



Understanding Thyroid Cancer

A guide for people with cancer,
their families and friends

Cancer
information

For information & support, call

13 11 20



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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.



Cancer Council Australia

Level 14, 477 Pitt Street, Sydney NSW 2000

Telephone 02 8063 4100 **Facsimile** 02 8063 4101

Email info@cancer.org.au **Website** cancer.org.au

ABN 91 130 793 725

About this booklet

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. The booklet also includes information about support services.

We cannot give advice about the best treatment for you. You need to discuss this with your doctors. However, this information may answer some of your questions and help you think about what to ask your treatment team (see page 52 for a question checklist).

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 (see page 53). You may also like to pass this booklet to 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.¹⁻²

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. You can also visit your local Cancer Council website (see back cover).



**Cancer
Council
13 11 20**

Contents

What is cancer?	4
The thyroid	6
Key questions	9
What is thyroid cancer?.....	9
What are the risk factors?	10
What are the symptoms?	11
How common is thyroid cancer?	12
Which health professionals will I see?.....	12
Diagnosis	14
Blood test	14
Ultrasound	14
Biopsy	15
Additional scans	16
Staging thyroid cancer	18
Prognosis	19
Making treatment decisions	21
Treatment	23
Active surveillance.....	23
Surgery	24
Thyroid hormone replacement therapy	28
Radioactive iodine treatment	31
Targeted therapy.....	35

External beam radiation therapy	37
Chemotherapy.....	38
Palliative treatment.....	39
Looking after yourself	41
Life after treatment	43
Follow-up appointments	44
What if the cancer returns?	47
Seeking support	48
Support from Cancer Council	49
Useful websites	50
Caring for someone with cancer	51
Question checklist.....	52
Glossary	53
How you can help	56



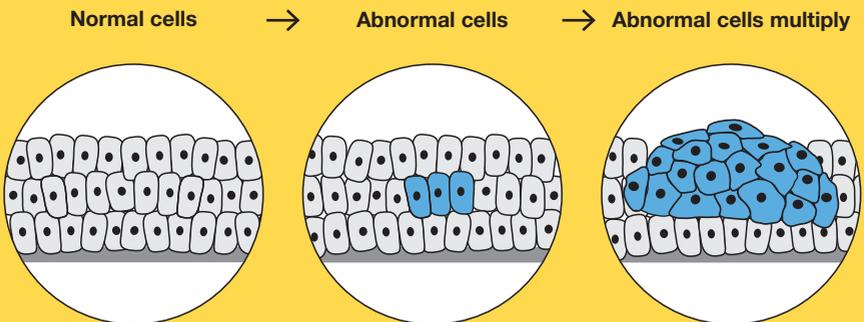
What is cancer?

Cancer is a disease of the cells. Cells are the body's basic building blocks – they make up tissues and organs. 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, so that each new cell replaces one lost. Sometimes, however, cells become abnormal and keep growing. In solid cancers, such as thyroid cancer, the abnormal cells form a mass or lump called a tumour. In some cancers, such as leukaemia, the abnormal cells build up in the blood.

Not all tumours are cancer. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into

How cancer starts

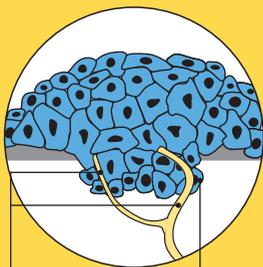


cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break away and travel through the bloodstream or lymph vessels to other parts of the body.

The cancer that first develops is called the primary cancer. It is considered localised cancer if it has not spread to other parts of the body. If the primary cancer 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 main symptoms may be coming from the lungs.

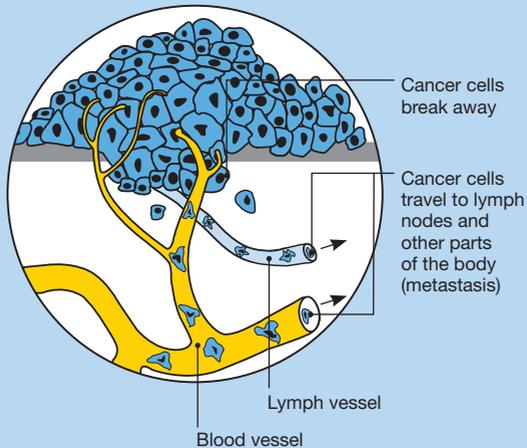
How cancer spreads

→ Malignant cancer



Grows own
blood vessels
(angiogenesis)

Invades
surrounding
tissue



Cancer cells
break away

Cancer cells
travel to lymph
nodes and
other parts of
the body
(metastasis)

Lymph vessel

Blood vessel



The thyroid

The thyroid is a butterfly-shaped gland found at the front of the neck and just below the voice box (larynx). It has 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 role of the thyroid

The thyroid is part of the endocrine system, which is a group of glands that makes and controls the body's hormones. Hormones are chemical messengers that help the body work properly.

The thyroid makes two hormones (T4 and T3) that control the speed of the body's processes, such as heart rate, digestion, body temperature and weight. This speed is known as your metabolic rate. See page 8 for more information about the role of T4 and T3. The thyroid also produces the hormone calcitonin, which plays a role in controlling the body's calcium levels.

Cells in the thyroid

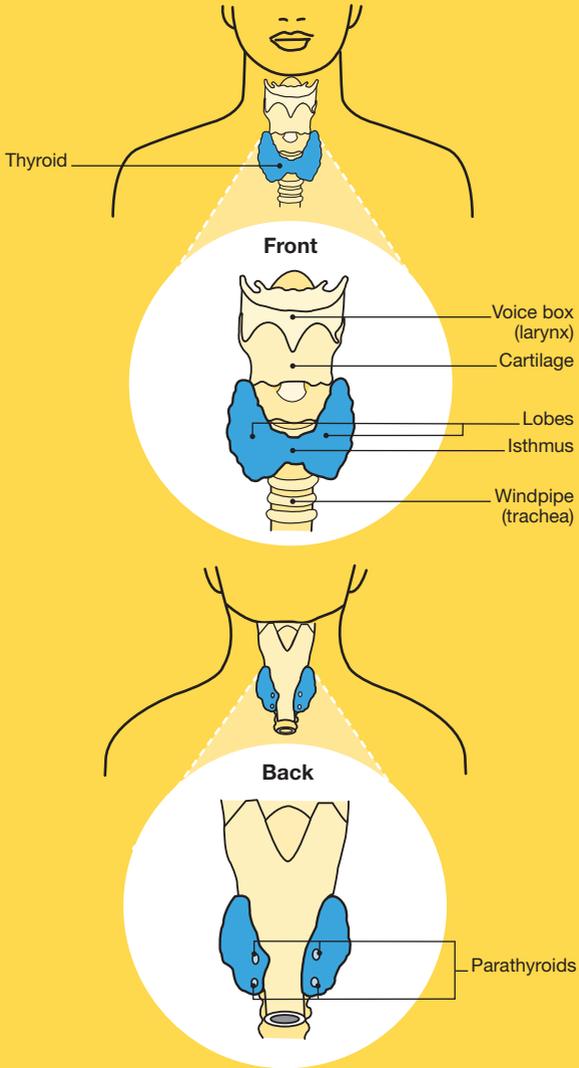
There are two main types of cells in the thyroid:

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

Parathyroid glands

Behind the thyroid are four additional glands known as the parathyroid glands. These glands produce parathyroid hormone (PTH), which works with calcitonin to control the amount of calcium in the blood.

The thyroid



The role of thyroid hormones

The hormones T4 (thyroxine) and T3 (tri-iodothyronine) are known as the thyroid hormones.

To make these hormones, the thyroid needs iodine, which is found in a range of foods such as seafood and iodised salt.

T4 is the main hormone made by the thyroid, but it is converted by the liver and kidneys into T3, a much more powerful hormone. Most T3 is created when the liver and kidneys convert T4 into T3, but the thyroid also makes small amounts.

To keep the body working properly, it is important that the thyroid makes the right amounts of T4 and T3. This is controlled by the pituitary gland, which is located at the base of the brain:

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

Changes in thyroid hormone levels affect your metabolism by slowing down or speeding up 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 difficulty concentrating, 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 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 grow and divide in an abnormal way. There are several types of thyroid cancer (see table below). It is possible to have more than one type at once, although this is unusual.

Types of thyroid cancer		
Common	papillary	<ul style="list-style-type: none">• most common type (about 70–80% of all thyroid cancer cases)• develops from the follicular cells• tends to grow slowly
	follicular	<ul style="list-style-type: none">• about 15–20% of all 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 cancer cases• develops from the parafollicular cells (C-cells)• can run in families (see next page)• may be associated with tumours in other glands
	anaplastic	<ul style="list-style-type: none">• a rare thyroid cancer (about 1% of all thyroid cancer cases)• may develop from papillary or follicular thyroid cancer• tends to grow quickly• usually occurs in people over 60

Q: What are the risk factors?

A: The cause of thyroid cancer is unknown, but some factors are known to increase the risk of developing it. Having a risk factor 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 cancers 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, such as the site of a nuclear accident. Thyroid cancer usually takes 10–20 years to develop after significant radiation exposure.

Family history – Only around 5% of thyroid cancer runs in families. Having a 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 – People who are overweight or obese possibly have a higher risk of developing thyroid cancer. Other thyroid

conditions, such as thyroid nodules, an enlarged thyroid (known as a goitre) or inflammation of the thyroid (thyroiditis), only slightly increase the chance of developing thyroid cancer.

Q: What are the symptoms?

A: Thyroid cancer usually develops slowly, without many obvious symptoms. However, some people experience one or more of the following:

- a painless lump in the neck (the lump may grow gradually)
- trouble swallowing
- difficulty breathing
- changes to the voice, e.g. hoarseness
- swollen lymph glands (lymph nodes) in the neck (the lymph nodes may slowly grow in size over months or years).

Although a painless lump in the neck is a typical sign of thyroid cancer, thyroid lumps (nodules) are common and turn out to be benign in 90% of adults.

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

Q: How common is thyroid cancer?

A: About 2900 people are diagnosed with thyroid cancer each year in Australia.³ Thyroid cancer can occur at any age. It affects almost three times as many women as men – it is the seventh most common cancer affecting Australian women of all ages, and the most common cancer diagnosed in women aged 20–24.⁴

Diagnoses of thyroid cancer in Australia have increased in recent years, with almost four times as many cases estimated in 2019 as there were in 1982.⁴ Some of this increase is due to the improved quality and greater use of diagnostic scans, such as ultrasounds. This has led to the detection of smaller, often insignificant, thyroid cancers that would otherwise not have been found. Researchers are trying to work out if there are any other causes of the increased rates of thyroid cancer.

Q: Which health professionals will I see?

A: Your general practitioner (GP) will arrange the first tests to assess your symptoms. If these tests do not rule out cancer, you will usually be referred to a specialist, such as an endocrinologist or endocrine surgeon. The specialist will arrange further tests.

If thyroid cancer is diagnosed, the specialist will consider treatment options. Often these will be discussed with other health professionals at a multidisciplinary team (MDT) meeting. During and after treatment, you will see a range of health professionals who specialise in different aspects of your care.

Health professionals you may see

endocrinologist*	diagnoses, treats and manages disorders of the endocrine system
endocrine surgeon*	operates on the endocrine system, including the thyroid, parathyroid and adrenal glands, and the pancreas
ENT (ear, nose and throat) surgeon*	operates on the ears, nose and throat, including the thyroid and lymph nodes in the neck; checks the vocal cords before and after surgery
head and neck surgeon*	diagnoses and treats cancer of the head and neck; may be an ENT surgeon or general surgeon
nuclear medicine specialist*	coordinates the delivery of radioactive iodine treatment and nuclear scans
nurses and nurse care coordinator	administer drugs and provide care, support and information throughout treatment
radiation oncologist*	treats cancer by prescribing and overseeing a course of radiation therapy
medical oncologist*	treats cancer with drug therapies such as chemotherapy and targeted therapy
counsellor	helps you understand and manage your emotional response to diagnosis and treatment, usually in the short term
social worker	links you to support services and helps you with emotional, practical and financial issues
dietitian	recommends an eating plan to follow while you are in treatment and recovery

* *Specialist doctor*



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.

Waiting for test results 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.

Blood test

A blood test cannot diagnose thyroid cancer, but you will have a blood test to check your levels of T3, T4 and thyroid-stimulating hormone (TSH). The thyroid 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 may have medullary thyroid cancer, the levels of calcitonin in the blood may also be checked. High levels of calcitonin in the blood can be a sign of this type of thyroid cancer.

Ultrasound

The best way to get detailed information about your thyroid is with an ultrasound. This scan can show the size of any thyroid nodule and whether it is full of fluid or solid. It can also show whether a nodule

has any features that suggest it may be a thyroid cancer rather than a benign nodule, and whether the lymph nodes in the neck appear to be affected.

An 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. An ultrasound 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. If you are having an FNA biopsy:

- the area may be numbed with a local anaesthetic – the procedure can sometimes be uncomfortable, although it is usually not painful
- a thin needle is inserted into the nodule to collect a sample of cells
- ultrasound may be used to guide the needle to the right spot.

The sample is sent to a laboratory, and a specialist doctor called a pathologist examines the sample under a microscope to see whether it contains cancer cells.

You should get the results of the biopsy within a week. If it's still unclear whether the nodule or enlarged lymph node is cancerous, you may need surgery to remove half of the thyroid (partial thyroidectomy, see pages 24–27). This will help confirm the diagnosis.

Genetic tests – You may be given the option of sending the biopsy sample overseas to test for changes (mutations) in the genes. Some thyroid cancers with mutations in the BRAF or RAS genes tend to respond to particular treatments. These genetic mutations are due to changes in the cancer cells – they are not the same thing as genes passed through families. Genetic tests for thyroid cancer are not yet routine in Australia and can be expensive.

Additional scans

To see if the cancer has spread from the thyroid to other parts of your body, you may have a CT (computerised tomography) scan and/or a PET (positron emission tomography) scan. This process is called staging (see pages 18–19). Some scans may be repeated after treatment to see how well the treatment has worked (see *Follow-up appointments*, pages 44–47).

CT scan

A CT 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 collarbone, or if your doctor suspects that the cancer has spread to other areas in the neck.

Before the scan, a special dye known as 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



Before having scans, tell the doctor if you have any allergies or have had a reaction to contrast during previous scans. You should also let them know if you have diabetes or kidney disease or are pregnant.

feel flushed or hot, and it may produce a strange taste in your mouth for a few minutes.

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 takes only a few minutes. You can go home once the scan is finished.

PET scan

A PET 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 usually 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.

Staging thyroid cancer

The tests described on pages 14–17 help your doctors work out whether you have thyroid cancer and whether it has spread from the thyroid to other parts of the body. Working out how far the cancer has spread is called staging. It is often not possible to precisely stage thyroid cancer until after surgery.

TNM staging system

The TNM staging system is often used for thyroid cancer. TNM stands for tumour–nodes–metastasis. Each letter is assigned a number (and sometimes also a letter) to show how advanced the cancer is.

T (Tumour) 0–4	Indicates the size of the tumour. T1 cancers are smaller and remain inside the thyroid, while T4 tumours are larger or have spread to other parts of the neck.
N (Nodes) 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.
M (Metastasis) 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.

To help work out the best treatment for you, your doctor will classify the cancer as low, intermediate or high risk. They will consider not only the stage but also a number of other factors, such as the cancer type and growth pattern, whether the tumour is growing into blood vessels, and your age and general health.

If you are having trouble understanding thyroid cancer staging and risk classification, ask a member of your treatment 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 anyone 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 an excellent long-term prognosis, especially if the cancer is found only in the thyroid or nearby lymph nodes in the neck. Even if the cancer has spread (metastasised), the outcome can still be good.

Doctors commonly use five-year survival rates as a way to discuss prognosis. This is because research studies often follow people for five years – it does not mean you will survive for only five years. Thyroid cancer has a very high five-year survival rate (97%).⁴



Key points about diagnosing thyroid cancer

Tests for thyroid cancer

- You will have a blood test to check the levels of thyroid hormones in your blood.
- An ultrasound is a painless scan that can give detailed information about your thyroid.
- The most common way to diagnose thyroid cancer is with a fine needle aspiration (FNA) biopsy. This removes a sample of cells from a nodule for examination under a microscope.
- Occasionally other tests, such as a CT scan or a PET scan, are used to check whether the thyroid cancer has spread.

Staging and prognosis

The doctor will tell you the size of the cancer and whether it has spread (its stage).

- The TNM system is often used for staging thyroid cancer. This stands for tumour–nodes–metastasis.
- In many cases, the information needed for accurate staging is available only after surgery.
- The cancer will be assessed as low, intermediate or high risk to help work out the best treatment.
- Your doctor may talk to you about your prognosis, which is the expected outcome of a disease.
- Thyroid cancer has a very high five-year survival rate (97%). Most thyroid cancers are treatable.



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, or you might be anxious to get started. Check with your specialist how soon treatment should begin – often it won't affect the success of the treatment to wait a while. Ask them to explain the options, and take as much time as you can before making a decision.

Know your options – Understanding the disease, the available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. Check if the specialist is part of a multidisciplinary team (see page 12) and if the treatment centre is the most appropriate one for you – you may be able to have treatment closer to home, or it might be worth travelling to a centre that specialises in a particular treatment.

Record the details – When your doctor first tells you that you have cancer, you may not remember everything you are told. Taking notes can help or you might like to ask if you can record the discussion. It is a good idea to have a family member or friend go with you to appointments to join in the discussion, write notes or simply listen.

Ask questions – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 52 for suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or nurse.

Consider a second opinion – You may want to get a second opinion from another specialist to confirm or clarify your specialist's recommendations or reassure you that you have explored all of

your options. Specialists are used to people doing this. Your GP or specialist 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 second specialist.

It's your decision – Adults have the right to accept or refuse any treatment that they are offered. For example, some people with advanced cancer choose treatment that has significant side effects even if it gives only a small benefit for a short period of time. Others decide to focus their treatment on quality of life. You may want to discuss your decision with the treatment team, GP, family and friends.

➤ See our *Cancer Care and Your Rights* booklet.

Should I join 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 modified new treatment. Over the years, trials have improved treatments

and led to better outcomes for people diagnosed with cancer.

You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time. For more information, visit australiancancertrials.gov.au.

➤ See our *Understanding Clinical Trials and Research* booklet.



Treatment

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

Active surveillance

In some cases, your doctor may recommend closely monitoring the cancer, rather than having treatment straightaway. This approach is known as active surveillance. It usually involves regular ultrasounds and physical examinations.

There is good evidence that active surveillance is safe for small papillary thyroid cancers where there is no sign that the cancer has spread from the thyroid. It may be an option when the tumour is under 10 mm, isn't causing any symptoms and is considered to be low risk.

Some people choose to have 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 that active surveillance makes them feel anxious and prefer to have treatment straightaway. Treatment 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.



Many people diagnosed with thyroid cancer are under 40 and may be concerned about how the treatment will affect their ability to conceive a child. Fertility usually is not affected by surgery or radioactive iodine treatment. In the short term, it is recommended that you delay pregnancy for six months after treatment.

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 the surgeon will make a small cut (5–7 cm) across your neck. How much tissue is removed will depend on how far the cancer has spread (see diagrams opposite).

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. The surgeon may arrange blood tests to check on your recovery. See *What to expect after thyroid surgery* on pages 26–27 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 work out if the cancer has spread to any of the nearby lymph nodes and whether you need further treatment. For some people, this may mean more surgery to remove any remaining thyroid tissue. Other people may need to have thyroid hormone replacement therapy (see pages 28–29), radioactive iodine treatment (see pages 31–35) or targeted therapy (see pages 35–36).

Types of thyroid surgery

 Area removed



Partial thyroidectomy

In a partial thyroidectomy (also called a hemithyroidectomy), only the affected lobe or section of the thyroid is removed. This surgery may be an option if the cancer is small and the other lobe looks normal on the ultrasound. It might also be used to diagnose thyroid cancer if a fine needle aspiration biopsy (see page 15) doesn't provide a clear diagnosis. If cancer is found after a partial thyroidectomy, you may need further surgery to remove the rest of your thyroid.



Total thyroidectomy

Most people with thyroid cancer need to have a total thyroidectomy. This involves removing the whole thyroid (both lobes and the isthmus).



Some lymph nodes may be removed

Lymph node removal

With either type of thyroid surgery, nearby lymph nodes may also be removed to help work out staging (see page 18) or if the initial scans show that the cancer has spread to them. This is called a neck dissection. Even if the cancer doesn't appear to have spread, the nodes behind the thyroid are occasionally removed to reduce the risk of the cancer returning.

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

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, but this is usually temporary.

Sore neck

You will probably feel some pain or discomfort where the cut was made. You will be given pain 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 medicine.



Eating and drinking

Most people start eating and drinking 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, see our *Nutrition and Cancer* booklet.

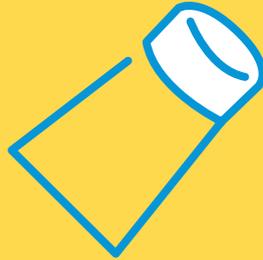
Painful swallowing

You will find it painful to swallow for a few days. Try to eat soft foods that are easy to swallow. Swallowing can feel stiff for a few months, but usually gradually improves.



Scarring

You will have a horizontal scar on your neck above the 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.



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 (such as running) and turning your neck quickly for a couple of weeks after surgery.

Low calcium levels

You may have low blood calcium levels (hypocalcaemia) if surgery affects the parathyroid glands. 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, vitamin D and/or calcium supplements need to be taken permanently. Calcium supplements should be taken at least two hours after your thyroid hormone replacement tablets.

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.



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 T4 (thyroxine).

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 thyroid hormone tablets stops your pituitary glands from releasing too much of another hormone called thyroid-stimulating hormone (TSH). It is thought that high levels of TSH may encourage 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. You'll have blood tests every 6–8 weeks to help your doctor adjust the dosage until it is right for you. Usually, the initial dose needs 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

- 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.
- 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. Some T4 medicines do not need refrigeration – check with your doctor or pharmacist.
- If you miss a dose, you should usually take it as soon as you remember. But if it's almost time to take the next dose, skip the dose you missed.
- Wait two 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 are 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.



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. Because 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, I should 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 T4 (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 – it doesn't hurt, it was just a bit boring being quarantined in a hospital room. Then at home, for a couple of weeks afterwards, I had to follow all the precautionary safety measures, such as sleeping separately from my partner.

I now have T4 once a day in the morning. It took a little while to get the dose right for me. When it wasn't enough, I was really tired.

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. It's really now just part of my life.

Radioactive iodine treatment

Radioactive iodine (RAI) is also known as I131 and is a type of radioisotope treatment. Radioisotopes are radioactive substances given in a pill that you swallow. Although RAI spreads through the body, it is mainly absorbed by thyroid cells or thyroid cancer cells. RAI kills these cells while leaving other body cells relatively 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 papillary or follicular thyroid cancers that have spread to the lymph nodes or that have a higher risk of coming back after surgery. RAI doesn't work for medullary or anaplastic thyroid cancer because these types do not take up iodine.

When to have RAI treatment

RAI is generally not given until some weeks after surgery, once any swelling has gone down. This is because swelling can affect the blood flow and stop the RAI circulating well.

It is not safe to have RAI treatment if you are pregnant or breastfeeding, so treatment may be delayed. RAI may be given up to six months after surgery. Ask your doctor for more information.

Preparing for RAI 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 treatment team will give you more detailed instructions.

Discussing imaging scans – CT scans and other imaging scans sometimes use an injection of a dye called contrast to make the images clearer. This contrast can interfere with how well RAI works, so it is important to tell your doctor if you have had a scan using contrast in the month before RAI treatment.

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

- You may be prescribed a synthetic type of TSH called recombinant human thyroid-stimulating hormone (rhTSH), also known by the brand name Thyrogen. You will need two injections of Thyrogen, usually into the muscle in your buttock, with the first injection two days before RAI treatment, and then the second injection the day before. Thyrogen allows you to continue taking your thyroid hormone replacement medicine.
- 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. In some people, stopping their hormone replacement medicine causes symptoms of hypothyroidism (see page 8). These symptoms may affect your ability to concentrate, so check with your doctor whether it is safe to drive and use heavy machinery.

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

Having RAI treatment

You will be admitted to hospital on the day of the RAI treatment. You may be given anti-nausea medicine before the RAI pill.

RAI treatment will make you radioactive for a few days, and you will need to stay in hospital during this time. See the table on 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 usually occurs within 36–48 hours. It may be a day longer if you stopped taking your thyroid hormone replacement medicine.

A few days after treatment, you will have a full body radioisotope scan (see page 45) to detect if any thyroid cancer cells are left in the body. It is normal to see an area of RAI uptake in the neck on this initial 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 radioisotope scan may also show if cancer has spread to your lymph nodes or other areas of your body.



If you or your partner want to have a baby after RAI treatment, talk to your doctor. RAI may have a short-term effect on eggs and sperm, so you'll be advised to use contraception for a time (usually 6 months for women, 3–6 months for men). Women also need to check that their thyroid hormone levels are normal before trying to get pregnant.

Safety precautions during RAI treatment

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

In hospital

Safety measures vary between hospitals, and the medical team 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
- wearing gloves to clean up body fluids (e.g. urine, sweat, saliva, blood) and leftover food and drink
- washing hands thoroughly and often.

At home

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

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

- sleeping alone
- washing your clothing separately
- washing hands extra well before preparing 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, tablet device, puzzles.

Side effects of RAI treatment

Usually, being temporarily radioactive is the only major side effect of RAI treatment. Drinking lots of water helps the RAI treatment pass out of your body faster and also reduces the bladder's exposure to radiation.

Because the salivary glands may absorb some iodine, you might have a dry mouth as well as taste and smell changes for a few weeks after treatment. Some people will have ongoing problems with swelling and pain in their salivary glands. Ask your treatment team for medicines (e.g. paracetamol) to relieve swelling and pain. Other side effects, such as tiredness, are often caused by thyroid hormone withdrawal, but will improve when your thyroid hormone levels return to normal.

Targeted therapy

Targeted therapy drugs attack specific features of cancer cells to stop the cancer growing and spreading. The most common targeted therapy drugs used for thyroid cancer are tyrosine kinase inhibitors (TKIs). These drugs block the chemical messengers (enzymes) that help tell cancer cells to grow, multiply and spread.

If you have advanced thyroid cancer that hasn't responded to RAI treatment, you may be offered a TKI such as lenvatinib or sorafenib. These drugs are given as a pill, which you take daily. You will usually keep taking the pills for several years.

Other TKIs may be available on clinical trials (see page 22). Talk with your doctor about the latest developments and whether you are a suitable candidate.

Side effects of targeted therapy

The most common side effects of TKIs include diarrhoea, skin rash, bleeding and high blood pressure. In some people, TKIs can affect the way the heart and kidneys work. Some TKIs can also cause tenderness, tingling and blisters on the skin of the palms and soles.

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

New treatments for thyroid cancer

Most thyroid cancers respond well to the standard treatments. However, a small number of thyroid cancers are more difficult to treat, so new treatments are being investigated.

Immunotherapy is a type of drug treatment that uses the body's own immune system to fight cancer. In Australia, immunotherapy drugs are currently available for some cancers, such as melanoma and lung cancer. Clinical trials are currently testing whether immunotherapy works for anaplastic thyroid cancer.

For advanced medullary thyroid cancer, a type of nuclear medicine known as radiopeptide therapy may be available. This is also known as peptide receptor radionuclide therapy (PRRT). The treatment involves an injection of a protein (peptide) that has been combined with a small amount of radioactive substance (radionuclide). This mixture targets cancer cells and delivers a high dose of radiation that kills or damages them.

Talk to your specialist to find out more about new treatments and clinical trials.

External beam radiation therapy

External beam radiation therapy (also known as external beam radiotherapy) uses a controlled dose of radiation to kill cancer cells or damage them so they cannot grow, multiply or spread. The radiation is usually in the form of x-ray beams. 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, but it may be recommended in particular circumstances. In a small number of cases, it may be given:

- after surgery and RAI treatment if the cancer has not been completely removed or if there is a high risk of the cancer returning (recurrence)
- as palliative treatment to relieve symptoms such as pain caused by cancer that has spread to nearby tissue or structures
- to help control medullary or anaplastic thyroid cancer (because these types do not respond to RAI).

Planning treatment – Before the treatment starts, you will have a planning session. The radiation therapist will take CT scans to work out 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 also 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 develop side effects during radiation therapy. 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 cancer cells or slow their growth. 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 RAI treatment or targeted therapy. It may also be used in combination with radiation therapy to treat anaplastic thyroid cancer.

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

Side effects of chemotherapy

The side effects of chemotherapy will vary depending on the drugs 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.



To read more about treatments and side effects, see our *Understanding Surgery*, *Understanding Targeted Therapy*, *Understanding Radiation Therapy* and *Understanding Chemotherapy* publications.

Most chemotherapy 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 or be given a different type of drug, or your doctor may recommend a break from treatment.

Palliative treatment

Most people with thyroid cancer respond well to treatment and do not need to access palliative care services. However, people at any stage of advanced thyroid cancer may benefit from palliative treatment.

Palliative treatment helps to improve people's quality of life by managing symptoms of cancer without trying to cure the disease. The treatment you are offered will be tailored to your individual needs. It may include radiation therapy, chemotherapy, targeted therapy or other medicines.

Palliative treatment is one aspect of palliative care, in which a team of health professionals aim to meet your physical, emotional, cultural, social and spiritual needs. Palliative care also provides support to families and carers.

- See our *Understanding Palliative Care* and *Living with Advanced Cancer* booklets.



Key points about treating thyroid cancer

Surgery

- Surgery is the most common and effective treatment for thyroid cancer.
- You may have a partial thyroidectomy or your whole thyroid may be removed (total thyroidectomy).
- Nearby lymph nodes may also be removed (neck dissection).

Additional treatments

- After a total thyroidectomy, you will be prescribed thyroid hormone replacement tablets 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 pill. You will need to stay in hospital for 36–72 hours in an isolated room to safely contain the radioactivity.

Less common treatments

- 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.
- Chemotherapy is sometimes used when advanced thyroid cancer has not responded to RAI treatment or targeted therapy.
- Chemotherapy may be used in combination with radiation therapy to treat anaplastic thyroid cancer.
- People with advanced thyroid cancer may have palliative treatment to improve their quality of life.



Looking after yourself

Cancer can cause physical and emotional strain, so it's important to look after your wellbeing. Cancer Council has free booklets and programs to help you during and after treatment. Call 13 11 20 to find out more, or visit your local Cancer Council website (see back cover).

Eating well – Healthy food can help you cope with treatment and side effects. A dietitian can explain how to manage any special dietary needs or eating problems and choose the best foods for your situation.

➤ See our *Nutrition and Cancer* booklet.

Staying active – Physical activity can reduce tiredness, improve circulation and lift mood. The right exercise for you depends on what you are used to, how you feel, and your doctor's advice.

➤ See our *Exercise for People Living with Cancer* booklet.

Complementary therapies – Complementary therapies are designed to be used alongside conventional medical treatments. Therapies such as massage, relaxation and acupuncture can 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.

➤ See our *Understanding Complementary Therapies* booklet.



Alternative therapies are therapies used instead of conventional medical treatments. These are unlikely to be scientifically tested and may prevent successful treatment of the cancer. Cancer Council does not recommend the use of alternative therapies as a cancer treatment.

Work and money – Cancer can change your financial situation, especially if you have extra medical expenses or need to stop working. Getting professional financial advice and talking to your employer can give you peace of mind. You can also check with a social worker or Cancer Council whether any financial assistance is available to you.

➤ See our *Cancer and Your Finances* and *Cancer, Work & You* booklets.

Relationships – Having cancer can affect your relationships with family, friends and colleagues in different ways. Cancer is stressful, tiring and upsetting, and this may strain relationships. It may also result in positive changes to your values, priorities or outlook on life. Give yourself time to adjust to what's happening, and do the same for those around you. It may help to discuss your feelings with each other.

➤ See our *Emotions and Cancer* booklet.

Sexuality – 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.

➤ See our *Sexuality, Intimacy and Cancer* booklet.

Contraception and fertility – If you can have sex, you may need to use certain types of contraception to protect your partner or avoid pregnancy for a time. Your doctor will explain what precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, discuss the options with your doctor before starting treatment.

➤ See our *Fertility and Cancer* booklet.



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 that every ache and pain means the cancer is coming back.

Some people say that they feel pressure to return to “normal life”. It is important to allow yourself time to adjust to the physical and emotional changes, and establish a new daily routine at your own pace. Your family and friends may also need time to adjust.

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.

➤ See our *Living Well After Cancer* booklet.

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 medication – even for a short time – may help. Some people

can get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Cancer Council may also run a counselling program in your area.

For information about coping with depression and anxiety, call Beyond Blue on **1300 22 4636** or visit beyondblue.org.au. For 24-hour crisis support, call Lifeline **13 11 14** or visit lifeline.org.au.

Follow-up appointments

After treatment ends, you will have regular appointments to monitor your health, manage any long-term side effects and check that the cancer hasn't come back or spread. How often you will need to see your doctor will depend on the type of cancer and which treatments you had. During these check-ups, you will also be able to discuss how you're feeling and mention any concerns, and you may have some blood tests and scans.

Blood tests to measure Tg – 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.

In the past, people often had to raise the TSH levels in their blood (see table, page 46) before having a Tg blood test. This improved the accuracy of the results. However, newer Tg tests are more sensitive, and most people will not need to do this.

If Tg is found in your blood, your doctor may suggest having some scans (see page 45). A small number of people have Tg antibodies. The antibodies cause no harm but they make it hard to accurately measure Tg. They tend to fade after RAI treatment.

Other blood tests – For medullary thyroid cancer, blood levels of calcitonin and carcinoembryonic antigen (CEA, a protein made 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. Once this dose is 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. It is used less often now as the Tg blood test and neck ultrasound usually provide enough information.

If you are having a radioisotope scan, you may need to raise your TSH levels beforehand – for more details, see the table on the next page and talk to your doctor.

For the scan, 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 the 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 other people.

Other scans – 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 (see pages 16–17).

Ways to raise TSH levels for accurate test results

Your doctor will give you instructions if you need to raise your TSH levels before a radioisotope scan (see previous page).

Option 1 Have rhTSH (Thyrogen) injections

- The synthetic drug known as rhTSH is a copy of the TSH produced by your body. It is often referred to by the brand name Thyrogen.
- It is given as two injections, 24 hours apart.
- You will have the radioisotope scan 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.

Option 2 Stop taking thyroid hormone replacement medicine

- Prepare to stop taking your T4 hormone replacement medicine about 2–6 weeks before the blood test or radioisotope scan.
- Once you stop, your TSH levels will increase but your thyroid hormone levels will decrease. This may cause hypothyroidism symptoms (see page 8). Some people find it difficult to cope with this, while others don't notice any difference.
- Symptoms of hypothyroidism 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, you stop all thyroid hormone replacement medicine until after the scan.

Anxiety about follow-up appointments

When a follow-up appointment or test is approaching, many people find that they think more about the cancer and may feel anxious.

Talk to your treatment team or call Cancer Council 13 11 20 if you are finding it hard to manage this anxiety.

Check-ups will become less frequent if you have no further problems. Between follow-up appointments, let your doctor know immediately of any symptoms or health problems.

What if the cancer returns?

For most people, thyroid cancer does not come back (recur) after the initial treatment. However, some people do have a recurrence. This is why it's important to have regular check-ups.

If thyroid cancer does come back, it will often just be in the lymph nodes and you may be offered further surgery, sometimes with a repeat of radioactive iodine (RAI) treatment. If the cancer has spread into other parts of the body, the first treatment will usually be RAI. Additional treatments such as targeted therapy, external beam radiation therapy or chemotherapy may also be used.



Seeking support

A cancer diagnosis can affect every aspect of your life. You will probably experience a range of emotions – fear, sadness, anxiety, anger and frustration are all common reactions. Cancer also often creates practical and financial issues.

There are many sources of support and information to help you, your family and carers navigate all stages of the cancer experience, including:

- information about cancer and its treatment
- access to benefits and programs to ease the financial impact of cancer treatment
- home care services, such as Meals on Wheels, visiting nurses and home help
- aids and appliances
- support groups and programs
- counselling services.

The availability of services may vary depending on where you live, and some services will be free but others might have a cost.

To find good sources of support and information, you can talk to the social worker or nurse at your hospital or treatment centre, or get in touch with Cancer Council 13 11 20.

“ 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*

Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary depending on where you live.

Cancer Council 13 11 20

Trained professionals will answer any questions you have about your situation and link you to services in your area (see inside back cover).



Information resources

Cancer Council produces booklets and fact sheets on over 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call **13 11 20** or visit your local Cancer Council website (see back cover).

Practical help

Your local Cancer Council can help you find services or offer guidance to manage the practical impact of a cancer diagnosis. This may include access to transport and accommodation services.



Legal and financial support

If you need advice on legal or financial issues, we can refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. Call Cancer Council **13 11 20** to ask if you are eligible.

Peer support services

You might find it helpful to share your thoughts and experiences with other people affected by cancer. Cancer Council can link you with individuals or support groups by phone, in person, or online. Call **13 11 20** or visit cancercouncil.com.au/OC.



Useful websites

You can find many useful resources online, but not all websites are reliable. These websites are good sources of support and information.

Australian

Cancer Council Australia	cancer.org.au
Cancer Australia	canceraustralia.gov.au
Cancer Council Online Community	cancercouncil.com.au/OC
Cancer Council podcasts	cancercouncil.com.au/podcasts
Carers Australia	carersaustralia.com.au
Department of Health	health.gov.au
eviQ	eviq.org.au
Healthdirect Australia	healthdirect.gov.au
Australian and New Zealand Endocrine Surgeons	endocrinesurgeons.org.au
The Australian Thyroid Foundation	thyroidfoundation.org.au

International

American Cancer Society	cancer.org
Cancer Research UK	cancerresearchuk.org
Macmillan Cancer Support (UK)	macmillan.org.uk
National Cancer Institute (US)	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
Thyroid Awareness (US)	thyroidawareness.com



Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. What this means for you will vary depending on the situation. Being a carer can bring a sense of satisfaction, but it can also be challenging and stressful.

It is important to look after your own physical and emotional wellbeing. Give yourself some time out and share your concerns with somebody neutral such as a counsellor or your doctor, or try calling Cancer Council 13 11 20. There is a wide range of support available to help you with both the practical and emotional aspects of your caring role.

Support services – Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local services, as well as information and resources, through the Carer Gateway. Call 1800 422 737 or visit carergateway.gov.au.

Support groups and programs – Many cancer support groups and cancer education programs are open to carers as well as to people with cancer. Support groups and programs offer the chance to share experiences and ways of coping.

Carers Associations – Carers Australia works with the Carers Associations in each state and territory to provide information and services to carers. Call 1800 242 636 or visit carersaustralia.com.au.

Cancer Council – You can call Cancer Council 13 11 20 or visit your local Cancer Council website to find out more about carers' services.

➤ See our *Caring for Someone with Cancer* booklet.



Question checklist

Asking your doctor questions will help you make an informed choice. You may want to include some of the questions below in your own list.

Diagnosis

- What type of thyroid cancer do I have?
- Has the cancer spread? If so, where has it spread? How fast is it growing?
- Are the latest tests and treatments for this cancer available in this hospital?
- Will a multidisciplinary team be involved in my care?

Treatment

- What treatment do you recommend? What is the aim of the treatment?
- Are there other treatment choices for me? If not, why not?
- If I don't have the treatment, what should I expect?
- How long do I have to make a decision?
- I'm thinking of getting a second opinion. Can you recommend anyone?
- How long will treatment take? Will I have to stay in hospital?
- Are there any out-of-pocket expenses not covered by Medicare or my private health cover? Can the cost be reduced if I can't afford it?
- How will we know if the treatment is working?
- Are there any clinical trials or research studies I could join?

Side effects

- What are the risks and possible side effects of each treatment?
- Can I work, drive and do my normal activities while having treatment?
- Will the treatment affect my sex life and fertility?
- Should I change my diet or physical activity during or after treatment?
- Are there any complementary therapies that might help me? Will these affect my thyroid hormone replacement medicine?

After treatment

- How often will I need check-ups after treatment?
- How will my thyroid hormone levels be monitored?
- If the cancer returns, how will I know? What treatments could I have?



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 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 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. They produce and store the thyroid hormones T3 and T4, and make the protein 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. 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 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.

lymph nodes (lymph glands)

Small, bean-shaped structures that collect and destroy bacteria and viruses.

malignant

Cancerous. Malignant cells can spread (metastasis) 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)

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 in one or both sides of the neck. Also called lymphadenectomy.

node

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 symptoms of cancer.

parafollicular cells (C-cells)

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

parathyroid glands

Four glands that are located behind the thyroid. They produce a hormone that helps control the amount of calcium 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 expected outcome of a particular 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 (RAI)

A form of iodine often used for imaging tests or as a treatment for thyroid cancer. Also known as 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). It is used to raise thyroid hormone levels before radioactive iodine (RAI) treatment, or before some follow-up tests after thyroid cancer treatment. Often known by the brand name Thyrogen.

staging

Performing tests to work out how far a cancer has spread.

T3, T4

See tri-iodothyronine and thyroxine.

Thyrogen

See rhTSH.

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. Also called a total thyroidectomy.

thyroiditis

Benign inflammation of the thyroid.

thyroid-stimulating hormone (TSH)

A hormone that prompts the thyroid 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 that regulates the body's metabolism. T4 can be converted by the liver and kidneys 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 that regulates the body's metabolism. A small amount is made by the thyroid, but it is mainly produced when the liver and kidneys convert T4 into T3.

tumour

A new or abnormal growth of tissue on or in the body. A tumour may be benign (not cancer) or malignant (cancer).

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](https://www.cancercouncil.com.au/words)
- [cancervic.org.au/glossary](https://www.cancervic.org.au/glossary)
- [cancersa.org.au/glossary](https://www.cancersa.org.au/glossary)

References

1. S Filetti et al. on behalf of the ESMO Guidelines Committee, "Thyroid cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up", *Annals of Oncology*, mdz400, 2019, available from: <https://doi.org/10.1093/annonc/mdz400>.
2. 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.
3. Australian Institute of Health and Welfare (AIHW), *Cancer Data in Australia, Australian Cancer Incidence and Mortality (ACIM) books: thyroid cancer*, AIHW, Canberra, 2018.
4. Australian Institute of Health and Welfare (AIHW), *Cancer in Australia 2019*, AIHW, Canberra, 2019.



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.

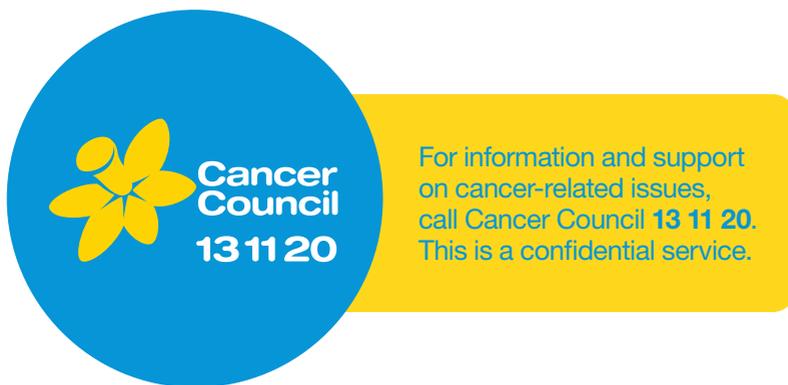
If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

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



Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
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