy that is sometimes known as I131 or radioactive iodine ablation. It is usually taken in gel tablet form. The radioactive iodine destroys tiny amounts of normal thyroid tissue and any cancer cells left behind after surgery.



If you are pregnant, you can't have radioactive iodine treatment. If you are breastfeeding, you will have to stop nursing during and after treatment. Ask your doctor for more details.

Preparing for radioactive iodine treatment

For the RAI treatment to be successful, you need a high level of TSH in your body. This means that a couple days before treatment, you will probably be prescribed an injection of a man-made type of thyroid-stimulating hormone called recombinant human thyroid-stimulating hormone (rhTSH) or Thyrogen®.

rhTSH is not suitable for everyone, and it may not be available in your hospital.

If rhTSH is not available, you may need to stop taking your thyroid hormone replacement medication for a few weeks. Stopping this medication often causes the side effects of hypothyroidism, and some people find it difficult to cope with this. For more details, see page 50 and discuss your situation with an endocrinologist.

Diet changes

A diet high in iodine makes the RAI treatment less effective. You will need to start eating a low iodine diet two weeks before treatment. Your health care team will give you advice about high-iodine foods to avoid, such as seafood, iodised table salt, some dairy products, and foods with certain colourings.

Safety measures

RAI treatment will make you radioactive for a few days, and you may have to stay in hospital for all or part of this time. Once the radiation has dropped to a safe level, you will be able to go home. If you are taking Thyrogen®, usually this is within about 36–48 hours.

Your medical team, family members and friends will have to take precautions to avoid being exposed to radiation. The safety measures vary for each hospital, but usually include:

- keeping you in an isolated, shielded room
- restricting visitors to the room – particularly children and pregnant women
- asking any visitors to stay 2–3 metres away from you
- limiting the time visitors can stay in the room
- measuring your radiation levels with an instrument called a Geiger counter – this is usually done daily
- taking extra precautions when dealing with body fluids (e.g. urine, sweat, saliva and blood) and leftover food and drink.

These RAI safety measures may make you feel frightened and lonely. Talk to your doctors, nurses or a counsellor who can provide support or help your family or friends to support you.

Safety at home

When you go home, you may have to continue following some safety measures. For example, you may have to sleep alone, wash your clothing separately, prepare your own food and take care with body fluids for a certain period of time. If precautions are necessary, your medical team will discuss it with you before treatment.

Side effects

Usually, being temporarily radioactive is the only major side effect of RAI treatment. Other side effects are often caused by thyroid hormone withdrawal. This may cause you to feel thirsty, tired, nauseated or breathless. You may find it difficult to concentrate or think logically or have an altered sense of taste and smell for about 24 hours after treatment.

After treatment, you will have a full body radioisotope scan (see page 16). This scan can help detect if any cancer cells are left in the body. It may also indicate if the cancer has spread to your lymph glands or other areas of your body, such as your lungs or bones.

tips

- Drink lots of water to help the RAI treatment pass out of your body faster. This also reduces the bladder's exposure to radiation.
- Ask for medication if your side effects continue.
- If you or your partner want to have a baby after RAI treatment, talk to your doctor. You may have to wait or take certain precautions. See pages 45–46 for more information.



Jenny's story

I was a 35-year-old new mum when I was diagnosed with thyroid cancer. One day, I noticed a lump in my neck. After doing some research online, I self-diagnosed it as postpartum thyroiditis.

When I went to my GP, she referred me to have an ultrasound and biopsy. The biopsy wasn't conclusive so I had a hemi-thyroidectomy. The pathology results showed I had papillary thyroid cancer.

When I found out it was cancer, it was very traumatic. I just wanted it out of my body. I went in as soon as possible to have the other half of my thyroid removed.

At the time, I was on maternity leave and I wanted to focus on my newborn. I was very worried about what would happen to me. I asked family and friends if they would look after my son if I died.

After this, I received radioactive iodine treatment. However, I waited six months after surgery because I'd been nursing my son and I needed to wean him.

The hardest part of having radioiodine treatment was being away from my family. I had to stay in the lead-lined room in hospital for three days, then I stayed at my dad's place for two weeks after discharge from hospital. My partner looked after our son at home – I was desperate to be there but I stayed away because I didn't want to expose the baby to any radiation.

Since then, I've followed up with an endocrinologist to regulate my hormones. I check in periodically and get a full-body scan every two years. It's been more than five years since surgery and the thyroid cancer is gone – I haven't needed any further treatment. My long-term prognosis is good.

External radiotherapy

External radiotherapy is the use of high-energy x-rays or electron beams to kill or damage cancer cells.

Radiotherapy may be given after surgery, or as an additional treatment to radioactive iodine treatment if the cancer has spread to lymph nodes in the neck. It is commonly used to treat medullary or anaplastic thyroid cancer because radioactive iodine treatment is usually less effective for these types of cancers.



You will not be radioactive after external radiotherapy treatment, so it is safe to be with other people.

Before the treatment starts, you will have a planning (simulation) session. Your doctor will take CT scans to determine the precise area to be treated, and may make small marks or tattoos on your skin. This ensures the same part of your body is targeted during each treatment session.

You may be fitted for a mask to wear during treatment. This will help make sure that you don't move and the radiation beams always treat the correct areas of your neck.

Radiotherapy is usually given five days a week over several weeks. Treatment sessions usually take about 10 minutes. During this time, you will be able to see and breathe through the mask. Let your doctor know if you are afraid of confined spaces (claustrophobic).

Side effects

The side effects of external radiotherapy treatment vary. Most are temporary and disappear within a few weeks or months after treatment. Common side effects include feeling tired, pain and difficulty swallowing, sore throat, dry mouth, and red, dry, itchy, sore or ulcerated skin.

Talk to your doctor and nurses about ways to reduce or manage any side effects you may experience. For more information about the side effects of radiotherapy, call 13 11 20 for a free copy of *Understanding Radiotherapy*.

Chemotherapy

Chemotherapy is the use of drugs to kill or slow the growth of cancer cells. It is sometimes used to treat advanced thyroid cancer that is not responding to radioactive iodine treatment.

The drugs are usually given by injection into a vein (intravenously). You will probably have several treatment sessions over a few weeks – your medical team will determine the schedule.

Side effects

The aim of chemotherapy is to kill cancer cells while doing the least possible damage to healthy cells. However, treatment can affect your healthy cells, and this may cause side effects.

The side effects of chemotherapy vary according to the drugs that are used.

Common side effects include tiredness and fatigue, nausea, appetite loss, diarrhoea, hair loss, hearing loss, mouth sores and anaemia.

Most side effects are temporary and there are ways to prevent or reduce them. Your doctor will talk to you about how to manage any side effects you experience. Some people are prescribed medication to treat the side effects, take a break from treatment, or receive a different type of treatment.

For more information about chemotherapy and its side effects, call the Helpline for a free copy of *Understanding Chemotherapy*. You can also view information about chemotherapy online – see your local Cancer Council website.

Tyrosine kinase inhibitors

There are some new drugs called tyrosine kinase inhibitors that are available to treat some types of thyroid cancer.

Sorafenib is the type of drug used for papillary thyroid cancers. Vandetanib and cabozantinib are used to treat some medullary thyroid cancers.

Some research shows that tyrosine kinase inhibitors can be beneficial by targeting new blood vessels or certain mutations. However, they aren't available in all cases and may be expensive because they aren't on the Pharmaceutical Benefits Scheme.

Talk to your medical team for more information.

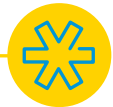
Palliative treatment

Palliative treatment helps improve people's quality of life by alleviating symptoms of cancer, without trying to cure the disease. It is particularly important for people with advanced cancer, however, it can be used at any stage of cancer.

Often treatment is concerned with pain relief and symptom control, but it can also involve the management of other physical and emotional problems. Treatment may include targeted radiotherapy, chemotherapy or other medication.

For more information on palliative treatment or advanced cancer, call the Helpline for free copies of *Understanding Palliative Care* or *Living with Advanced Cancer*, or view them online.

Many people with thyroid cancer do not need to access palliative care services.





Key points

- Surgery is the most common treatment for thyroid cancer.
- There are different types of surgery for thyroid cancer. The operation you have depends on where the cancer is in the thyroid, the type and size of the cancer and whether it has spread.
- You may have the whole thyroid gland removed (total thyroidectomy) or only part of the thyroid (partial or hemi-thyroidectomy). The nearby lymph nodes may also be removed (neck dissection).
- After surgery, you will need to take thyroid hormone replacement medication for the rest of your life.
- You may need to have radioactive iodine (RAI) treatment after surgery to kill remaining cancer cells.
- RAI is taken as a gel tablet. You will need to stay in hospital in an isolated room for 2–3 days, so that the radioactivity can be safely contained.
- You may prepare for RAI by taking a hormone known as rhTSH or Thyrogen®. If this is unavailable, you may need to stop taking thyroid hormone replacement medication for a few weeks before having RAI.
- External radiotherapy may be given to some people who have cancer in several lymph nodes in the neck, for people who have medullary thyroid cancer, or to target cancer that has spread to the bones.
- Chemotherapy or tyrosine kinase inhibitors (drug treatments) may be used if the cancer no longer responds to RAI.



Making treatment decisions

Sometimes it is difficult to decide on the right treatment. You may feel that everything is happening so fast you don't have time to think things through. If you are feeling unsure about your options, check with your doctor how soon your treatment should start, and take as much time as you can before making a decision.

Understanding details about the disease, the available treatments and their possible side effects will help you make a well-informed decision. This decision will also take into account your personal values and the things that are important to you and your family. It is common to feel overwhelmed by information, so it may help if you read and talk about the cancer gradually.

- Weigh up the advantages and disadvantages of different treatments, including the impact of any side effects.
- If only one type of treatment is recommended, ask your doctor why other choices have not been offered.
- If you have a partner, you may want to discuss the treatment options together. You can also talk to friends and family.

You have the right to accept or refuse any treatment offered by your doctors and other health care professionals. Some people with advanced cancer choose treatment even if it only offers a small benefit for a short period of time. Others want to make sure the benefits outweigh the side effects so that they have the best possible quality of life. Some people choose options that focus on reducing symptoms and make them feel as well as possible.

Talking with doctors

When your doctor first tells you that you have cancer you may not remember all the details about what you are told. You may want to see the doctor again before deciding on treatment. Ask for the time and support to make your decision.

If you have questions, it may help to write them down before you see the doctor. You can also check the list of suggested questions on page 56. Taking notes or recording the discussion can help too. Many people like to have a family member or friend go with them to take part in the discussion, take notes or simply listen.

If your doctor uses medical terms you don't understand, ask for an explanation in everyday language. You can also check a word's meaning in the glossary (see page 57).

tip

If you have several questions for your doctor, ask if it is possible to book a longer appointment.

A second opinion

Getting a second opinion from another specialist may be a valuable part of your decision-making process. It can confirm or clarify your doctor's recommendations and reassure you that you have explored all of your options.

Some people feel uncomfortable asking their doctor for a second opinion, but specialists are used to people doing this.

Your doctor can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. Alternatively, you may decide you would prefer to be treated by the doctor who provided the second opinion.

Taking part in a clinical trial

Your doctor may suggest you consider taking part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. Over the years, trials have improved treatments and led to better outcomes for people diagnosed with cancer.

If you join what is called a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the promising new treatment.

To help you decide whether or not to participate, you can talk to your specialist or the clinical trials nurse. If you're still unsure, you can also ask for a second opinion from an independent specialist. If you do decide to take part, you have the right to withdraw from the trial at any time; doing so will not jeopardise your ongoing treatment for cancer.

For more information about clinical trials and other research, including questions to ask your doctor and how to find a suitable study, call Cancer Council Helpline 13 11 20. You can also find trials on the website www.australiancancertrials.gov.au.



Looking after yourself

Cancer can cause physical and emotional strain. It can also impact on your body image, relationships and outlook for the future. It's important to take time to look after yourself by eating well, exercising, reducing stress and improving your wellbeing.

Healthy eating

Eating nutritious food will help you keep as well as possible and cope with cancer and treatment side effects. Depending on your treatment, you may have special dietary needs. A dietitian can help you manage any eating difficulties, and choose the best foods and meals for your situation.

Cancer Council Helpline 13 11 20 can send you free information about nutrition and cancer.

Staying active

Research shows it is helpful to stay active and exercise regularly if you can. Physical activity, even if gentle or for a short duration, helps to improve circulation, reduce tiredness and elevate mood. The amount and type of exercise you do will depend on what you are used to, how well you feel and what your doctor advises.

If you aren't used to exercise or haven't exercised for a while, make small changes to your daily activities. You could walk to the shops, take the stairs, do some gardening or join a gentle exercise class. If you want to do more vigorous or weight-bearing exercise, ask your medical team what is best for you.

Complementary therapies

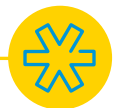
Complementary therapies are treatments that may help you cope better with side effects such as pain. They may also increase your sense of control over what is happening to you, decrease your stress and anxiety, and improve your mood.

There are many types of complementary therapies, such as herbal medicine, acupuncture, massage, relaxation and meditation. Some cancer treatment centres offer these therapies as part of their services, but you may have to go to a private practitioner. Self-help CDs or DVDs can also guide you through different techniques.

Let your doctor know about any complementary therapies you are using or thinking about trying. Some therapies may not be appropriate, depending on your medical treatment. For example, herbs and nutritional supplements may interact with your medication or surgery, resulting in harmful side effects. Massage, acupuncture and exercise therapies should also be modified if you have lowered immunity, low platelets or fragile bones.

Call Cancer Council Helpline 13 11 20 for more information about complementary therapies and alternative therapies.

Alternative therapies are often defined as those used instead of conventional medical treatments. These therapies may be harmful if people with cancer delay or stop using medical treatment in favour of them. Examples are coffee enemas and magnet therapy.



Relationships with others


For many people, the experience of having cancer and any ongoing challenges causes them to make some changes in their life. You may also have a new outlook on your values, priorities, or life in general. Some people find that these changes can affect their relationships. However, sharing your thoughts and feelings with family, friends and colleagues may help to strengthen your relationships with them.

If you feel uncomfortable talking about your feelings, take your time and approach others when you are ready. People usually appreciate insight into how you are feeling and guidance on providing support during and after treatment.

Calling Cancer Council Helpline may help you build your confidence to discuss your feelings with others.

Give yourself time to adjust to your cancer diagnosis, and do the same for friends and family. People often react in different ways, for example being overly positive, playing down fears, or avoiding you. They are also dealing with the diagnosis and the changes.

If someone's behaviour upsets you, it might help to discuss how you both feel about the situation.

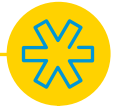
“ My husband has been a great help. He will discuss the cancer, but he prefers to remove the emotion and talk about it on a medical or practical level. ”  Barbara

Sexuality, intimacy and cancer

Having cancer can affect your sexuality in both physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, the way you and your partner communicate, the way you see your changed body, and your self-confidence. Knowing the potential challenges and addressing them will help you adjust to these changes.

Some people with cancer have the support of a partner, while others do not. If you meet a new partner during or after treatment, it can be difficult to talk about your experiences, particularly if the cancer has had an impact on your sexuality.

If you have RAI treatment, there may be certain precautions you should take. Talk to your doctor for information.



While sexual intercourse may not always be possible during and immediately after treatment, closeness and sharing can still be part of your relationship. For more information on sexuality, call 13 11 20.

Contraception and fertility

Some treatments may also affect your fertility permanently or temporarily. If having children is important to you, talk to your doctor before you start treatment.

Depending on the type of cancer and treatment you have, and your sexual preferences, your doctors may advise you to use

certain types of contraception, such as condoms, for some time during and after treatment. This is to protect your partner and to avoid pregnancy, as some treatments can be toxic to your partner or harm a developing baby. For example, after RAI treatment, your doctor will probably advise you not to conceive a child for about 6–12 months.

Ask your doctors what precautions to take and discuss any fertility issues, especially if you want to have children in the future.

Changing body image

Cancer treatment can change the way you feel about yourself (your self-esteem). You may feel less confident about who you are and what you can do. This is common whether your body has changed physically or not.

Give yourself time to adapt to any changes. Try to see yourself as a whole person (body, mind and personality) instead of focusing only on the parts of you that have changed.

For practical suggestions about hair loss, weight changes and other physical changes, call Cancer Council Helpline.

“ The surgeon made the incision in a crease in my neck. I worried about the appearance of the scar, but the redness faded after applying vitamin E cream. It’s not noticeable – people can’t tell I’ve had cancer. ” Jenny

Life after treatment

Life after cancer treatment can present its own challenges. You may need to take some time to adjust to any physical and emotional changes.

You may have mixed emotions. Beforehand, you may have been busy with appointments and focused on treatment, but afterwards you may feel anxious or vulnerable. You might worry about every ache and pain and wonder if the cancer is coming back.

Some people say that after cancer they have changed priorities and see life in a new way. For example, you may decide to travel, spend more time with family, or do volunteer work.

Although you might feel pressure to return to normal life, you may find that you don't want your life to return to how it was before cancer.

You might find it helpful to:

- take time to adjust to physical and emotional changes
- re-establish a new daily routine at your own pace
- spend time on a leisure activity you enjoy
- maintain a healthy diet and lifestyle
- schedule regular check-ups with your doctor
- share your concerns with family and friends and tell them how they can support you
- call Cancer Council Helpline 13 11 20 to connect with other people who have had cancer, or to request a free booklet about life after cancer.

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression. This is quite common among people who have had cancer.

Talk to your GP, as counselling or medication – even for a short time – may help. Some people are able to get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Your local Cancer Council may also run a counselling program.

The organisation beyondblue has information about coping with depression and anxiety. Visit www.beyondblue.org.au or call 1300 224 636 to order a fact sheet.

Follow-up after treatment

After your treatment has finished, you will need regular check-ups and tests. This may include some of the following tests:

Ultrasound – Having an annual neck ultrasound scan is usually a routine part of follow-up for thyroid cancer. The doctor uses the ultrasound to look for evidence of remaining cancer where the thyroid was removed (an area called the thyroid bed), and check the lymph nodes around the neck.

Blood tests – If you have been treated for papillary or follicular thyroid cancer, you will probably have blood tests to check the levels of thyroglobulin (Tg). This protein is made by normal thyroid tissue. It may also be made by papillary or follicular

thyroid cancer cells. You should have little or no thyroglobulin in your body after surgery – levels will rise if the cancer comes back. If thyroglobulin is detected in your blood, your doctor may perform some additional scans (see pages 17–19).

Blood tests are also done regularly to help determine if the dose of thyroid hormone replacement is correct. When it's stable, thyroid function blood tests are usually needed every 6–12 months.

Radioisotope scan – This test may detect thyroid cancer cells that are still in your body. For more information, see page 16. If the scan results are inconclusive, or if there are cancer cells elsewhere in your body, you may have a CT or PET scan.

Before follow-up tests

You may need to stop taking thyroid hormone replacement medication before having a thyroglobulin blood test or a radioisotope scan. This is because you need a certain level of thyroid-stimulating hormone (TSH) in your body for these tests, but TSH is suppressed when you are taking hormone replacements.

To improve the accuracy of your follow-up tests, your doctor will give you two options, described on page 50.

🗨️ I had rhTSH injections for a recent follow-up. I didn't experience any side effects, and I was able to continue taking my daily T4 hormone replacement. 🗨️ *Claire*

Ensuring follow-up tests are accurate

Your doctor will give you instructions about what to do before your blood test or radioisotope scan.

Option 1 **Stop taking T4 hormone for 2–6 weeks before your appointment**

- You will be told to stop taking the T4 hormone replacements about 2–6 weeks before your scheduled follow-up appointment.
- Without hormone replacements, your thyroid hormone levels will decrease and you will experience the symptoms of hypothyroidism (see page 8).
- This can be improved by taking T3 for 10–14 days before the scan.

Option 2 **Take rhTSH to reduce side effects of stopping T4**

- rhTSH is a man-made drug that is similar to the TSH produced by your body, and it ensures there is enough TSH in your body for accurate test results.
- It is given as two injections, 24 hours apart.
- You will have the radioactive iodine scan and/or blood test about 48–72 hours after your second rhTSH injection.
- You don't have to stop taking your thyroid hormone pill.
- rhTSH has few side effects, but some people experience temporary headaches, nausea or weakness. Talk to your doctor about side effects.



Seeking support

When you are first diagnosed with cancer, and during different stages of treatment and recovery, you may experience a range of emotions, such as fear, sadness, anxiety, anger or frustration. If sadness or anxiety is ongoing or severe, speak to your doctor.

It may help to talk about your feelings. Your partner, family members and friends can be a good source of support, or you might prefer to talk to:

- your treatment team
- a counsellor, social worker or psychologist
- your religious or spiritual adviser
- a support group or someone who has had a similar experience to you – see page 53
- Cancer Council Helpline.

If you need practical assistance, such as help around the house, it may be hard to tell people what would be useful. You might prefer to ask a family member or friend to coordinate offers of help.

You may find that while some people you know are supportive, others struggle to know what to say to you. If you have children, the prospect of telling them you have cancer can be unsettling. Cancer Council has a range of free resources to help people talk about cancer and deal with the emotions that cancer may bring up. Publications are available for people with cancer, partners, carers, children, friends and colleagues.

Call 13 11 20 for resources and support. You can also download booklets from the Cancer Council website.

Practical and financial help

A serious illness can cause practical and financial difficulties. Many services are available so you don't have to face these problems alone:

- Financial or legal assistance – through benefits, pensions and programs – may help pay for prescription medicines, transport costs to medical appointments, utility bills or basic legal advice.
- Meals on Wheels, home care services, aids and appliances can be arranged to help make life easier at home.
- Subsidised travel and accommodation may be available if you need to travel long distances for treatment.
- Home nursing care may be available through community nursing services or local palliative care services.

Ask Cancer Council Helpline or your hospital social worker, occupational therapist or physiotherapist which services are available in your area and if you are eligible to receive them.

Cancer Council library*

Following a cancer diagnosis many people look for information about new types of treatment, the latest research findings and stories about how other people have coped. Cancer Council has a range of books, CDs, DVDs and medical journals that may be helpful for you. Call the Helpline for more information.

**Not available in Victoria and Queensland*

Talk to someone who's been there

Coming into contact with other people who have had similar experiences to you can be beneficial. You may feel supported and relieved to know that others understand what you are going through and that you are not alone.

In these support settings, people often feel they can speak openly and share tips with others. You may find that you are comfortable talking about your diagnosis and treatment, your relationships with friends and family, and your hopes and fears for the future.

Ask your nurse, social worker or Cancer Council Helpline about suitable support groups and peer support programs in your area. You may also contact the Australian Thyroid Foundation on www.thyroidfoundation.com.au for more details.

Types of support services*

Face-to-face support groups – often held in community centres or hospitals

Online discussion forums – where people can connect with each other at any time – see www.cancerconnections.com.au

Telephone support groups – for certain situations or types of cancer, which trained counsellors facilitate

Peer support programs – match you with a trained volunteer who has had a similar cancer experience, e.g. Cancer Connect

** Not available in all areas*

Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. Being a carer can be stressful and cause you much anxiety. Try to look after yourself – give yourself some time out and share your worries and concerns with somebody neutral, such as a counsellor or your doctor.

Many cancer support groups and cancer education programs are open to carers, as well as people with cancer. Support groups and some types of programs can offer valuable opportunities to share experiences and ways of coping.

Support services such as Home Help, Meals on Wheels or visiting nurses can help you in your caring role. There are also many groups and organisations that can provide you with information and support, such as Carers Australia, the national body representing carers in Australia. Carers Australia works with the Carers Associations in each of the states and territories. Phone 1800 242 636 or visit www.carersaustralia.com.au for more information and resources.

You can also call Cancer Council Helpline 13 11 20 to find out more about different services and to request free information for carers and families looking after someone with cancer.



Useful websites

The internet has many useful resources, although not all websites are reliable. The websites listed below are good sources of information.

Australian

- Cancer Council Australia..... www.cancer.org.au
- Cancer Australia <http://canceraustralia.gov.au>
- Carers Australia www.carersaustralia.com.au
- Department of Health www.health.gov.au
- HealthInsite..... www.healthinsite.gov.au
- Australian and New Zealand
Endocrine Surgeons www.endocrinesurgeons.org.au
- Australian Thyroid Foundation www.thyroidfoundation.com.au

International

- American Cancer Society..... www.cancer.org
- Macmillan Cancer Support..... www.macmillan.org.uk
- National Cancer Institute..... www.cancer.gov
- American Thyroid Association..... www.thyroid.org
- British Thyroid
Association www.british-thyroid-association.org
- ThyCa: Thyroid Cancer Survivors' Association www.thyca.org



Question checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor about your disease and treatment. If your doctor gives you answers that you don't understand, ask for clarification.

- What type of thyroid cancer do I have?
- Has the cancer spread? How fast is it growing?
- What treatment do you recommend and why?
- Are there other treatment choices for me? If not, why not?
- What are the risks and possible side effects of each treatment?
- How long will treatment take? Will I have to stay in hospital? Will I be radioactive?
- How much will treatment cost? How can the cost be reduced?
- Will I have pain due to treatment? What will be done about this?
- Are the latest tests and treatments for this type of cancer available in this hospital?
- Are there any clinical trials or research studies I could join?
- How frequently will I need check-ups after treatment?
- Who should I go to for my check-up appointments?
- How will my thyroid replacement hormone medication and hormone levels be monitored?
- Are there any complementary therapies that might help me? How will these interact with my thyroid replacement medication?
- Should I change my diet during or after treatment?
- If the cancer comes back, how will I know?



Glossary

Adam's apple

The laryngeal prominence. The cartilage that covers the voice box (larynx).

anaesthetic

A drug that stops a person feeling pain during a medical procedure. A local anaesthetic numbs a part of the body; a general anaesthetic causes temporary loss of consciousness.

benign

Not cancerous or malignant.

biopsy

The removal of a small sample of tissue from the body, for examination under a microscope, to diagnose a disease.

calcitonin

A hormone produced by the thyroid gland that controls calcium levels in the blood.

cartilage

Firm, flexible connective tissue found in the thyroid gland and other parts of the body, such as the respiratory tract and ears.

chemotherapy

The use of cytotoxic drugs to treat cancer by killing cancer cells or slowing their growth.

CT scan

A computerised tomography scan. This type of scan uses x-rays to create a picture of the body.

endocrine system

The system of the body that produces hormones.

follicular cells

One of the two main types of cells that make up the thyroid gland. They create, produce and store T3 and T4.

Geiger counter

A machine used to measure radiation levels.

goitre

A benign enlarged thyroid.

hemi-thyroidectomy

The surgical removal of part of the thyroid gland. Also called a partial thyroidectomy.

hormones

Chemical messages that communicate with the body and bring about changes.

hyperthyroidism

A benign condition that occurs when the thyroid makes too many hormones. Also known as overactive thyroid.

hypothalamus gland

An endocrine gland in the brain that produces a type of thyroid-stimulating hormone.

hypothyroidism

A benign condition that occurs when the thyroid does not produce enough hormones. Also known as underactive thyroid.

I131

See radioactive iodine.

intravenous

Inserted into a vein.

iodine

An element found in food such as seafood, some dairy products, eggs and iodised salts. Iodine is

necessary for the body to make thyroid hormones.

isthmus

The band of tissue that connects the two lobes of the thyroid.

larynx

The voice box.

lymph nodes

Small, bean-shaped structures that form part of the lymphatic system. Also called lymph glands.

lymphatic system

A network of tissues, capillaries, vessels, ducts and nodes that removes excess fluid from tissues, absorbs fatty acids and transports fat, and produces immune cells.

malignant

Cancer. Malignant cells can spread (metastasise) and can eventually cause death if they cannot be treated.

metabolism

The chemical process that is necessary for a living being to stay alive. It causes cells to grow, reproduce, respond to their environment and remain alive.

metastasis

A cancer that has spread from another part of the body.

MRI scan

A magnetic resonance imaging scan. A scan that uses magnetism and radio waves to take detailed cross-sectional pictures of the body.

multiple endocrine neoplasia (MEN)

A benign condition that increases the risk of developing endocrine tumours.

neck dissection

Surgery to remove lymph nodes and some surrounding muscle, fat or nerves in the neck.

nodule

A lump on the thyroid.

palliative treatment

Medical treatment for people with cancer to help them manage pain and other physical and emotional symptoms.

parafollicular cells (C-cells)

One of the two main types of cells that make up the thyroid gland. They produce calcitonin.

parathyroid glands

Four glands located behind the thyroid gland. They make hormones that control the amount of calcium and phosphorus in the blood.

PET scan

A positron emission tomography scan. This uses a radioactive tracer to identify cancer cells in the body.

pituitary gland

A gland in the brain that produces different hormones. The hormones control many body functions – growth, metabolism and production of sex hormones.

prognosis

The expected or predicted outcome of a person's disease.

radioactive iodine

A radioactive form of iodine often used for imaging tests or as a treatment for cancer. Also known as RAI or I131.

radioactive iodine (RAI) treatment

A type of internal radiotherapy. It is usually taken in gel tablet form, known as I131.

radiotherapy

The use of radiation, usually x-rays or gamma rays, to kill cancer cells or injure them so they cannot grow and multiply.

rhTSH

Recombinant human thyroid-stimulating hormone. A type of man-made thyroid stimulating hormone (TSH).

staging

Performing tests to determine how far a cancer has spread.

Thyrogen®

A man-made brand of thyroid stimulating hormone that is made in the laboratory (rhTSH). It is used to test for remaining or recurring cancer cells in people treated for thyroid cancer, or to prepare for RAI treatment.

thyroglobulin (Tg)

A protein used by the thyroid to make thyroid hormones.

thyroid

A butterfly-shaped endocrine gland located at the base of the neck. It produces hormones to control the body's metabolism and calcium levels.

thyroidectomy

The surgical removal of the thyroid gland. Also called a total thyroidectomy.

thyroiditis

Benign inflammation of the thyroid.

thyroid-stimulating hormone (TSH)

A hormone produced by the pituitary gland that prompts the thyroid gland to produce and release T3 and T4. The pituitary and hypothalamus glands are responsible for TSH production.

thyroxine (T4)

A hormone produced by the thyroid gland, which regulates the body's metabolism.

trachea

The windpipe. This is the airway that brings air inhaled from the nose and mouth into the lungs.

tri-iodothyronine (T3)

A hormone produced by the thyroid gland, which regulates the body's metabolism.

tumour

A new or abnormal growth of tissue on or in the body. A tumour can be benign or malignant.

tyrosine kinase inhibitors

A group of drugs that specifically target mutations within cancer cells or blood vessels that feed cancer cells.

Can't find what you're looking for?

For more cancer-related words, visit www.cancercouncil.com.au/words or www.cancervic.org.au/glossary.



How you can help

At Cancer Council we're dedicated to improving cancer control. As well as funding millions of dollars in cancer research every year, we advocate for the highest quality care for cancer patients and their families. We create cancer-smart communities by educating people about cancer, its prevention and early detection. We offer a range of practical and support services for people and families affected by cancer. All these programs would not be possible without community support, great and small.

Join a Cancer Council event: Join one of our community fundraising events such as Daffodil Day, Australia's Biggest Morning Tea, Relay For Life, Girls Night In and Pink Ribbon Day, or hold your own fundraiser or become a volunteer.

Make a donation: Any gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

Buy Cancer Council sun protection products: Every purchase helps you prevent cancer and contribute financially to our goals.

Help us speak out for a cancer-smart community: We are a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us improve cancer awareness by living and promoting a cancer-smart lifestyle.

Join a research study: Cancer Council funds and carries out research investigating the causes, management, outcomes and impacts of different cancers. You may be able to join a study.

To find out more about how you, your family and friends can help, please call your local Cancer Council.



Cancer Council Helpline 13 11 20

Cancer Council Helpline is a telephone information service provided by Cancer Council NSW for people affected by cancer.

For the cost of a local call (except from mobiles), you can talk confidentially about any concerns with oncology health professionals. Helpline consultants can send you information and put you in touch with services in your area. If you need information in a language other than English, an interpreting service is available.

You can call the Helpline, Monday to Friday, 9am to 5pm.

If you have difficulty communicating over the phone, contact the National Relay Service (www.relayservice.com.au) to help you communicate with a Cancer Council Helpline consultant.

For more information, go to www.cancercouncil.com.au.

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02 9334 1900

Hunter and Central Coast

Charlestown
02 4923 0700

North Sydney

Crows Nest
02 9334 1600

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Byron Bay
02 6639 1300

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North Wollongong
02 4223 0200

Western

Wagga Wagga
02 6937 2600

Western Sydney

Parramatta
02 9354 2000



Cancer Council
Helpline

13 11 20

For support and information on cancer and cancer-related issues, call Cancer Council Helpline. This is a confidential service.

For further information and details please visit our website: www.cancercouncil.com.au