



# Understanding Thyroid Cancer

A guide for people with cancer,  
their families and friends

A blue circular callout box containing the text "Cancer information". A thin orange line extends from the bottom of the circle, curving to the left and ending in a telephone handset icon.

Cancer  
information

For information & support, call

**13 11 20**

## Understanding Thyroid Cancer

A guide for people with cancer, their families and friends

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*Understanding Thyroid Cancer* is reviewed approximately every two years. Check the publication date above to ensure this copy is up to date.

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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 independent advice relevant to your specific situation from appropriate professionals, 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

Cancer Council is Australia's peak non-government cancer control organisation. Through the eight state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit [cancer.org.au](http://cancer.org.au) or call your local Cancer Council.



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# Introduction

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

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

We cannot give advice 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 other questions to ask your treatment team.

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 to your family and friends for their information.

## How this booklet was developed

This information was developed with help from a range of health professionals and people affected by thyroid cancer. It is based on international clinical practice guidelines for thyroid cancer.<sup>1,2</sup>

If you or your family have any questions, call Cancer Council **13 11 20**. We can send you more information and connect you with support services in your area. Turn to the last page of this book for more details.



**Cancer  
Council  
13 11 20**

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# What is cancer?

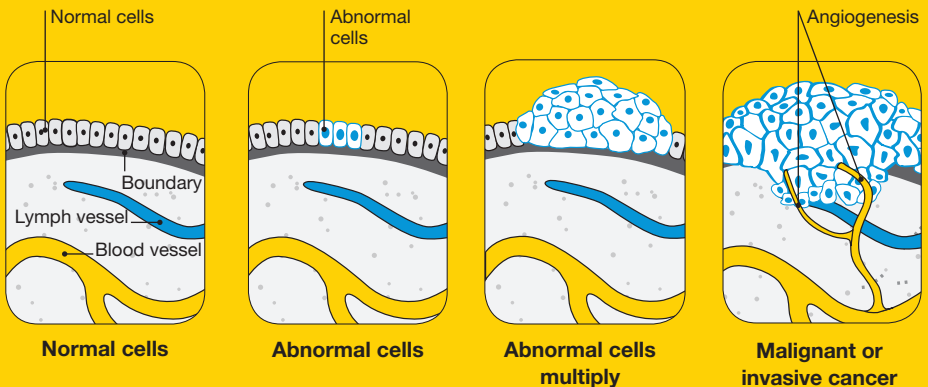
Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

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 in a process called 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 at the front of the neck. It is found below the voice box (larynx). The thyroid gland is made up of two halves, called lobes, which lie on either side of the windpipe (trachea). The lobes are connected by a small band of thyroid tissue known as the isthmus.

The thyroid gland is part of the endocrine system, which consists of a group of glands responsible for producing the body's hormones. Hormones are chemical messengers that help the body function properly. The thyroid gland makes hormones that control the speed of the body's processes, such as heart rate, digestion, body temperature and weight. This is known as your metabolic rate.

## How the thyroid gland works

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

**Thyroxine (T4)** – One of the hormones that controls the body's metabolism. T4 is converted into another thyroid hormone called T3.

**Tri-iodothyronine (T3)** – The active form of the thyroid hormone, T3 also helps control metabolism. The

thyroid produces only small amounts of T3. The majority of this hormone is created when the liver and kidneys convert T4 into T3.

**Calcitonin** – This hormone plays a role in controlling the body's calcium levels.

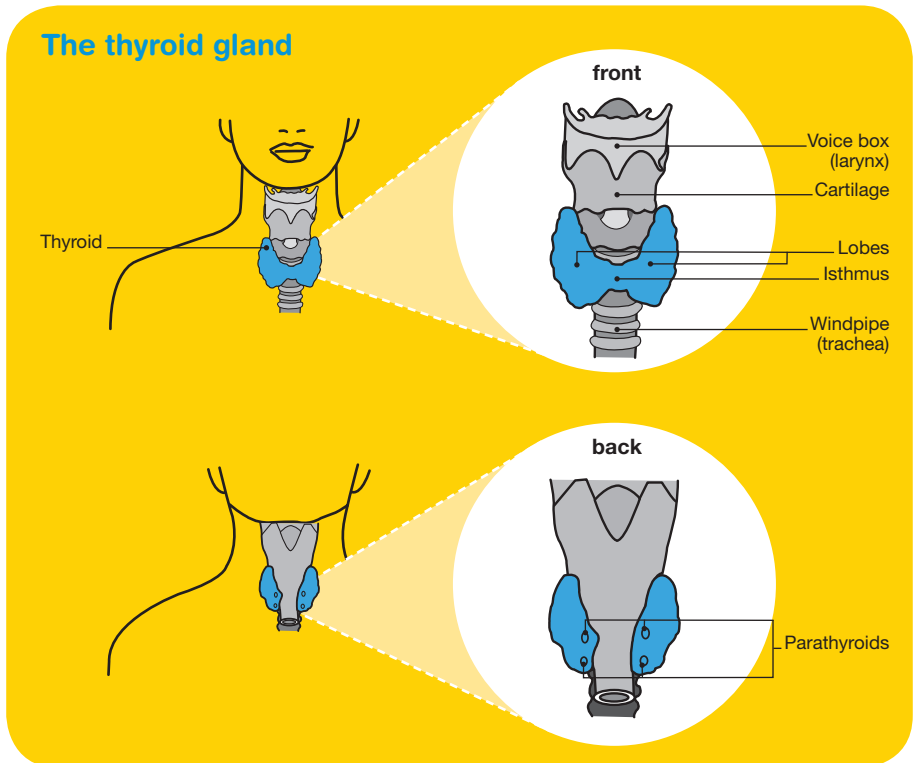
The thyroid gland makes T4 and T3 from iodine, which is found in a range of foods such as seafood and iodised salt.



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

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

Behind the thyroid gland are four additional glands called the parathyroid glands. These glands produce parathyroid hormone (PTH), which controls the amount of calcium in the blood.



## Thyroid hormones

To keep the body working properly, it is important that the thyroid gland makes the right amount of hormones. This is controlled by the pituitary gland, which is located at the base of the brain:

- If the levels of T3 and T4 drop below normal, the pituitary gland produces a hormone called thyroid-stimulating hormone (TSH). TSH prompts the thyroid gland to make and release more T3 and T4.
- If the levels of T3 and T4 are too high, the pituitary gland produces less TSH.

Changes in thyroid hormone levels affect your metabolism by altering the speed of the body's processes:

**Underactive thyroid (hypothyroidism)** – If you don't have enough thyroid hormones, your metabolism slows down. As a result, you may feel tired or depressed, and gain weight easily. Other symptoms may include constipation, brittle and dry hair and skin, sluggishness and fatigue. In severe cases, heart problems could occur.

**Overactive thyroid (hyperthyroidism)** – If you have too many thyroid hormones, your metabolism speeds up. As a result, you may lose weight, have an increased appetite, feel shaky and anxious, or have rapid, strong heartbeats called palpitations. Over time, untreated hyperthyroidism can result in loss of bone strength and problems with heart rhythm.



# Key questions

## Q: What is thyroid cancer?

**A:** Thyroid cancer develops when the cells of the thyroid gland grow and divide in an abnormal way.

## Q: What types are there?

**A:** There are several types of thyroid cancer.

### Types of thyroid cancer

Common	papillary	<ul style="list-style-type: none"><li>• most common type (about 70–80% of all thyroid cancer cases)</li><li>• develops from the follicular cells</li><li>• tends to grow slowly</li></ul>
	follicular	<ul style="list-style-type: none"><li>• about 15–20% of all thyroid cancer cases</li><li>• develops from the follicular cells</li><li>• includes Hürthle cell carcinoma, a less common subtype</li></ul>
Rare	medullary	<ul style="list-style-type: none"><li>• about 4% of all thyroid cancer cases</li><li>• develops from the parafollicular cells (C-cells)</li><li>• can run in families (see pages 11–12)</li><li>• may be associated with tumours in other glands</li></ul>
	anaplastic	<ul style="list-style-type: none"><li>• a rare thyroid cancer (about 1% of all thyroid cancer cases)</li><li>• may develop from papillary or follicular thyroid cancer</li><li>• tends to grow quickly</li><li>• usually occurs in people over 60</li></ul>

## 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, which may grow gradually
  - trouble swallowing
  - difficulty breathing
  - changes to the voice, e.g. hoarseness
  - swollen lymph glands in the neck, which may slowly grow in size over months or years.

Although a painless lump in the neck is the most common sign, thyroid lumps (or nodules) are common and are benign in 90% of adults.



Having an underactive or overactive thyroid (hypothyroidism or hyperthyroidism) is not typically a sign of thyroid cancer.

## Q: How common is thyroid cancer?

- A:** About 2700 people are diagnosed with thyroid cancer each year in Australia.<sup>3</sup> Thyroid cancer occurs three times more often in women than men – it is the seventh most common cancer affecting Australian women.<sup>4</sup>

Thyroid cancer can occur at any age. It is the most common cancer diagnosed in women aged 25–29, and the third most common cancer in women aged 25–49.

Diagnoses of thyroid cancer in Australia have increased in recent years. Between 1982 and 2017, cases of thyroid cancer more than tripled.<sup>4</sup>

A significant portion of this increase is due to the improved quality of ultrasounds and other scans. This has led to the detection of smaller, often insignificant, thyroid cancers that would otherwise not have been found. Researchers are trying to determine if there are any other causes of the increased rates of thyroid 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. Having some of these risk factors does not necessarily mean that you will develop thyroid cancer. Most people with thyroid cancer have no known risk factors.

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

**Family history** – Only around 5% of thyroid cancer runs in families. Having a first-degree relative (parent, child or sibling) with papillary thyroid cancer may increase your

risk. Some inherited genetic conditions, such as familial adenomatous polyposis or Cowden syndrome, may also increase your risk of developing papillary thyroid cancer.

Most cases of medullary thyroid cancer do not run in families. However, some people inherit a faulty gene called the RET gene. This gene can cause familial medullary thyroid cancer (FMTC) or multiple endocrine neoplasia (MEN).

If you are concerned about having a strong family history of thyroid cancer, talk to your doctor. They may refer you to a genetic counsellor or a family cancer clinic to assess your risk.

**Other factors** – Being overweight or obese may also increase the risk of developing thyroid cancer.

Having a thyroid condition, such as thyroid nodules, an enlarged thyroid (known as a goitre) or inflammation of the thyroid (thyroiditis), only slightly increases your chance of developing thyroid cancer.

“ 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*



# Diagnosis

If your doctor suspects you have thyroid cancer, they will feel your neck to check for any swelling or lumps. If you have a thyroid lump, your doctor may then perform one or more of the following tests to confirm whether the lump is cancerous. You may not have all of the tests described in this chapter, depending on your particular circumstances.

## Blood test

You will have a blood test to check your levels of T3, T4 and thyroid-stimulating hormone (TSH). The thyroid gland generally functions normally even if thyroid cancer is present, and your hormone production won't be affected. However, this blood test may rule out benign thyroid conditions, such as hypothyroidism or hyperthyroidism.

If your doctor suspects you have medullary thyroid cancer, the levels of calcitonin in the blood may also be checked. High calcitonin levels in the blood can be a sign of this type of thyroid cancer.

## Ultrasound

An ultrasound is the best way to get detailed information about your thyroid gland. The scan can show:

- the size of any thyroid nodule and whether it is full of fluid or solid
- whether a nodule has any characteristics that suggest it may be a thyroid cancer rather than a benign nodule
- whether the lymph nodes in the neck appear to be affected.

The ultrasound 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. This creates a picture of the internal structure of your thyroid on a computer monitor. This test uses soundwaves and does not expose you to any radiation.

## Biopsy

If you have a thyroid nodule or enlarged lymph node in your neck, you may need a fine needle aspiration (FNA) biopsy. This is an outpatient procedure that takes about 15–30 minutes.

During a FNA biopsy, a thin needle is inserted into the nodule to collect a sample of cells. You may be given local anaesthesia (pain relief) to numb the area, however, this is often not required. Ultrasound can also be used to guide the needle to the right spot. A pathologist will examine the sample under a microscope to see whether it contains cancer cells. If not enough cells are removed, the process may need to be repeated.

If it is not possible to determine whether a nodule is cancerous with a biopsy, it may be necessary to remove half of the thyroid (hemithyroidectomy) to help confirm the diagnosis (see page 25).

Biopsy results are usually available in around a week. This waiting period can be an anxious time and it may help to talk to a supportive friend, relative or health professional about how you are feeling. You can also call Cancer Council 13 11 20 for information and support.



## Additional scans

The following scans are sometimes used to see if the cancer has spread from the thyroid gland to other parts of your body. This process is called staging (see page 17). Some scans may be repeated after treatment to see how well the treatment has worked (see pages 45–47).

### CT scan

A CT (computerised tomography) scan uses x-rays and a computer to create a detailed picture of an area inside the body.

In most cases, an ultrasound provides the information your doctor needs to make a diagnosis. However, you may need a CT scan if your thyroid is very enlarged, if it extends below the collar bones, or if your doctor suspects that the thyroid cancer has spread to other areas in the neck.

Before the scan, a special dye known as a contrast may be injected into one of your veins. This helps ensure that anything unusual can be seen more clearly on the pictures. The dye may make you feel flushed or hot, and it may produce a strange taste in your mouth for a few minutes.

The dye used in a CT scan can cause allergies in some people. If you know you're allergic to contrast or dyes, let the person performing the scan know in advance. You should also let them know if you are diabetic, have kidney disease or may be pregnant.



The CT scanner is a large, doughnut-shaped machine. You will lie on a table that moves in and out of the scanner. You will be asked to remain still and hold your breath for a few seconds during the scan. While it may take 30–60 minutes to prepare for the scan, the scan itself only takes a few minutes. Although a CT scan can be noisy, it is painless. You can go home once the scan is finished.

Let your health care team know if you feel uncomfortable or claustrophobic during the scan. You may be able to use headphones to listen to music, wear an eye mask or take a mild sedative.

## **PET scan**

A PET (positron emission tomography) scan is rarely needed for thyroid cancer. However, it may be useful in some types of thyroid cancer, particularly if other tests give conflicting results.

To prepare for the PET scan, you will be asked not to eat or drink for a period of time (fast). Before the scan, you will be injected with a glucose solution containing a small amount of radioactive material. Cancer cells show up brighter on the scan because they take up more of the glucose solution than normal cells do.

You will be asked to sit quietly for 30–90 minutes while the glucose solution moves around your body. You will then have a scan of your entire body to locate any cancer cells. The scan itself takes about 30 minutes.

You should tell the doctor if you're diabetic, have kidney disease, are breastfeeding or if there is a possibility you may be pregnant.

## Staging thyroid cancer

The tests described on pages 13–16 help your doctors determine whether you have thyroid cancer and whether it has spread from the thyroid to other parts of the body. This testing process is called staging and it helps your health care team recommend the best treatment for you. It is often not possible to completely stage thyroid cancer until after surgery.

The TNM staging system is the method most commonly used to describe the different stages of thyroid cancer. Each letter is assigned a number to describe the cancer. Your age and cancer type will also help determine the stage of thyroid cancer.

### TNM system

<b>T (Tumour)</b> 0–4	Indicates the size of the tumour. T1 cancers are smaller and remain inside the thyroid gland, while T4 tumours are larger or have spread to other parts of the neck.
<b>N (Nodes)</b> 0–1	Indicates whether the cancer has spread to the lymph nodes. N0 means the cancer has not spread to the lymph nodes; N1 means the cancer has spread to the nodes.
<b>M (Metastasis)</b> 0–1	Indicates if the cancer has spread to other parts of the body, such as the lungs or the bones (metastatic or secondary cancer). M0 means the cancer has not spread; M1 means the cancer has spread.

Doctors use all this information to determine whether the cancer is low, intermediate or high risk.

If you are having trouble understanding staging, ask a member of your treating team to explain it in clearer terms.

## 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 person 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 the same type of thyroid cancer as you.

To work out your prognosis, your doctor will consider:

- your test results
- the type of thyroid cancer you have
- the size of the tumour and how quickly it is growing
- how well you respond to treatment
- other factors such as 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. See the next page for more information on survival rates.

## Five-year survival rate

Doctors commonly use five-year survival rates as a way to discuss prognosis. This is because research studies often follow people for five years.

This statistic estimates the impact of the cancer on longer-term survival – it does not mean you will only survive for five years.

To determine the five-year survival rate, doctors collect information from people

treated at least five years ago. Improvements in treatments may mean that your outlook is now better.

Thyroid cancer has a very high five-year survival rate (96%).<sup>3</sup>

Women diagnosed with thyroid cancer generally have a slightly better prognosis than men (97% five-year survival rate compared with 93%). Younger people also have a better prognosis than older people.

## Which health professionals will I see?

Your GP will arrange the first tests to assess your symptoms. If these tests do not rule out cancer, you will usually be referred to an endocrinologist or endocrine surgeon. They will organise more tests and advise you about treatment options.

You will probably be cared for by a range of health professionals who specialise in different aspects of your treatment. This is called a multidisciplinary team (MDT). This team will meet regularly to discuss and plan the most appropriate treatment for you. Turn the page for a list of some of the people who make up this MDT.

## Health professionals for early thyroid cancer

<b>endocrinologist*</b>	diagnoses, treats and manages disorders of the endocrine system
<b>endocrine surgeon*</b>	operates on the thyroid gland, parathyroid glands, adrenal glands and the pancreas
<b>ear, nose and throat (ENT) surgeon*</b>	operates on the ears, nose and throat, including the thyroid gland and lymph nodes in the neck; checks the vocal cords before and after surgery
<b>head and neck surgeon*</b>	diagnoses and treats cancer of the head and neck; may be an ENT or general surgeon
<b>nuclear medicine specialist*</b>	coordinates the delivery of radioactive iodine treatment and nuclear scans
<b>nurses and nurse care coordinator</b>	administer drugs and provide care, support and information throughout treatment

## Additional health professionals you may see

<b>radiation oncologist</b>	prescribes and coordinates the course of radiation therapy
<b>medical oncologist</b>	prescribes and coordinates drug therapies such as chemotherapy and targeted therapy
<b>counsellor, social worker</b>	provide emotional and practical support; link you to support services
<b>dietitian</b>	recommends an eating plan to follow during treatment and recovery

\* Specialist doctor



## Key points

- Different types of tests are used to check for thyroid cancer, but the diagnosis is usually made by a fine needle aspiration (FNA) biopsy.
- During a FNA biopsy a sample of cells is removed from a nodule for examination under a microscope. In some cases, an ultrasound is used to guide the needle to the right spot.
- You will have a blood test to check the levels of thyroid hormones in your blood.
- Occasionally other tests, such as a CT scan or a PET scan, are used to investigate if the thyroid cancer has spread.
- 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.
- Treatment recommendations will depend on whether the cancer is assessed as low, intermediate or high risk.
- Sometimes, the information needed for accurate staging is available only after surgery.
- Your doctor will talk to you about your prognosis, which is the expected outcome of a disease. Thyroid cancer has a very high five-year survival rate (96%). Most thyroid cancers are treatable.
- You should 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 treat you.
- You will probably see more professionals if you have advanced thyroid cancer or need extra support.



# Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast. Check with your doctor how soon your treatment should start, and take as much time as you can before making a decision.

Understanding the disease, the available treatments and possible side effects can help you weigh up the pros and cons of different treatments and make a well-informed decision that's based on your personal values. You may also want to discuss the options with your doctor, friends and family.

You have the right to accept or refuse any treatment offered. Some people with more advanced cancer choose treatment even if it offers only a small benefit for a short period of time. Others want to make sure the benefits outweigh the side effects so they have the best possible quality of life.

## Talking with doctors

When your doctor first tells you that you have cancer, you may not remember the details about what you are told. Taking notes or recording the discussion may help. 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 you are confused or want clarification, you can ask questions – see page 52 for some suggestions. If you have several questions, you may want to talk to a nurse or ask the office manager if it is possible to book a longer appointment.



## A second opinion

You may want to get a second opinion from another specialist to confirm or clarify your doctor's recommendations or reassure you that you have explored all of your options. 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. You might decide you would prefer to be treated by the doctor who provided the second opinion.

## Taking part in a clinical trial

Your doctor or nurse may suggest you take 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. For example, if you join 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.

Over the years, trials have improved treatments and led to better outcomes for people diagnosed with cancer.

It may be helpful to talk to your specialist or clinical trials nurse, or get a second opinion. If you decide to take part, you can withdraw at any time. For more information, call Cancer Council 13 11 20 for a free copy of *Understanding Clinical Trials and Research* or visit [australiancancertrials.gov.au](http://australiancancertrials.gov.au).



# Treatment

The type of treatment your doctor recommends will depend on the type and stage of thyroid cancer you have, your age and your general health.

## Active surveillance

Your doctor may recommend active surveillance for papillary thyroid cancer that isn't causing any symptoms and is considered to be low risk. There is good evidence that active surveillance is safe for some small papillary thyroid cancers where there is no sign that the cancer has spread from the thyroid.

Typically, active surveillance involves regular ultrasounds and physical examinations to monitor the cancer. Some people may prefer active surveillance if the possible side effects from treatment would have more impact on their quality of life than the cancer itself. Other people find active surveillance makes them feel anxious and prefer to have surgery immediately.

### Fertility concerns

Many women diagnosed with thyroid cancer are under 40 and are concerned about the impact of treatment on their ability to get pregnant. If having children is important to you, talk to your doctor before starting

treatment. Long-term fertility is not usually affected by surgery or radioactive iodine treatment. In the short-term, you may need to delay pregnancy for some months after treatment (see pages 42–43).

Active surveillance is usually recommended only for papillary tumours under 10 mm. Surgery can be considered at any stage if you change your mind or if the cancer grows or spreads. If you agree to active surveillance, your doctor will talk to you about the changes to look out for.

## Surgery

Surgery is the most common treatment for thyroid cancer. Before the operation, a member of the surgical team and, in some hospitals, a specialist nurse will talk to you about the operation. This is your opportunity to ask questions and discuss any concerns you have.

You will be given a general anaesthetic and a 5–7 cm cut will be made across your neck. There are two main types of thyroid surgery:

**Partial or hemithyroidectomy** – Only the affected lobe or section of the thyroid is removed. This is usually performed if the cancer is small and the other lobe of the thyroid looks normal on the ultrasound. Sometimes it is also used to diagnose thyroid cancer if a fine needle aspiration biopsy doesn't provide a clear diagnosis. If thyroid cancer is found after a hemithyroidectomy, you may need further surgery to remove the rest of your thyroid. This will depend on the size and type of cancer, and whether you have nodules in the other thyroid lobe.

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



## Jen's story

I was diagnosed with a papillary thyroid cancer 10 years ago when I was 31.

I'd had laryngitis on and off for a while, but as I'm a receptionist I put it down to talking too much. As my husband and I were going overseas for a month, I had it checked out so I could get any prescriptions I needed here. The doctor felt a lump in my neck and sent me for an ultrasound.

I could tell by the technician's face that something was wrong. He called a doctor, who immediately did a fine needle biopsy. The next day, I was told I had cancer – all from a little lump I couldn't even feel or see.

My doctor referred me to a specialist who said that as it's a fairly slow-growing cancer, to have my holiday and he'd operate when I returned. A couple of weeks after coming back, I had a total thyroidectomy. I had no real

side effects other than a scar, which has faded. I recovered quickly and was back at work after a couple of weeks.

After the surgery I was put on thyroxine to get my hormones stable. Two months later, I had the radioactive iodine. I was in hospital for two nights while I was radioactive, and then at home I had to follow all the precautionary safety measures, such as sleeping separately from my partner.

I now have thyroxine once a day in the morning. I was really tired until the dose was right.

Some people say that thyroid cancer is a good cancer to get. I know that their hearts are in the right place, and yes, it is a "good" cancer because the remission rate is pretty high, but it's still cancer. The diagnosis has reminded me to appreciate the small things in life.

**Total thyroidectomy** – The whole thyroid gland (both lobes), including the isthmus, is removed.

**Lymph node removal** – With either type of thyroid surgery, nearby lymph nodes may also be removed if the cancer has spread to them. This is called a neck dissection. Occasionally, the nodes behind the thyroid are removed as a precautionary measure, even if the cancer doesn't appear to have spread.

**Other tissue** – In very rare cases, the surgeon removes other tissue near the thyroid that has been affected by the cancer.

## After the operation

You will probably stay in hospital for one or two nights to recover from surgery. Your neck wound will be closed with stitches, adhesive strips or small clips. Your nursing team will talk to you about how to care for your surgical wound site once you go home to prevent it becoming infected. Your surgeon may order blood tests during this period to check on your recovery. See *What to expect after thyroid surgery* on pages 28–29 for more information.

## Further treatment after surgery

All tissue removed during the surgery is examined for cancer cells by a pathologist. The results will help confirm the type of cancer you have and determine whether you will require further treatment. For some people this may mean more surgery to remove any remaining thyroid tissue. Other people may need thyroid hormone replacement therapy (see page 30), radioactive iodine treatment (see page 32) or targeted therapy (see page 36).

## What to expect after thyroid surgery

Most people who have thyroid surgery will feel better within 1–2 weeks, but recovery may take longer for some people.



### 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. Your singing voice may be affected. This is often temporary, but sometimes it is permanent. Most patients complain their voice gets tired after thyroid surgery, and this is usually temporary.

### Sore neck

You will probably feel some pain or discomfort where the cut was made. You will be given pain relief medicines to manage this.

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 medicine.



### Eating and drinking

Most people are able to eat or drink normally within a few hours after the operation. To help your body recover from surgery, you need to be well nourished. Try to eat small amounts of healthy, nutritious food. For more information, call Cancer Council **13 11 20** for a free copy of *Nutrition and Cancer*.

### Activity levels

Most people return to their usual activities within a week, but some people need more time to recover. You will most likely need to avoid heavy lifting, vigorous exercise and turning your neck quickly for a couple of weeks after surgery.



### Scarring

You will have a horizontal scar on your neck above your collarbone. In most cases, the scar is about 5–7 cm long and is often in a natural skin crease. At first, this scar will look red, but it should fade and become less noticeable with time. Your doctor may recommend using special tape on the scar to help it heal. Keep the area moisturised to help the scar fade more quickly over time. Ask your pharmacist or doctor to recommend a suitable cream.

### Mood changes

Changes in hormone levels may affect your mood. If you feel anxious or have panic attacks, let your doctor or nurse know as they may recommend medicines to help. Some people find meditation or relaxation techniques helpful.



### Low calcium levels

If surgery affected the parathyroid glands, you may have low blood calcium levels (hypocalcaemia). This may cause headaches and tingling in your hands, feet and lips, as well as muscle cramps.

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. If the parathyroid glands don't recover, calcium supplements need to be taken permanently. Calcium supplements should be taken at least 2 hours after your thyroid hormone replacement tablets.



### Painful swallowing

You will find it painful to swallow for a few days. Try to eat soft foods that are easy to swallow.

## Thyroid hormone replacement therapy

Many people who have a partial thyroidectomy won't need thyroid hormone replacement therapy because the remaining lobe will continue to make enough hormones.

After the whole thyroid is removed, your body will no longer produce the hormones that maintain your metabolism, and you will be prescribed a hormone tablet to replace thyroxine (T4).

You will usually start taking hormone replacement tablets while in hospital recovering from the surgery. You will need to take a hormone tablet every day for the rest of your life.

Taking thyroid hormone tablets can have two roles:

**Keeping your body's metabolism functioning at a normal healthy rate** – Without hormone replacement medicine, your metabolism will slow down and you will develop the symptoms of hypothyroidism, such as depression or weight gain (for more symptoms, see page 8).

**Reducing the risk of the cancer coming back** – Taking the T4 hormone in tablet form stops your pituitary glands from producing another hormone called thyroid-stimulating hormone (TSH). It is thought that high levels of TSH may cause any thyroid cancer cells remaining after treatment to grow. For this reason, if the doctor thinks the cancer has a medium to high risk of recurring, they will recommend you take a high dose of T4 to reduce the level of TSH. This is known as TSH suppression.



## Finding the right dose

You'll be carefully monitored when you start thyroid hormone replacement therapy. The starting dose of thyroxine (T4) is calculated based on your weight. You will have blood tests every 6–8 weeks to help your doctor adjust the dosage until it is right for you. Usually, the initial dose is close to the correct dose and requires only small adjustments.

A small number of people may experience hypothyroidism or hyperthyroidism during the adjustment period. However, once you are taking the right dose, you should not experience side effects.



### Tips for taking T4 medicines

- Store medicines in the fridge to maintain the T4 level in the tablets. If you are travelling, the medicine will last up to 30 days without refrigeration.
- Take your T4 medicine at the same time every day to get into a routine. Take it on an empty stomach with a glass of water and wait 30 minutes before eating.
- If you miss a dose, take the missed dose as soon as you remember.
- Wait 2 hours before taking calcium or iron supplements as these affect the stomach's ability to absorb the T4.
- Check with your doctor if it's safe to continue taking other medicines or supplements.
- Tell your doctor if you are pregnant or planning to get pregnant, as you may need to take a higher dose.
- Don't stop taking the T4 medicine without discussing it with your doctor.

## Radioactive iodine treatment

Radioactive iodine (RAI) is a type of radioisotope treatment. It is also known as I131. Radioisotopes are radioactive substances given as a capsule that you swallow. Although RAI spreads through the body, it is only absorbed by thyroid cells or thyroid cancer cells. RAI kills these cells while leaving other body cells unharmed.

You may be given RAI to destroy tiny amounts of remaining cancer cells or healthy thyroid tissue left behind after surgery. It is usually recommended for cancers with a higher risk of coming back after surgery.

Radioactive iodine treatment is suitable for people diagnosed with papillary or follicular thyroid cancer. RAI doesn't work for medullary or anaplastic thyroid cancer because these types do not take up iodine. The radioactive iodine treatment often starts 4–5 weeks or more after surgery to allow your surgical wound time to heal.



If you are pregnant or breastfeeding, you can't have RAI treatment. If you are breastfeeding, in most cases treatment will be delayed until you have weaned your child. Ask your doctor for more information.

## Preparing for radioactive iodine treatment

**Limiting foods high in iodine** – A diet high in iodine makes RAI treatment less effective. You will need to start avoiding high-iodine foods two weeks before treatment. This includes foods such as seafood, iodised table salt and sushi. Your health care team can give you more information.

**Raising TSH levels** – For RAI treatment to work, you need a high level of TSH in your body. There are two ways to increase TSH levels:

- You can stop taking your thyroid hormone replacement medicine for a few weeks. You will have a blood test before RAI treatment to check that the TSH levels have risen enough.
- You may be prescribed injections of a synthetic type of TSH called recombinant human thyroid-stimulating hormone (rhTSH) or Thyrogen. You will need an injection once a day for the two days before RAI treatment. This enables you to continue taking your thyroid hormone replacement medicine.

The option recommended for you will depend on your stage of disease and what is suitable for you. For more details, see page 46 and talk to your endocrinologist.

## **Having radioactive iodine treatment**

You will be admitted to hospital on the day of the radioactive iodine treatment. You may be given anti-nausea medicine before the RAI capsule. RAI treatment will make you radioactive for a few days, and you will need to stay in hospital during this time. See the next page for an outline of the safety measures that will be in place while you are having treatment.

Once the radiation has dropped to a safe level, you will be able to go home. If you had Thyrogen injections, this is usually within 36–48 hours. It may be a day longer if you stopped taking your thyroid hormone replacement medicine.

## Safety precautions during radioactive iodine treatment

Your medical team, family members and friends will have to take precautions to limit their exposure to radiation.

### In hospital

Safety measures vary at each hospital and the staff looking after you will discuss the specific details with you before treatment starts.

Safety measures usually include:

- keeping you in an isolated, shielded room
- not allowing or restricting visitors to the room – particularly children and pregnant women
- if visitors are allowed, limiting the time they can stay in the room and asking them to stay 2–3 metres away from you
- measuring your radiation levels with an instrument called a Geiger counter – this is usually done daily
- wearing gloves to clean up body fluids (e.g. urine, sweat, saliva and blood), and leftover food and drink.

### At home

When you go home, you may have to continue following some safety measures for a few days.

Your medical team will discuss any safety measures with you before treatment. These precautions usually include:

- sleeping alone
- washing your clothing separately
- preparing your own food
- taking care with body fluids for a certain period of time
- sitting down to urinate and putting the lid down and flushing the toilet several times after use.

Following these safety measures may make you feel frightened and lonely. Discuss any concerns you have with your doctors, nurses or a counsellor. It's a good idea to take something to hospital to occupy your time, e.g. a book.

## After radioactive iodine treatment

You will have a full body radioisotope scan (see page 46) to detect if any thyroid cancer cells are left in the body. It is normal to see an area of RAI uptake on the scan, due to small amounts of healthy thyroid tissue remaining in your neck after surgery. The RAI will take several months to destroy this tissue. The scan may also show if cancer has spread to your lymph nodes or other areas of your body.

## Side effects of radioactive iodine treatment

Usually, being temporarily radioactive is the only major side effect of RAI treatment. You may also have a dry mouth, or have taste and smell changes for a few weeks after treatment. Some people will have ongoing problems with swelling and pain in their salivary glands. Other side effects, such as tiredness, are often caused by thyroid hormone withdrawal, but these side effects will improve when your thyroid hormone levels return to normal. In some cases, RAI can increase the risk of developing a second cancer. Talk to your doctor for more details.

### Managing side effects of RAI

- 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 medicine if the side effects continue.
- If you or your partner want to have a baby after RAI treatment, talk to your doctor. You may have to use barrier contraception such as condoms for six months or more (see pages 42–43).



## Targeted therapy

Targeted therapy drugs can get inside cancer cells and block certain enzymes that tell the cancer cells to grow. The most common type of targeted therapy drugs used for thyroid cancer are tyrosine kinase inhibitors (TKIs). These drugs block the function of a group of enzymes called tyrosine kinases, which tell cancer cells to grow, multiply and spread.

If you have advanced thyroid cancer that hasn't responded to radioactive iodine treatment you may be treated with a TKI called lenvatinib. This drug is given as a capsule, which you will take daily at home.

Other TKIs may be available on clinical trials (see page 23). Talk with your doctor about the latest developments and whether you are a suitable candidate.

## Side effects of targeted therapy

Ask your doctor what side effects you may experience and how long your treatment will last. Potential side effects of lenvatinib include diarrhoea, skin rash, bleeding and high blood pressure. In some people, lenvatinib can affect the way the heart and kidneys work. Lenvatinib can also cause a skin reaction on the palms and soles, causing tenderness, tingling and blisters.

It is important to discuss any side effects with your doctor immediately. If left untreated, some symptoms can become life-threatening. Your doctor will explain what to watch out for, and will monitor you throughout treatment.



For more information on treatments and managing side effects, read Cancer Council's *Understanding Surgery*, *Understanding Chemotherapy* and *Understanding Radiation Therapy* booklets.

## External beam radiation therapy

External beam radiation therapy (also known as radiotherapy) is the use of high-energy x-rays or electron beams to kill or damage cancer cells. Radiation is delivered precisely to the affected area, which reduces treatment time and side effects.

Most people diagnosed with thyroid cancer do not need external beam radiation therapy. In a small number of cases, it may be given in the following circumstances:

- after surgery and radioactive iodine treatment if the cancer has not been completely removed or if there is a high risk of the cancer coming back (recurrence)
- as palliative treatment to relieve symptoms if the cancer has spread to nearby tissue or structures
- to help control medullary or anaplastic thyroid cancer because these types do not respond to RAI (see page 32).

### Planning session

Before the treatment starts, you will have a planning session. The radiation therapist will take CT scans to determine the exact 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 plastic mask to wear during treatment. This will help you stay still so that the radiation is targeted at the same area of your neck during each session. You can see and breathe through the mask, but it may feel strange and uncomfortable at first. The radiation therapy team can help you manage this.

## Having treatment

Radiation therapy is usually given five days a week over several weeks. Treatment sessions usually take about 10 minutes, but it will take longer to position the machine correctly.

## Side effects of external beam radiation therapy

Many people will develop temporary side effects during treatment. Common side effects include feeling tired, difficulty swallowing, sore throat, dry mouth, and red, dry, itchy, sore or ulcerated skin. Most of these will disappear within a few weeks or months. Your treatment team can help you prevent or manage any side effects.

## Chemotherapy

Chemotherapy is the use of drugs to kill or slow the growth of cancer cells. While chemotherapy is not often used to treat thyroid cancer, it may sometimes be used to treat advanced thyroid cancer that is not responding to radioactive iodine treatment. It may also be used to treat anaplastic thyroid cancer.

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



## Side effects of chemotherapy

The side effects of chemotherapy vary greatly for each person depending on the drugs that are used. Common side effects include fatigue, nausea, appetite loss, diarrhoea, hair loss, mouth sores and anaemia. You may also be more likely to catch infections.

Most side effects are temporary and your doctor will talk to you about ways to prevent or reduce them. You could be prescribed medicines to treat the side effects, be given a different type of drug, or your doctor may recommend a break from treatment.

## Palliative treatment

Palliative treatment aims to relieve symptoms and improve people's quality of life without trying to cure the disease. It may be beneficial for people at any stage of advanced thyroid cancer.

The treatment you are offered will be tailored to your individual needs. It may include radiation therapy, chemotherapy, targeted therapy or other medicines.

For more information or free copies of *Understanding Palliative Care* and *Living with Advanced Cancer*, call Cancer Council 13 11 20 or visit your local Cancer Council website.

Most people with thyroid cancer respond well to treatment and do not need to access palliative care services.





## Key points

- Surgery is the most common and effective treatment for thyroid cancer.
- There are different types of surgery for thyroid cancer. The operation you have depends on where the cancer is located, the type and size of the cancer, and whether it has spread to nearby lymph nodes.
- You may have a partial thyroidectomy or your whole thyroid gland may be removed (total thyroidectomy).
- Nearby lymph nodes may also be removed (neck dissection).
- After a total thyroidectomy, you will need to take thyroid hormone replacement medicine for the rest of your life.
- Your doctor may recommend radioactive iodine (RAI) treatment after surgery to kill any remaining thyroid tissue or cancer cells.
- RAI treatment is taken as a capsule. You will need to stay in hospital for 2–3 days in an isolated room to safely contain the radioactivity.
- You will need to prepare for RAI treatment by limiting foods high in iodine and increasing the level of TSH in your body.
- Targeted therapy (tyrosine kinase inhibitors) may be used if the cancer no longer responds to RAI treatment.
- Radiation therapy may be used as an additional treatment after surgery and RAI.
- Chemotherapy may sometimes be used to treat advanced thyroid cancer that has not responded to RAI treatment.
- Chemotherapy may be used in combination with radiation therapy to treat anaplastic thyroid cancer.



# Looking after yourself

Cancer can cause physical and emotional strain. It's important to try to look after your wellbeing as much as possible.

**Nutrition** – Eating healthy food can help you cope with treatment and side effects. A dietitian can help you manage special dietary needs or eating problems, and choose the best foods for your situation. Call Cancer Council 13 11 20 for a free copy of the *Nutrition and Cancer* booklet, or download a digital version from your local Cancer Council website.

**Staying active** – Physical activity may help to reduce tiredness, improve circulation and elevate mood. The amount and type of exercise you do depends on what you are used to, how you feel, and your doctor's advice. Cancer Council's *Exercise for People Living with Cancer* booklet provides more information about the benefits of exercise, and outlines simple exercises that you may want to try.

**Complementary therapies** – These therapies are used with conventional medical treatments. You may have therapies such as massage, relaxation and acupuncture to increase your sense of control, decrease stress and anxiety, and improve your mood. Let your doctor know about any therapies you are using or thinking about trying, as some may not be safe or evidence-based.

Alternative therapies are used instead of conventional medical treatments. These therapies, such as coffee enemas and magnet therapy, can be harmful. For more information, call 13 11 20 for a free copy of the *Understanding Complementary Therapies* booklet or visit your local Cancer Council website.



Call **13 11 20** for free copies of *Sexuality, Intimacy and Cancer* and *Emotions and Cancer*, or download the booklets from the website.

## Sexuality, intimacy and fertility

Cancer can affect your sexuality in physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, your self-confidence, and if you have a partner. Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

### Contraception and fertility

Depending on the type of cancer and treatment you have, and your sexual preferences, if you are able to have sex 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. Your doctor will talk to you about the precautions to take.

Your doctors will also tell you if treatment is likely to affect your fertility permanently or temporarily. If having children is important to you, talk to your doctor before starting treatment.

**Special concerns for men** – RAI treatment may affect sperm production, and men should ensure they use contraception for 3–6 months after treatment.

**Special concerns for women** – After RAI treatment, it is generally recommended that women:

- don't conceive a child for six months since the ovaries are exposed to radiation after the treatment
- ensure that thyroid hormone levels are normal and stable before trying to get pregnant.

## Body image

Cancer treatments, such as surgery, chemotherapy and radiation therapy, can cause changes to your body. Whether these changes are temporary or permanent, they can change the way you feel about yourself (your self-esteem) and make you feel self-conscious. You may feel less confident about who you are and what you can do. Give yourself time to adapt to any changes.

It's common to have a scar after thyroidectomy surgery, but this usually fades with time (see page 29). In most cases your doctor will do everything possible to make the scar less noticeable.

Look Good Feel Better is a national program that helps men, women and teenagers manage the appearance-related effects of cancer treatment. For information about services in your area, visit [lgfb.org.au](http://lgfb.org.au) or call 1800 650 960.

●● 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

For most people, the cancer experience doesn't end on the last day of treatment. Life after cancer treatment can present its own challenges. You may have mixed feelings when treatment ends, and worry if every ache and pain means the cancer is coming back.

Some people say that they feel pressure to return to “normal life,” but they don't want life to return to how it was before cancer. Take some time to adjust to the physical and emotional changes, and re-establish a new daily routine at your own pace.

Cancer Council 13 11 20 can help you connect with other people who have had cancer, and provide you with information about the emotional and practical aspects of living well after cancer.

### Dealing with feelings of sadness

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 medicine – 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.

The organisation [beyondblue](http://beyondblue.org.au) has information about coping with depression and anxiety. Go to [beyondblue.org.au](http://beyondblue.org.au) or call their support service on **1300 22 4636**.

## Follow-up appointments

After your treatment, you will need regular check-ups to confirm that the cancer hasn't come back and to manage any long-term side effects of treatment. How often you will need to see your doctor will depend on the type of cancer and which treatments you had. You may have the following tests:

**Blood tests** – If you have been treated for papillary or follicular thyroid cancer, you will have blood tests to check the levels of thyroglobulin (Tg). This protein is made by normal thyroid tissue and it may also be made by papillary or follicular thyroid cancer cells. After a total thyroidectomy you should have little or no Tg in your body, but levels will rise if the cancer comes back. If Tg is found in your blood, your doctor may suggest having some scans (see pages 15–16). A small number of people have Tg antibodies. This causes no harm but makes it hard to accurately measure Tg. The antibodies tend to fade after RAI treatment.

For medullary thyroid cancer, blood levels of calcitonin and carcinoembryonic antigen (CEA), which is a protein produced by some cancer cells, will be measured periodically.

Blood tests are also done regularly to check if you are on the right dose of thyroid hormone replacement. When it's stable, thyroid function blood tests are needed only every 6–12 months.

**Neck ultrasound** – An ultrasound is used to see if any cancer is left or has come back in the area where the thyroid was removed. It also checks for cancer in the lymph nodes around the neck.

**Radioisotope scan** – This test is used to check if there are any thyroid cancer cells remaining in your body after treatment. You may need to raise your TSH levels before the scan – for more details see the table opposite and talk to your doctor.

A small amount of radioactive dye (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, which takes a scan.

The camera measures the amount of radioactive dye taken up by any remaining thyroid tissue or other areas of disease. A radioisotope scan is painless and causes few side effects. After the scan, you will not be radioactive and it is safe to be with others.

If your doctor needs more information, or if cancer cells are found elsewhere in your body, you may also need a CT or PET scan.

### **Before follow-up tests**

Usually the Tg blood test (see page 45) is done while you are taking thyroid hormone replacement medicines. Sometimes the doctor may want to measure a stimulated Tg. This is done after you have stopped taking thyroid hormone medicines for a period of time to raise the TSH level as this is the time when Tg is most accurate. For more details see the table opposite or talk to your doctor.

Newly developed Tg tests are more sensitive. Most people will not need to withdraw from thyroid hormone replacement medicines.



## Ways to raise TSH levels for accurate test results

Your doctor will give you instructions about how to prepare for your blood test or radioisotope scan.

### Option 1 Stop taking thyroid hormone replacement medicines

- Prepare to stop taking your T4 hormone replacement medicine about 2–6 weeks before your follow-up appointment.
- Once you stop, your thyroid hormone levels will decrease and you may experience symptoms of hypothyroidism (see page 8).
- Some people find it difficult to cope with this, while others don't notice any side effects.
- These symptoms can be improved by taking T3 hormone replacement instead of T4.
- You can take T3 until 10–14 days before the scan. After this time, all thyroid hormone replacement therapy is stopped.

### Option 2 Have rhTSH (Thyrogen) injections

- rhTSH is a synthetic drug that is a copy of the TSH produced by your body.
- 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 medicine.
- rhTSH has few side effects, but some people experience headaches, nausea or weakness for a short time. Talk to your doctor for more information.



# Seeking support

Cancer may cause you to experience a range of emotions, such as fear, sadness, anxiety, anger or frustration. It can also cause practical and financial problems.

## Practical and financial help

There are many services that can help deal with practical or financial problems caused by the cancer. Benefits, pensions and programs can help pay for prescription medicines, transport costs or utility bills. Home care services, aids and appliances can also be arranged to help make life easier.

Ask the hospital social worker which services are available in your local area and if you are eligible to receive them.

If you need legal or financial advice, you should talk to a qualified professional about your situation. Cancer Council offers free legal and financial services in some states and territories for people who can't afford to pay – call 13 11 20 to ask if you are eligible.

## 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.

People often feel they can speak openly and share tips with others who have gone through a similar experience.

In a support setting, you may find that you are comfortable talking about your diagnosis and treatment, relationships with friends and family, and hopes and fears for the future. Some people say they can be even more open and honest because they aren't trying to protect their loved ones.

## Types of support

There are many ways to connect with others for mutual support and to share information. These include:

- **face-to-face support groups** – often held in community centres or hospitals
- **telephone support groups** – facilitated by trained counsellors
- **peer support programs** – match you with someone who has had a similar cancer experience, e.g. Cancer Connect
- **online forums** – such as Cancer Council Online Community at [cancercouncil.com.au/OC](http://cancercouncil.com.au/OC).

Talk to your nurse, social worker or Cancer Council 13 11 20 about what is available in your area.

“ My family members don't really understand what it's like to have cancer thrown at you, but in my support group, I don't feel like I have to explain. ” *Sam*



# 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 programs can offer valuable opportunities to share experiences and ways of coping. Cancer Council offers support for carers through Cancer Council Online Community ([cancercouncil.com.au/OC](http://cancercouncil.com.au/OC)).

Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local support services, as well as practical information and resources, through the Carer Gateway. Visit [carergateway.gov.au](http://carergateway.gov.au) or call 1800 422 737.

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. Visit [carersaustralia.com.au](http://carersaustralia.com.au) or phone 1800 242 636 for more information and resources.

Call Cancer Council 13 11 20 to find out more about carers' services and support groups in your area. You can also ask for a copy of the *Caring for Someone with Cancer* booklet, or download a digital copy from your local Cancer Council website.



# Useful websites

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

## Australian

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Cancer Council Australia.....	<b>cancer.org.au</b>
Cancer Australia.....	<b>canceraustralia.gov.au</b>
Cancer Council Online Community.....	<b>cancercouncil.com.au/OC</b>
Carer Gateway.....	<b>carergateway.gov.au</b>
Carers Australia.....	<b>carersaustralia.com.au</b>
Department of Health.....	<b>health.gov.au</b>
healthdirect Australia.....	<b>healthdirect.gov.au</b>
beyondblue.....	<b>beyondblue.org.au</b>
Radiation Oncology: Targeting Cancer.....	<b>targetingcancer.com.au</b>
Australian and New Zealand Endocrine Surgeons.....	<b>endocrinesurgeons.org.au</b>
The Australian Thyroid Foundation Ltd.....	<b>thyroidfoundation.org.au</b>

## International

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American Cancer Society.....	<b>cancer.org</b>
Macmillan Cancer Support.....	<b>macmillan.org.uk</b>
National Cancer Institute (US).....	<b>cancer.gov</b>
American Thyroid Association.....	<b>thyroid.org</b>
British Thyroid Association.....	<b>british-thyroid-association.org</b>
ThyCa: Thyroid Cancer Survivors' Association.....	<b>thyca.org</b>
Thyroid Federation International.....	<b>thyroid-fed.org</b>
Thyroid Awareness.....	<b>thyroidawareness.com</b>



## 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?
- Will the treatment cause any pain?
- How will the pain be managed?
- Will the treatment affect my sex life and fertility?
- Are the latest tests and treatments for thyroid 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 follow-up appointments?
- How will my thyroid hormone replacement medicine and hormone levels be monitored?
- Are there any complementary therapies that might help me? How will these interact with my thyroid hormone replacement medicine?
- Should I change my diet during or after treatment?
- If the thyroid cancer comes back, how will I know?
- What are my treatment options if the thyroid cancer comes back?



# Glossary

## **anaesthetic**

A drug that stops a person feeling pain during a medical procedure. Local and regional anaesthetics numb part of the body; a general anaesthetic causes a temporary loss of consciousness.

## **benign**

Not cancerous or malignant.

## **biopsy**

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

## **calcitonin**

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

## **chemotherapy**

A cancer treatment that uses drugs to kill cancer cells or slow their growth. May be given alone or in combination with other treatments.

## **CT scan**

Computerised tomography scan. This scan uses x-rays to create a detailed, cross-sectional 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 produce and store the thyroid hormones T3 and T4, and make a protein called thyroglobulin (Tg).

## **Geiger counter**

An instrument used to measure radiation levels.

## **goitre**

An enlarged thyroid, usually benign.

## **hemithyroidectomy**

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

## **hormones**

Chemicals in the body that send information between cells to bring about changes in the body.

## **hyperthyroidism**

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

## **hypothalamus gland**

An endocrine gland in the brain that controls the release of hormones from the pituitary gland.

## **hypothyroidism**

A benign condition that occurs when the thyroid produces too few hormones. Also known as underactive thyroid.

## **I131**

See radioactive iodine.

## **intravenous**

Injected into a vein.

## **iodine**

An element that allows the thyroid gland to produce hormones. Iodine is found in foods such as seafood, iodised table salt, eggs and some breads.

## **isthmus**

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

### **lymphatic system**

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

### **lymph nodes**

Small, bean-shaped structures that collect and destroy bacteria and viruses. Also called lymph glands.

### **malignant**

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

### **metabolism**

The chemical process by which food is changed into energy in the body.

### **metastasis (plural: metastases)**

Cancer that has spread from a primary cancer in another part of the body. Also called secondary cancer.

### **multiple endocrine neoplasia (MEN)**

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

### **neck dissection**

Surgery to remove lymph nodes in one or both sides of the neck. Also called lymphadenectomy.

### **nodule**

A swelling or lump in the thyroid that may be cancerous or non-cancerous.

### **palliative treatment**

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

### **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 produce hormones that control the amount of calcium and phosphate in the blood.

### **PET scan**

Positron emission tomography scan. A scan in which a person is injected with a small amount of radioactive glucose solution to find cancerous areas.

### **pituitary gland**

A gland in the brain that produces hormones. These hormones control many of the body's functions, including growth and metabolism.

### **prognosis**

The predicted outcome of a person's disease.

### **radiation therapy**

The use of radiation, most commonly x-ray beams, to kill or damage cancer cells so they cannot grow, multiply or spread. Also known as radiotherapy.

### **radioactive iodine**

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

### **radioactive iodine (RAI) treatment**

A type of internal radiation therapy used to treat thyroid cancer.

### **rhTSH**

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



## staging

Performing tests to determine how far a cancer has spread.

## Thyrogen

A brand of synthetic thyroid-stimulating hormone. It is used to test for remaining or recurring cancer cells in people treated for thyroid cancer, or to prepare for radioactive iodine (RAI) treatment.

## thyroglobulin (Tg)

A protein made by both normal and cancerous thyroid cells. It can be measured in the bloodstream.

## 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 that prompts the thyroid gland to produce and release the hormones T3 and T4. The pituitary and hypothalamus glands produce TSH.

## thyroxine (T4)

One of the hormones produced by the thyroid gland that regulates the body's metabolism. T4 can be converted into a hormone called tri-iodothyronine (T3).

## trachea

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

## tri-iodothyronine (T3)

One of the hormones produced by the thyroid gland that regulates the body's metabolism.

## tumour

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

## tyrosine kinase inhibitor (TKI)

A small molecule inhibitor that blocks enzymes involved with cell growth. A targeted therapy drug.

### Can't find a word here?

For more cancer-related words, visit:

- [cancerCouncil.com.au/words](http://cancerCouncil.com.au/words)
- [cancervic.org.au/glossary](http://cancervic.org.au/glossary)
- [cancersa.org.au/glossary](http://cancersa.org.au/glossary)

## References

1. BR Haugen et al., "2015 American Thyroid Association management guidelines for adult patients with thyroid nodules and differentiated thyroid cancer", *Thyroid*, vol. 26, no. 1, 2016, pp. 1–133.
2. P Perros et al., "British Thyroid Association guidelines for the management of thyroid cancer", *Clinical Endocrinology*, vol. 81, suppl. 1, 2014, pp. 1–122.
3. Australian Institute of Health and Welfare (AIHW), *Australian Cancer Incidence and Mortality (ACIM) books: Thyroid cancer*, AIHW, Canberra, December 2017.
4. Australian Institute of Health and Welfare (AIHW), *Cancer in Australia 2017*, AIHW, Canberra, 2017.



# 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 other Pink events, 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

## 13 11 20

Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn't just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

When disruption and change happen in our lives, talking to someone who understands can make a big difference. Cancer Council has been providing information and support to people affected by cancer for over 50 years.

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our cancer nurses are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

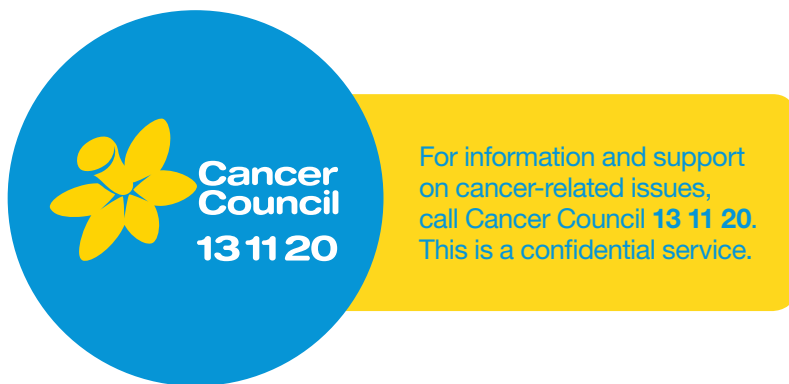
Cancer Council services and programs vary in each area.

13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



**If you need information in a language other than English, an interpreting service is available. Call 13 14 50.**

**If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. [www.relayservice.gov.au](http://www.relayservice.gov.au)**



## Visit your local Cancer Council website

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actcancer.org

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