



Understanding Thyroid Cancer

A guide for people with cancer,
their families and friends

Cancer
information

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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 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 guidelines¹ for thyroid cancer.

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.



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What is cancer?

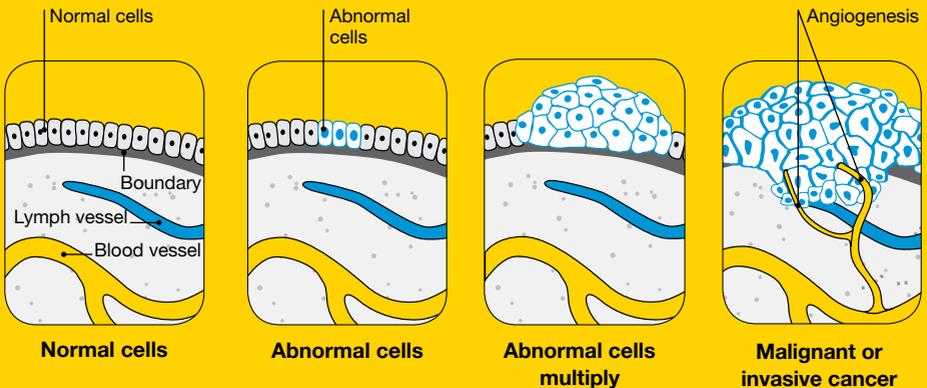
Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

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

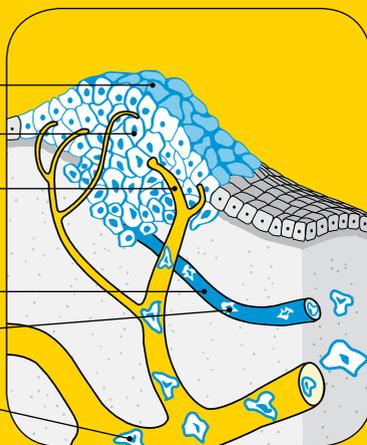
Primary cancer

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) 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 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, blood pressure, body temperature and weight – this is known as your metabolic rate.

How the thyroid gland works

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.

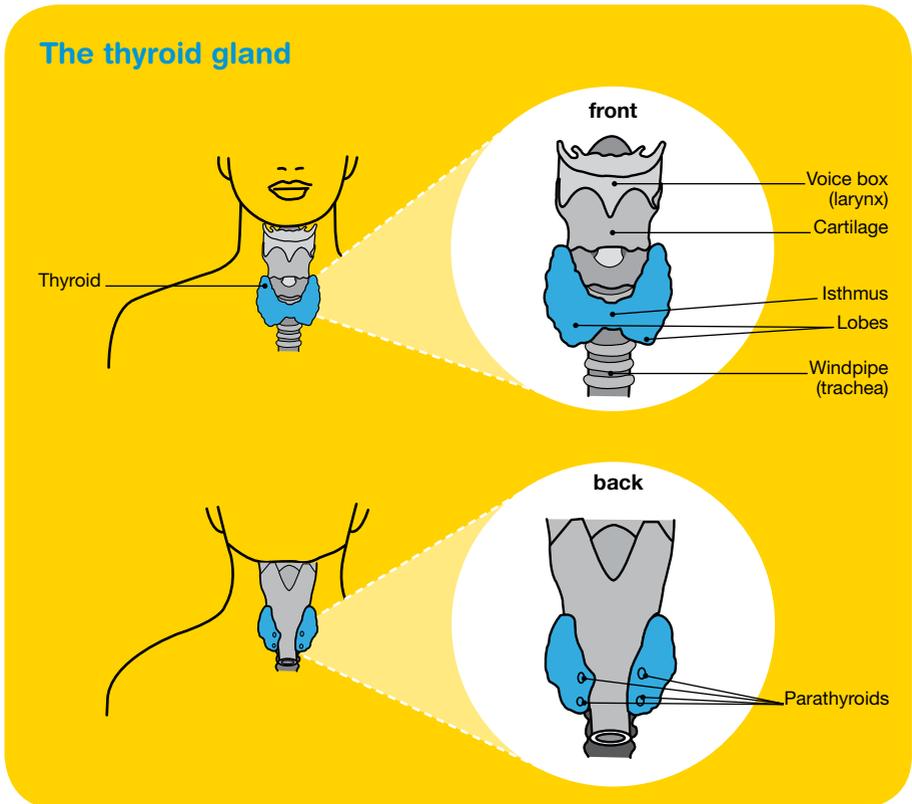
Calcitonin – This hormone has a small role in controlling the body's calcium levels.

The thyroid gland needs iodine – found in foods such as seafood, iodised table salt, some dairy products, soy beans and soy-containing products, and eggs – 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 four parathyroid glands. These glands produce a hormone called parathyroid hormone or 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 thyroid hormone.

The pituitary gland, located at the base of the brain, controls the release of thyroid hormone from the thyroid gland.

If thyroid hormone (T3 and T4) levels drop below normal, the pituitary gland produces a hormone called thyroid-stimulating hormone (TSH) to prompt the thyroid gland to make and release more T3 and T4. Too much T3 and T4 lowers, or suppresses TSH production by the pituitary gland.

Changes in thyroid hormone levels can affect how your cells respond (metabolism):

Underactive thyroid (hypothyroidism) – When there is not enough thyroid hormone, your metabolism slows down. You may feel tired or depressed, and gain weight easily.

Overactive thyroid (hyperthyroidism) – When there is too much thyroid hormone, your metabolism speeds up. You may lose weight, have an increased appetite, feel shaky and anxious, or have rapid, strong heartbeats (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 a disorderly (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">• most common type (about 70–80% of all cases)• develops from the follicular cells• tends to grow slowly
	follicular	<ul style="list-style-type: none">• about 20% of thyroid cancer cases• develops from the follicular cells• includes Hürthle cell carcinoma, a less common subtype
Rare	medullary	<ul style="list-style-type: none">• about 4% of all thyroid cancers• develops from the parafollicular cells (C-cells)• can run in families
	anaplastic	<ul style="list-style-type: none">• a rare thyroid cancer (1% of cases)• may develop from papillary or follicular thyroid cancer• usually grows quickly, and affects people over 60

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
 - trouble swallowing
 - difficulty breathing
 - a hoarse voice
 - swollen lymph glands in the neck, which may slowly grow in size over months or years.

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 9 out of 10 cases, a thyroid nodule is a symptom of a goitre (a benign enlarged thyroid gland) or another condition affecting the head or neck.

When to see a doctor

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

The earlier a cancer is picked up, the easier it is to treat and the more successful treatment is likely to be.



Having an underactive or overactive thyroid (hypothyroidism or hyperthyroidism) is not typically a sign 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 radiotherapy to the head and neck area 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.

Family history

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

Having a first-degree relative (parent, child or sibling) with papillary thyroid cancer may also increase your risk.

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

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

Q: How common is thyroid cancer?

A: About 2100 people are diagnosed with thyroid cancer each year in Australia. Thyroid cancer occurs three times more often in women than men – it is the seventh most common cancer affecting Australian women.²

The average age of a woman diagnosed with thyroid cancer is 51; the average age for a man to be diagnosed with thyroid cancer is 54.

Thyroid cancer cases have increased in recent years. Between 1982 and 2014, cases of thyroid cancer increased by 281%.² Researchers are trying to determine the cause of this increase. One contributing factor is improved imaging quality that can detect smaller cancers during ultrasounds and other scans performed of the area for other reasons.



Key points

- The thyroid gland is at the front of the neck below the voice box (larynx). It produces hormones that help control the body's heart rate, blood pressure, body temperature and weight.
- These hormones are called thyroxine (T4), tri-iodothyronine (T3) and calcitonin.
- 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 people diagnosed 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 most cases, a thyroid nodule is a symptom of a goitre. This is when the thyroid becomes enlarged, and it is a benign condition (not cancer).
- An underactive thyroid (hypothyroidism) or overactive thyroid (hyperthyroidism) isn't usually a sign of thyroid cancer.
- The exact cause of thyroid cancer is unknown, but exposure to radiation either in the environment or due to radiation in childhood, or family history may increase the chance of developing thyroid cancer.
- About 2100 people are diagnosed with thyroid cancer each year in Australia. It's three times more common in women than men.



Diagnosis

If you have thyroid nodules, your doctor will suggest you have one or more of the following tests to work out whether the nodules could be cancer and whether you need treatment. It's unlikely you will have all of the tests described in this chapter. Some of these tests can also show whether the cancer has spread to other parts of your body.

Blood test

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

Ultrasound

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

The doctor will also check if the nodule has characteristics that suggest 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 in your neck or sees one during an ultrasound, they may suggest a fine needle aspiration (FNA) biopsy.

During a FNA biopsy, a thin needle is inserted into the nodule and a very small tissue sample is taken from the nodule for examination under a microscope. You may be given local anaesthesia (pain relief) to numb the area. Sometimes an ultrasound is used to guide the needle to the right spot. If not enough cells are removed the first time, the process may be repeated.

If it's not possible to determine the characteristics of the nodule with a FNA, the doctor may remove part of the thyroid (hemi-thyroidectomy) to help confirm the diagnosis (see page 25). If thyroid cancer is found after a hemi-thyroidectomy, you may need further surgery to remove the rest of your thyroid and possibly some lymph nodes in the neck. This will depend on the size and type of cancer, and if 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*

Further scans

The following scans are sometimes used to see if the cancer has spread to other parts of your body. This process is called staging, and it will help your doctors to decide on the best treatment for you. See page 18 for more details about the stages of thyroid cancer.

A CT scan and/or PET scan may also be repeated after surgery, such as a thyroidectomy (see page 25), to check your health and how well the treatment is working.

CT scan

A CT (computerised tomography) scan uses x-ray beams to create a detailed three-dimensional picture of the inside of the body.

In most cases, the ultrasound gives enough information before thyroid surgery, but you may need a CT scan if your thyroid is very enlarged, if it is extending well into the chest, or if there is concern that cancer has spread to other areas in the neck.

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



The dye used in a CT scan usually contains iodine. If you know you're allergic to iodine or dyes, let the person performing the scan know in advance. You should also tell the doctor if you're diabetic, have kidney disease or are pregnant.

The CT scanner is a large, doughnut-shaped machine. You will lie on a table that moves in and out of the scanner, and you may be asked to hold your breath for a few seconds during the scan. While it may take 30–60 minutes to prepare for the scan, especially if using a dye, the scan takes a few minutes. A CT scan can be noisy, but it is painless. Most people can go home as soon as the scan is over.

Some people feel afraid of confined spaces (claustrophobic). Let your health care team know if you are uncomfortable or claustrophobic during the scan. They may help you relax by allowing you to use headphones to listen to music, wear an eye mask or take a mild sedative.

PET scan

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

Before the PET scan, you will be asked not to eat or drink for a period of time (fast). During 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, then you will be scanned to create pictures of radioactive areas in the body. While it may take several hours to prepare for the test, the scan itself takes only about 30 minutes.

Staging thyroid cancer

The tests described on pages 14–17 help your doctors 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. Knowing the stage helps doctors recommend the best treatment for you. It is often not possible to completely stage the cancer until after surgery.

There are different ways of staging cancers; however, most cancers follow a general international staging system known as TNM (tumour, nodes, metastasis). 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.

TNM system

T (Tumour)	indicates the size of the tumour – there are four main T stages for thyroid cancer. T1 is the smallest and T4 is the largest
N (Nodes)	indicates whether the cancer has spread to the lymph nodes. There are two main N groups – either the cancer has not spread to the lymph nodes (N0) or it has spread to the nodes (N1)
M (Metastasis)	indicates whether the cancer has spread to other parts of the body, such as the lungs or the bones (metastatic or secondary cancer)

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 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 rate of tumour growth
- 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.

“ 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*

Five-year survival rate

Most research studies monitor patients up to five years after treatment, so doctors commonly use five-year survival rates as a way to discuss prognosis.

This statistic estimates 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 the highest five-year survival rate of all cancers (96%).²

Women diagnosed with thyroid cancer generally have a slightly better prognosis than men (97% five-year survival rate).

Younger people also tend to 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, who will organise more tests and advise you about treatment options. This can be a worrying and tiring time, especially if you need several tests.

You will probably be cared for by a range of health professionals who specialise in different aspects of your treatment. This multidisciplinary team (MDT) will depend on the stage of the cancer. A list of people who make up this team is opposite.

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 and nurse care coordinators	support patients and families throughout treatment and liaise with other staff

Additional health professionals you may see

radiation oncologist	prescribes and coordinates the course of radiotherapy
medical oncologist	prescribes and coordinates the course of chemotherapy
counsellor, social worker	provide emotional support and link you to support services
dietitian	recommends an eating plan to follow during treatment and recovery



Key points

- Different types of tests are used to diagnose or check for thyroid cancer, but the diagnosis is usually made by a fine needle aspiration (FNA) biopsy.
- During a FNA biopsy a small amount of tissue 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.
- 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 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 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 a list of suggested questions. 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.



Treatment

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

Surgery

Surgery is the most common treatment for thyroid cancer. There are two main types of thyroid surgery. In some cases, lymph nodes may also need to be removed.

Total thyroidectomy – The whole thyroid gland (both lobes), including the isthmus, is removed. You will be given a general anaesthetic and a small cut will be made across your neck.

Partial or hemi-thyroidectomy – Only the affected lobe or section of the thyroid is removed. Sometimes this surgery is also used to diagnose thyroid cancer if a fine needle aspiration biopsy doesn't provide enough tissue, or to treat small cancers if the other side of the thyroid looks normal on the ultrasound.

Lymph node removal – With either type of operation, nearby lymph nodes may be removed at the same time as the surgery. This is called a neck dissection. It is performed if the lymph nodes become enlarged from the cancer spreading. 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 (for example, the thymus gland and vascular tissues) near the thyroid that has been affected by the 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.

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 caring for your surgical wound site. Your surgeon may order blood tests during this period to check on your recovery. See the table on pages 28–29 for tips on managing side effects.

Further treatment after surgery

For some people, surgery is the only treatment they need. Others may require further treatment. This may include:

- **thyroid hormone replacement therapy** – after a total thyroidectomy, medicine is needed to replace the function of the thyroid. See page 30.
- **radioactive iodine treatment** – may be used to destroy any normal thyroid cells and any cancerous tissue left behind after surgery. It usually starts 4–5 weeks or more after surgery to allow your surgical wound time to heal. See page 32.
- **external radiotherapy** – usually not required. See page 36.
- **chemotherapy** – usually not required. See page 38.



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.

Two months after the surgery, I started radioactive iodine. I was put on thyroxine to get my hormones stable and then did the radioactive iodine. I was in hospital for two nights while I was radioactive, and then for two weeks 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.

Managing the side effects of thyroid surgery



Sore neck

You will probably feel some pain or discomfort where the cut 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 medicine.



Painful swallowing

You will find it painful to swallow for a few days. In some cases, you may be referred to a speech pathologist and/or dietitian.



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 swallow gently, and eat small amounts of healthy, nutritious food.

For more information, call Cancer Council 13 11 20 for a free copy of *Nutrition and Cancer*.



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.



Scarring

You will have a horizontal scar on your neck above your collarbone. In most cases, the scar is about 5–7cm 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.



Low calcium levels

If surgery affected the parathyroid glands, you will have low blood calcium levels (hypocalcaemia). This may cause headaches and 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. If the parathyroid glands don't recover, calcium supplements need to be taken permanently.



Feeling tired

Most people return to their usual activities within days of the surgery, but some people need more time to recover.

Thyroid hormone replacement therapy

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 need to take this hormone replacement tablet every day for the rest of your life.

For many people who have a partial thyroidectomy, the remaining lobe will continue to make enough thyroid hormone, which means they won't need daily tablets.

Taking thyroid hormone tablets can have two roles:

Keeping your body's metabolism functioning at a normal healthy rate – Without hormone replacement medication, you will probably develop the symptoms of hypothyroidism, such as weight gain, constipation, brittle and dry hair and skin, depression, sluggishness and fatigue. In severe cases, heart problems could occur.

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 cancer cells to grow in other parts of the body. 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 taking 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 water only 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.
- Don't stop taking the T4 medicine without discussing it with your doctor.
- Tell your doctor if you are pregnant as you may need to take a higher dose.

Radioactive iodine treatment

Radioactive iodine (RAI) is a type of radioisotope treatment. Radioisotopes are radioactive substances given as capsules. Cancer cells absorb more radioisotope than normal cells, which causes the cancer cells to die. Radioactive iodine is also known as I131 or radioactive iodine ablation treatment. RAI is usually given to destroy tiny amounts of remaining cancer cells or healthy thyroid tissue left behind 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.



If you are pregnant, you can't have radioactive iodine treatment. If you are breastfeeding, you will have to stop nursing before starting treatment. 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, some dairy products, eggs, soy beans or soy-containing products and foods with E127 colouring. Your health care team can give you more information.

Raising TSH levels – For RAI treatment to work, you need a high level of TSH. There are two ways to increase the TSH level in your body, and the option recommended for you will depend on availability at your hospital and what is suitable for you.

- **Recombinant human thyroid-stimulating hormone (rhTSH) injections** – You will be prescribed an injection of a man-made type of thyroid-stimulating hormone called recombinant human thyroid-stimulating hormone (rhTSH) or Thyrogen®. You will need an injection once a day for the two days before you start RAI treatment.
- **Thyroid hormone replacement** – You stop taking your thyroid hormone replacement medicine for a few weeks. This often causes the side effects of hypothyroidism, and some people find it difficult to cope with this, while others don't notice any side effects. For more details about stopping thyroid hormone replacement, see page 47 and talk to your endocrinologist.

Having radioactive iodine treatment

You will usually be admitted to hospital on the day of the radioactive iodine treatment. 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. 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 are taking Thyrogen®, this is usually within 36–48 hours.

After radioactive iodine treatment

You will have a full body radioisotope scan (see pages 45–46). There is often a small amount of normal thyroid in your neck after surgery, which will be destroyed by the RAI. The scan can also help detect if any cancer cells are left in the body. It may also show if the cancer has spread to your lymph nodes or other areas of your body, such as your lungs or bones.

Safety measures in hospital

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

The safety measures vary for 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
- restricting visitors to the room – particularly children and pregnant women
- asking 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
- wearing gloves to clean up body fluids (e.g. urine, sweat, saliva and blood) and leftover food and drink.

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

Safety measures 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. It's usually required that you sit to urinate, and you put the lid down and flush the toilet several times after use.

If these precautions are necessary, your medical team will discuss them 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 make you feel thirsty, tired, nauseated or breathless. You may also have a dry mouth, or have taste and smell changes for about 24 hours after treatment.



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 for further details.

External radiotherapy

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

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

- after surgery
- in addition to radioactive iodine treatment if the cancer has not been completely removed
- if there is a high risk of the cancer coming back (recurrence)
- if the cancer has spread to nearby tissue or structures.

External radiotherapy is commonly used to treat anaplastic thyroid cancer because radioactive iodine treatment is usually not effective.

Planning treatment

Before the treatment starts, you will have a planning (simulation) 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 mask to wear during treatment. This will help make sure that you keep still and the radiation beams treat the same area of your neck at each session. You can see and breathe through the mask, but you may feel strange and uncomfortable at first. The radiotherapy team can help you manage this.

Having treatment

Radiotherapy 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

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.

For ways to reduce or manage any side effects you experience, talk to your doctor and nurses or call Cancer Council 13 11 20 for a free copy of *Understanding Radiotherapy*.

Targeted therapies

Some newer types of drug treatments, called targeted therapies, attack specific cancer cells or blood vessels to stop or slow down growth or reduce the size of the tumour. Targeted therapies may be recommended for people with advanced thyroid cancer or as part of a clinical trial.

The most common type of targeted therapies used are tyrosine kinase inhibitors (TKIs). These block the signals that tell cancer cells to grow and divide, and are used to treat certain types of thyroid cancer. Some research shows that tyrosine kinase inhibitors help by targeting new blood vessels or certain mutations.

The drug sorafenib is used for papillary thyroid cancers. Vandetanib and cabozantinib are used to treat some medullary thyroid cancers. 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.

Chemotherapy

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

The drugs are usually given intravenously (injection into a vein). 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 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. You could be prescribed

medicines to treat the side effects, or a different type of treatment, or your doctor may recommend a break from treatment.

For more information about chemotherapy and its side effects, call Cancer Council 13 11 20 for a free copy of *Understanding Chemotherapy*. You can also download a digital version from your local Cancer Council website.

Palliative treatment

Palliative treatment helps improve people's quality of life by alleviating symptoms of cancer, when it's not possible to cure the disease. It is particularly important for people with advanced cancer, however, it can be used at any stage of cancer.

Often palliative 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 medicine.

For more information on palliative treatment or advanced cancer, call Cancer Council for free copies of *Understanding Palliative Care* or *Living with Advanced Cancer*, or download digital versions from your local Cancer Council website.

Most people with thyroid cancer do not need to access palliative care services because five-year survival rates are high.





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 in the thyroid, the type and size of the cancer and whether it has spread to nearby lymph nodes.
- You may have a total thyroidectomy (whole thyroid gland removed) or partial or hemi-thyroidectomy (part of the thyroid only). The nearby lymph nodes may also be removed (neck dissection).
- After a total thyroidectomy, you may 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 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 may prepare for RAI treatment by taking a hormone known as rhTSH or Thyrogen®. If this is unavailable, you may need to stop taking thyroid hormone replacement medicine for a few weeks before having RAI treatment.
- External radiotherapy may be given to some people who have cancer in several lymph nodes in the neck, for locally advanced or thyroid cancer that can't be removed by surgery, or to target cancer that has spread to the bones.
- Targeted therapies (tyrosine kinase inhibitors) or chemotherapy may be used if the cancer no longer responds to RAI.



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.

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.

If you are able to have sex, you may be advised to use certain types of contraception to protect your partner or avoid pregnancy for a certain period of time. Your doctor will talk to you about the precautions to take. They 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.



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

Contraception and fertility

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.

Special concerns for women

After RAI treatment, it is generally recommended not to conceive a child for six months since the ovaries are exposed to radiation after the treatment, and to ensure that thyroid hormone levels are normal and stable prior to pregnancy.

Special concerns for men

Men who have RAI treatment may experience temporary infertility. If having children is important to you, talk to your doctor before you start treatment. Ask your doctors what precautions to take and discuss any fertility issues, especially if you want to have children in the future.

Body image

Cancer treatments, such as surgery, chemotherapy and radiotherapy, 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.

It's common to have a scar after thyroidectomy surgery, but this usually fades with time.

“ 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, specialist or nurse 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. Your local Cancer Council may also run a counselling program.

The organisation [beyondblue](http://beyondblue.org.au) has information about coping with depression and anxiety.

Go to beyondblue.org.au or call **1300 22 4636** to order a fact sheet.

Follow-up after treatment

After your treatment, you will need regular check-ups. You may have the following tests:

Neck ultrasound – An ultrasound is used to see if there is any cancer left in the area where the thyroid was removed and to check the lymph nodes around the neck.

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 16–17).

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.

Radioisotope scan – This test is used to check if there are any cancer cells remaining in your body after treatment. 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. 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 further information is needed, or if cancer cells are found elsewhere in your body, you may have a CT or PET scan.

Before follow-up tests

Usually Tg is measured when you are still on thyroid hormone replacement medication. Sometimes the doctor may want to measure stimulated Tg as the test can be more accurate when TSH is elevated.

To raise TSH to measure stimulated Tg you will need to either withdraw from thyroid hormone replacement medication or have injections of the drug recombinant human thyroid-stimulating hormone (rhTSH) or Thyrogen®.

Once your Tg is elevated, it will be measured. See the table opposite for more details.

Newer Tg tests are more sensitive, and in some cases it may not be necessary to withdraw from thyroid hormone.

●● 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*

Ways to increase accuracy of follow-up tests

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 appointment

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

Option 2

Take rhTSH (Thyrogen®) to reduce side effects of stopping T4

- rhTSH is a man-made drug that is a copy of 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 medication.
- rhTSH has few side effects, but some people experience temporary headaches, nausea or weakness. 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 in these support settings 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 cancerconnections.com.au.

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.

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 carersaustralia.com.au for more information and resources.

You can also call Cancer Council 13 11 20 to find out more about carers' services and to get a copy of the *Caring for Someone with Cancer* booklet, or download a digital version of the booklet 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

- Cancer Council Australia.....**cancer.org.au**
- Cancer Australia..... **canceraustralia.gov.au**
- Carers Australia.....**carersaustralia.com.au**
- Department of Health..... **health.gov.au**
- healthdirect Australia..... **healthdirect.gov.au**
- beyondblue..... **beyondblue.org.au**
- Australian and New Zealand
Endocrine Surgeons..... **endocrinesurgeons.org.au**
- The Australian Thyroid Foundation Ltd.....**thyroidfoundation.org.au**

International

- American Cancer Society.....**cancer.org**
- Macmillan Cancer Support..... **macmillan.org.uk**
- US National Cancer Institute..... **cancer.gov**
- American Thyroid Association..... **thyroid.org**
- British Thyroid Association.....**british-thyroid-association.org**
- ThyCa: Thyroid Cancer Survivors' Association..... **thyca.org**
- Thyroid Federation International **thyroid-fed.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?
- 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. A local anaesthetic numbs part of the body; a general anaesthetic causes a person to lose consciousness for a period of time.

benign

Not cancerous or malignant.

biopsy

The removal of a small 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.

cartilage

Firm, flexible connective tissue found in the thyroid gland and other parts of the body.

chemotherapy

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

CT scan

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

An instrument used to measure radiation levels.

goitre

An enlarged thyroid, usually benign.

hemi-thyroidectomy

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

Occurs when the thyroid makes too much thyroid hormone. Also known as overactive thyroid.

hypothalamus gland

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

hypothyroidism

Occurs when the thyroid does not make enough thyroid hormone. Also known as underactive thyroid.

I131

See radioactive iodine.

intravenous

Injected into a vein.

iodine

An element found in foods such as seafood, some dairy products, eggs and iodised salts. The thyroid gland takes up iodine to make thyroid hormones.

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 and transports fat, and produces immune cells.

lymph nodes

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

malignant

Cancer. Malignant cells can spread (metastasise) and eventually cause death if they can't 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 a primary cancer in another part of the body. Also known as secondary cancer.

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 swelling or lump on 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 symptoms of cancer.

Treatment may include radiotherapy, chemotherapy or other medicines. It is an important part of palliative care.

parafollicular cells (C-cells)

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

parathyroid glands

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

PET scan

A positron emission tomography scan. The person is injected with a small amount of radioactive glucose solution, and cancerous areas show up brighter in the scan because they take up more of the glucose.

pituitary gland

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

prognosis

The predicted outcome of a person's disease.

radioactive iodine

A 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 as a capsule called 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 made by normal thyroid cells and thyroid cancer 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 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 that 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 that 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 a word here?

For more cancer-related words, visit:

- cancerCouncil.com.au/words
- cancervic.org.au/glossary
- cancersa.org.au/glossary

References

1. F Pacini, MG Castagna, L Brilli and G Pentheroudakis on behalf of ESMO Guidelines Working Group, 'Thyroid cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up, *Annals of Oncology*, vol. 23 (suppl 7), 2012, vii110-vii119. doi: 10.1093/annonc/mds230
2. Australian Institute of Health and Welfare (AIHW), *Cancer in Australia: an overview 2014*, Cancer series No 90. Cat. No. CAN 88. Canberra, 2014.



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 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.

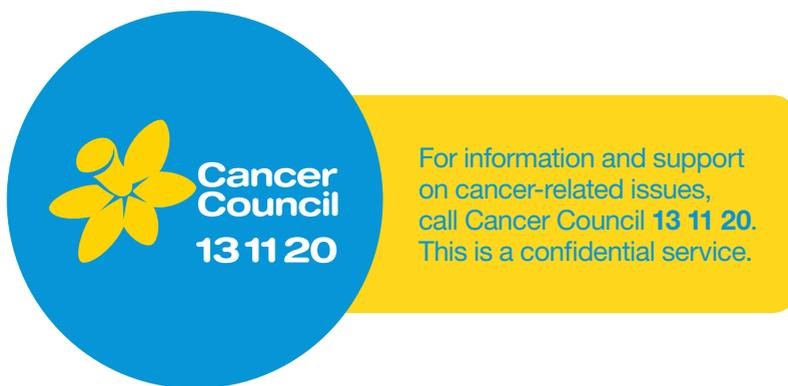
Cancer Council services and programs vary in each area.
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



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, contact us through the National Relay Service.
www.relayservice.gov.au



Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancertas.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

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To support Cancer Council, call your local Cancer Council or visit your local website.*