

# Understanding Thyroid Cancer

*A guide for people with cancer, their families and friends*



For information & support, call **13 11 20**

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A guide for people with cancer, their families and friends

First published October 2008. This edition April 2023.

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*Understanding Thyroid Cancer* is reviewed approximately every 2 years.

Check the publication date above to ensure this copy is up to date.

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### Acknowledgements

This edition has been developed by Cancer Council NSW on behalf of all other state and territory Cancer Councils as part of a National Cancer Information Subcommittee initiative. We thank the reviewers of this booklet: A/Prof Diana Learoyd, Endocrinologist, GenesisCare North Shore, Faculty of Medicine and Health, University of Sydney, NSW; Emeritus Professor Leigh Delbridge AM, The University of Sydney, Thyroid Surgeon, The Mater and North Shore Private Hospitals, NSW; Prof Ruta Gupta, Tissue Pathology and Diagnostic Oncology, Royal Prince Alfred Hospital and The University of Sydney, NSW; Susan Leonard, Cancer Nurse Coordinator Thyroid and Brachytherapy, Cancer Care Services, Royal Brisbane and Women's Hospital, QLD; Dr Dean Lisewski, Endocrine and General Surgeon, Fiona Stanley Hospital and St John of God Hospital, Murdoch, WA; Cairtriona Nienaber, 13 11 20 Consultant, Cancer Council WA; Jonathan Park, Consumer; A/Prof David Pattison, Deputy Director and Senior Staff Specialist, Department of Nuclear Medicine and Specialised PET Services, Royal Brisbane and Women's Hospital and School of Medicine, University of Queensland, QLD; Prof Bruce Robinson, Endocrinologist, Co-Head, Cancer Genetics, Kolling Institute of Medical Research, The University of Sydney and Royal North Shore Hospital, NSW; Marissa Ryan, Team Leader (Cancer) Pharmacist, Princess Alexandra Hospital, Brisbane, QLD. We also thank the health professionals, consumers and editorial teams who have worked on previous editions of this title.

### 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 8 state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit [cancer.org.au](http://cancer.org.au) or call your local Cancer Council.



*Cancer Council acknowledges Traditional Custodians of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past, present and emerging.*



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# 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. 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, this information may answer some of your questions and help you think about what to ask your treatment team (see page 51 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 52). 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.<sup>1-2</sup>



If you or your family have any questions or concerns, 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).




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## Key to icons

Icons are used throughout this booklet to indicate:

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-  Alert
  -  Personal story
  -  Tips
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# What is cancer?

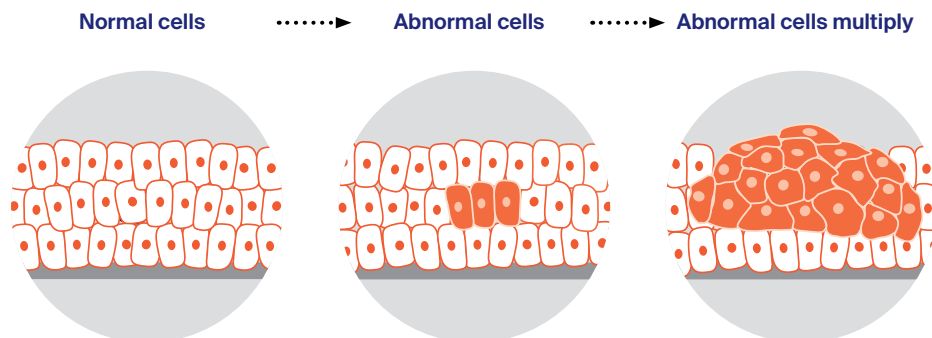
Cancer is a disease of the cells. Cells are the body's basic building blocks - they make up tissues and organs. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries.

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. These abnormal cells may turn into cancer.

In solid cancers, such as thyroid cancer, the abnormal cells form a mass or lump called a tumour or nodule. In some cancers, such as leukaemia, the abnormal cells build up in the blood.

## How cancer starts

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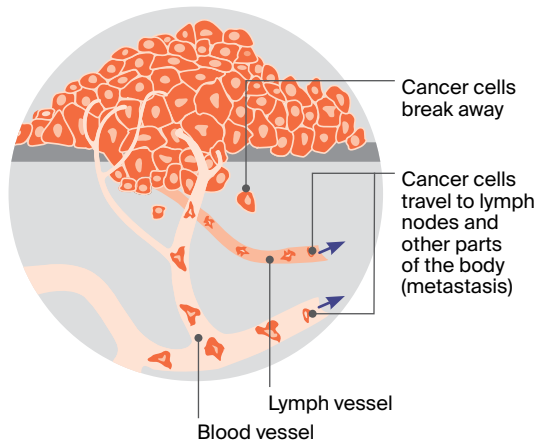
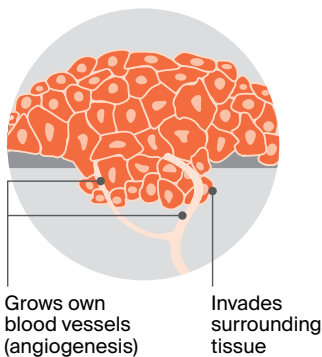


Not all tumours or nodules are cancer. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break away and travel through the bloodstream or lymph vessels to other parts of the body.

The cancer that first develops in a tissue or organ 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





# The thyroid

The thyroid is a butterfly-shaped gland that sits at the front of the throat. It has two halves, called lobes, that are connected by a small band of thyroid tissue called the isthmus. These two lobes sit on either side of the windpipe (trachea), just below the voice box (larynx).

## The role of the thyroid

The thyroid is part of the endocrine system. This system is made up of glands that make hormones, which are chemical messengers that help the body function.

The thyroid makes hormones that control your metabolic rate, including your heart rate, how fast you digest food, your body temperature and weight. These hormones are called T4 and T3.

The thyroid also makes a hormone called calcitonin, which helps to control calcium levels in your bloodstream. See page 8 for more information about the role of these hormones.

## Cells in the thyroid

There are 2 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

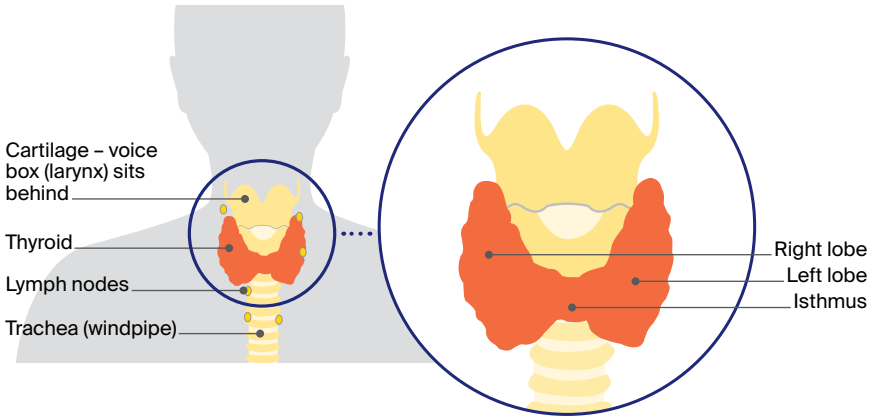
Behind the thyroid are 4 small glands known as the parathyroid glands. They make parathyroid hormone (PTH), which works with calcitonin to control the amount of calcium in the bloodstream.



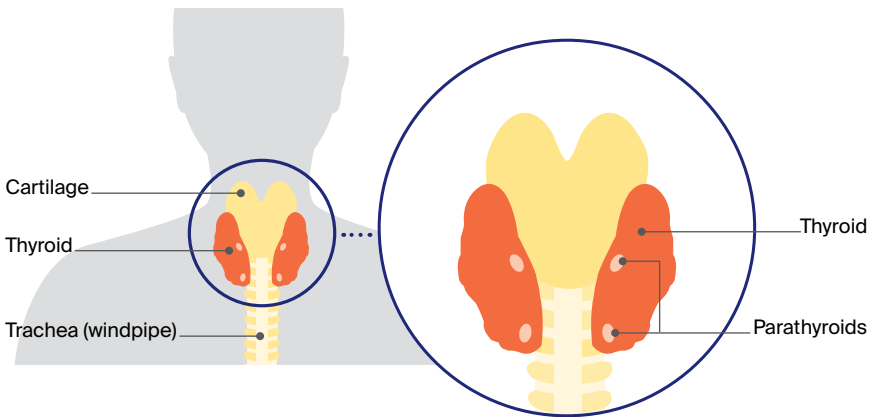
# The thyroid

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## Front view



## Rear view



## The role of thyroid hormones

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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 foods such as seafood and iodised salt.

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

To keep the body's metabolism working properly, it is important that the thyroid makes the right amounts of T4 and T3. This balance of hormones 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 more of a hormone called thyroid-stimulating hormone (TSH). TSH causes 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, as outlined below.

### **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 and heart function.

# 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. It's rare but possible to have more than one type at once. Thyroid nodules called adenomas are not cancer (benign).

### Types of thyroid cancer

#### Common

##### **papillary**

- most common – about 80% of all thyroid cancer cases
- develops from the follicular cells
- tends to grow slowly

##### **follicular**

- about 10% of all thyroid cancer cases
- develops from the follicular cells

#### Rare

##### **medullary**

- about 6% 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

##### **oncocytic**

- also known as oxyphilic or Hürthle cell carcinoma
- about 3% of all thyroid cancers
- develops from thyroid follicles

##### **anaplastic**

- only about 1% of all thyroid cancer cases
- develops from papillary or follicular thyroid cancer
- grows quickly
- usually occurs in people over 60

## Q: How common is thyroid cancer?

**A:** Around 4000 people are diagnosed with thyroid cancer each year in Australia.<sup>3</sup>

Women are almost 3 times more likely to develop thyroid cancer than men. It's the 7th most common cancer in Australian women and the most diagnosed cancer in women who are aged 20–24.<sup>3</sup>

Even though people of any age can get thyroid cancer (including children), it is most often diagnosed in women in their 40s and 50s, and men in their 60s and 70s.

Rates of thyroid cancer in Australia have been increasing since the 1980s. What's causing the rise in cases is unclear. Ultrasound, CT and MRI scans now find smaller thyroid cancers that once weren't noticed, which may explain some of the increase in cases.

## Q: What are the symptoms?

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

- a lump or nodule in the neck (which is usually painless, and may grow gradually)
- swelling in the neck
- trouble swallowing
- difficulty breathing
- changes to the voice, e.g. hoarseness that doesn't go away
- swollen lymph nodes in the neck (which may slowly grow over months or years)
- a cough that doesn't go away.

Even though a painless lump in the neck is a typical sign of thyroid cancer, around 90% of painless lumps found in adults aren't cancer.

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

## Q: What are the risk factors?

**A:** What exactly causes thyroid cancer is unknown, but some things may increase your risk of developing it. Having one of these risk factors does not mean that you will develop thyroid cancer.

**Exposure to radiation** – A small number of thyroid cancers may be from having radiation therapy to the head and neck as a child, living in an area with high levels of radiation, or from exposure to radiation at work (e.g. medical or military). Thyroid cancer usually takes 10–20 years to develop after significant radiation exposure.

**Family history** – A small number of thyroid cancers (about 5%) are linked to a family history. These include:

- Papillary thyroid cancers – Having a parent, child or sibling with papillary thyroid cancer or an inherited genetic condition, such as familial adenomatous polyposis (FAP) or Cowden syndrome, may increase your risk.
- Medullary thyroid cancers – Some people inherit a faulty gene, called the RET gene, that can cause familial medullary thyroid cancer (FMTC) or multiple endocrine neoplasia (MEN).

If you have a family history of thyroid cancer, talk to your doctor about a referral to a genetic counsellor or a family cancer clinic to check your risk.

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

**Obesity** – Being overweight or obese may increase the risk of developing thyroid cancer.

**Iodine levels** – Studies have linked having both too much and too little iodine with a possible higher risk 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 a surgeon or endocrinologist. The specialist will arrange further tests.

If thyroid cancer is diagnosed, the specialist will consider treatment options. Sometimes these will be discussed with other health professionals at what is known as 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.

*“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

## Health professionals you may see

<b>endocrinologist</b>	diagnoses, treats and manages disorders of the endocrine system
<b>endocrine surgeon</b>	operates on the endocrine system, including the thyroid, parathyroid and adrenal glands, and pancreas
<b>ENT (ear, nose and throat) surgeon</b>	operates on the ears, nose, throat, thyroid and lymph nodes in the neck
<b>head and neck surgeon</b>	diagnoses and treats cancer of the head and neck; may be an ENT or general surgeon
<b>nuclear medicine specialist</b>	coordinates the delivery of radioactive iodine treatment and certain imaging tests
<b>nurse</b>	administers medicines and provides care, information and support throughout treatment
<b>cancer nurse specialist</b>	provides care, information and support throughout treatment and recovery; helps with symptom management and wellbeing after treatment
<b>radiation oncologist</b>	treats cancer by prescribing and overseeing a course of radiation therapy
<b>radiation therapist</b>	plans and delivers radiation therapy
<b>medical oncologist</b>	treats cancer with drug therapies such as chemotherapy, targeted therapy and immunotherapy
<b>pharmacist</b>	dispenses medicines and gives advice about dosage and side effects
<b>counsellor</b>	helps you understand and manage your emotional response to diagnosis and treatment
<b>social worker</b>	links you to support services and helps you with emotional, practical and financial issues
<b>speech pathologist</b>	evaluates and treats communication, voice and swallowing difficulties during and after treatment
<b>dietitian</b>	helps with nutrition concerns and recommends changes to diet during treatment and recovery



# Diagnosis

Your doctor will feel your neck to check for any swelling or lumps (often called nodules). If you have a lump in or near the thyroid, you will usually have one or more of the following tests to check if it is cancerous. You may also have tests to see whether it has spread. 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 more information and support.

## Blood test

A blood test cannot diagnose thyroid cancer, but it may help rule out other conditions, such as hypothyroidism or hyperthyroidism. Your levels of T3, T4 and thyroid-stimulating hormone (TSH) (see page 8) are usually checked first. But because the thyroid may still work normally with cancer, hormone levels are not always affected.

If your doctor suspects you may have medullary thyroid cancer, they may check your calcitonin levels. 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 lump (nodule) and whether it is solid, cystic (full of fluid) or a mix of both.



An ultrasound can also show other signs that suggest thyroid cancer, and if the lymph nodes in the neck look like they have been affected.

The nodule will usually be rated as high or low risk, based on its size and appearance. This will help the doctors decide whether you should have a biopsy.

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

**Fine needle aspiration** – If you have a thyroid nodule or an enlarged lymph node in your neck, you may need a fine needle aspiration (FNA) biopsy, also sometimes called a fine needle biopsy. This is done as an outpatient, sometimes during the ultrasound appointment, and takes about 15–30 minutes. If you are having an FNA biopsy:

- the area may be numbed with a local anaesthetic, the needle may be uncomfortable, but isn't usually very painful and is over quickly
- a thin needle is inserted into the nodule or node to collect some cells
- ultrasound may be used to guide the needle to the right spot
- the biopsy sample is sent to a laboratory, and a specialist doctor called a pathologist examines it under a microscope to see whether the sample contains cancer cells.

**Surgical biopsy** – If your doctor can't tell whether the nodule or lymph node is cancerous, you may have more scans or surgery to remove thyroid tissue to test (partial thyroidectomy, see pages 24–25). This

will usually confirm the diagnosis. Some thyroid nodules are difficult to biopsy because of where they are located. In this case you may also need a surgical biopsy (see page 25). It can be difficult to tell if follicular tumours are cancerous from an FNA – so they may also need a surgical biopsy.

**Genetic tests** – Also called molecular or genomic tests, genetic tests look for changes (mutations) in the genes. These changes are in the tumour cells. They are not usually needed for thyroid cancer and aren't covered by Medicare. Genetic testing (on DNA from the blood) may be used in very rare cases of medullary thyroid cancer. Genetic tests from a FNA are sent overseas and can cost over \$2100. They may give a better indication that cancer is unlikely, and avoid unnecessary surgery. In rare cases, genetic tests may be done on tissue (removed during surgery) for certain cancers that are likely to need targeted therapy. These tests are done in Australia and the cost varies.

## Other imaging scans

To see if the cancer has spread from the thyroid to other parts of your body, some people may have a CT (computerised tomography) scan or a PET (positron emission tomography) scan. This process is called staging (see pages 18–19). These scans may be done before or after any initial treatment, or at a later time to see how well treatment is working (see *Follow-up appointments*, pages 45–46).

### CT scan

A CT scan uses x-rays and a computer to create a detailed picture of an area inside the body. 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 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 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. It may take 30–60 minutes to prepare, but the scan itself takes only a few minutes.

## **PET-CT scan**

A PET-CT scan is sometimes used if other tests are unclear or if thyroid cancer has come back (recurred). To prepare for the PET scan, you will be asked not to eat or drink for a period of time (fast). Before the scan, you will be injected with a glucose solution containing a small amount of radioactive material. Cancer cells show up brighter on the scan because they take up more of the glucose solution than normal cells do. You will be asked to sit quietly for 30–90 minutes while the glucose solution moves around your body. You will then have a scan of your entire body to locate any cancer cells. The scan takes about 30 minutes.

## **Full body scan**

After RAI treatment (see pages 30–35) you usually have a full body scan to see if any thyroid or cancer cells remain in the body. This is one way your doctor can stage thyroid cancer and see if it is likely to come back (recur). It is usually only used for people who have RAI treatment.



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 or breastfeeding.

## Staging thyroid cancer

The tests described on pages 14–17 help to work out whether you have thyroid cancer and if it has spread. This is called staging. It may not be possible to precisely stage thyroid cancer until after surgery. Staging with the traditional TNM system (see below) isn't as helpful for thyroid cancer as it is for other cancers. This is because thyroid cancer usually has a good outcome, even if cancer has spread to the lymph nodes.

To help work out the best treatment for you, your doctor will classify the cancer as low, intermediate or high risk. They will consider the stage as well as the cancer type and growth pattern, whether the tumour is growing into blood vessels, and your age and general health.

### TNM staging system

The TNM staging system may be 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 if thyroid cancer has spread to 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.



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's not possible for anyone to predict the exact course of the disease.

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 in nearby lymph nodes in the neck. Even if the cancer has spread (metastasised), the outcome may often still be good.

Doctors may talk about 5-year survival rates. This is because research studies often follow people for 5 years, as cancer may be less likely to come back after that. It does not mean that you will survive for only 5 years. Thyroid cancer has a very high 5-year survival rate (97%).<sup>4</sup>

## Key points about diagnosing thyroid cancer

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### 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.
- Some people may have a surgical biopsy to remove a sample of tissue from the thyroid.
- Occasionally other tests, such as a CT scan or a PET-CT scan, are used to check whether the thyroid cancer has spread.

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### Staging and prognosis

- The doctor will tell you the size of the cancer and whether it has spread (its stage).
- The TNM system may be 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 5-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, as it may not 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 treatments available to you, possible side effects and any extra costs can help you to weigh up the options and make a well-informed decision. Check whether the specialist or MDT and the treatment centre are the most appropriate ones 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 says you have cancer, you may not remember everything you are told. Taking notes can help. If you would like to record the discussion, ask your doctor first. 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 51 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?

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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](http://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, your age and your general health. Sometimes no treatment is needed right away (see active surveillance below), but when it is, a combination of treatments is often used.

Treatment commonly includes surgery, thyroid hormone replacement therapy and radioactive iodine treatment. Less often, people may also have targeted therapy, radiation therapy or chemotherapy.

## 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 when 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.

If you choose active surveillance, a specialist thyroid radiologist will need to map the tumour. Your doctor may suggest that cancers close to muscle, the vocal nerve, trachea or oesophagus be treated with surgery.

Some people choose active surveillance if treatment side effects would make them feel worse than the cancer itself. Other people are worried or stressed by the idea of active surveillance and want to have treatment

straightaway. Some people – especially those who are younger – may not want to commit to having lifelong checks and appointments. You can usually start treatment at any stage if you change your mind about having active surveillance, or if the cancer grows or spreads.

If you agree to having active surveillance, your doctor will talk to you about what changes to look out for.

## Surgery

Surgery is the most common treatment for thyroid cancer. Before the operation, a surgeon and sometimes a specialist nurse will talk to you about what to expect. Ask them any questions and discuss any concerns you have. It is now more common to have just one lobe of the thyroid removed for smaller papillary cancers.

You will be given a general anaesthetic, and the surgeon will make a cut (usually around 3–5 cm) across your neck. How much tissue and how many lymph nodes are removed will depend on how far the cancer may have spread (see diagrams opposite).

## After the operation

You will probably stay in hospital for 1–2 nights to recover from surgery. Sometimes you may need to stay a little longer. 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 after 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 about helping your recovery.



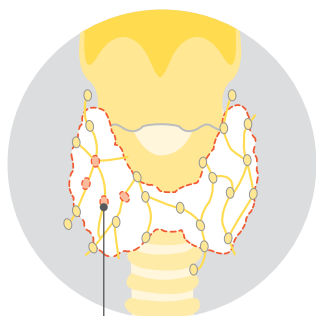
### Partial thyroidectomy

In a partial thyroidectomy (also called a hemithyroidectomy), only the affected lobe or section of the thyroid is removed. This is the most common surgery if the cancer is small and the other lobe looks normal on ultrasound. It may be used to diagnose thyroid cancer if a fine needle biopsy (see page 15) doesn't give a clear diagnosis. This is called a surgical biopsy. If cancer is found after a partial thyroidectomy, you may need further surgery to remove all or most 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). Sometimes a small amount of thyroid may be left in a near-total thyroidectomy.



Some lymph nodes may be removed

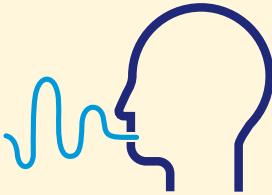
### Lymph node removal

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

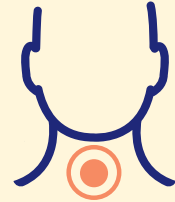
Most people who have thyroid surgery will feel better within 1–2 weeks, but recovery can take longer for some people.

### Hoarse voice



Sometimes thyroid surgery affects the nerves to the voice box, which can make your speaking or singing voice sound hoarse or weak. This is usually temporary and improves with time, but in a small number of cases can be permanent. Most people notice that 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 help with this. The position you are placed in for surgery can sometimes give you a stiff neck and back. This is temporary, and 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.

### Activity levels



Most people return to their usual activities within a week, but others may need more time to recover. You will need to avoid heavy lifting, intense exercise like running, and turning your head quickly, for a couple of weeks after surgery.

### 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.

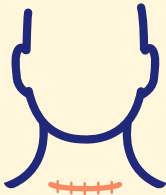
## Eating and drinking



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 improves gradually. Most people start eating and drinking 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.

► See our *Nutrition for People Living with Cancer* booklet.

## Scarring



You will have a horizontal scar on your neck above the collarbone. In most cases, the scar is about 3–5 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 suggest using special tape on the scar to encourage it to heal. Keep the area moisturised to help the scar fade more quickly over time. Ask your pharmacist or doctor to recommend a suitable cream.

## 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, you will need to take vitamin D and/or calcium supplements permanently. Calcium supplements should be taken at least 2 hours after your thyroid hormone replacement tablets (see page 28).

## Further treatment after surgery

Tissue removed during surgery is checked for cancer by a pathologist. The results help confirm the type of cancer, if it has spread to nearby lymph nodes and if any more treatment is needed. In a small number of cases, more surgery is needed to remove any remaining thyroid tissue, the thymus gland or other tissue near the thyroid.

If your whole thyroid is removed, you will need thyroid hormone replacement therapy (see below), radioactive iodine treatment (see pages 30–35) or targeted therapy (see page 36).

## Thyroid hormone replacement therapy

When the whole thyroid is removed, your body doesn't make certain hormones, so you'll need a hormone tablet to replace T4 (thyroxine). You usually start taking T4 straight after surgery, and while still in hospital. You will need to take it every day for the rest of your life. After a partial thyroidectomy, the remaining lobe usually makes hormones, so most people won't need thyroid hormone replacement therapy. Taking thyroid hormones has two roles:

**Keeping your body's metabolism at a normal healthy rate** – Without hormone replacement tablets, your metabolism will slow down and you will develop the symptoms of hypothyroidism (see page 8).

**Reducing the risk of the cancer coming back** – T4 medicine stops your pituitary gland from releasing too much thyroid-stimulating hormone (TSH). High levels of TSH can encourage the growth of any thyroid cancer cells left after treatment. If your doctor thinks there's a medium or high risk of cancer returning, you may have a high dose of T4 to reduce your TSH level – called TSH suppression.

## Finding the right dose

When you start thyroid hormone replacement therapy, you'll be monitored and have blood tests every 6–8 weeks to help get the right dosage for you. Usually, the initial dose needs only minor adjustments.

A small number of people may experience hypothyroidism or hyperthyroidism during the adjustment period. Side effects can include anxiety, problems sleeping, racing heart and sweating. However, once you are taking the right dose, you shouldn't have any side effects.



### Tips for taking T4 medicine

- Get into a routine of taking your T4 medicine at the same time every day. Take it on an empty stomach with a glass of water and wait 30 minutes before eating. Most people find it easiest to take before breakfast.
- You may need to 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 out of the fridge. Some T4 medicines do not need refrigeration – check with your doctor or pharmacist.
- Wait 2 hours before taking calcium or iron supplements as these affect the stomach's ability to absorb the T4.
- 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.
- Check with your doctor if it's safe to continue taking other medicines or supplements.
- Tell your doctor if you are pregnant or planning to get pregnant, as you may need to take a higher dose.
- Do not stop taking your T4 medicine without talking about it with your doctor first.



## 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 2 nights while I was radioactive – it doesn't hurt, it was just a bit boring being quarantined in a hospital room. Then at home, 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

This treatment is sometimes called radioactive iodine ablation or thyroid ablation. Radioactive iodine (RAI) is also known as I-131 and is a type of radioisotope treatment. Radioisotopes are radioactive substances given as a tablet or capsule (sometimes a liquid).

Radioactive iodine treatment is given in hospital, and takes a few days.

Although RAI spreads through the body, it is mainly absorbed by thyroid cells or thyroid cancer cells. RAI kills these cells while having little effect on other body cells.

You may be given RAI to destroy tiny amounts of remaining cancer cells or healthy thyroid tissue left after surgery. It is usually suggested for papillary, follicular or oncocytic thyroid cancers that have spread to lymph nodes or have a high risk of coming back (recurring) after surgery.

RAI isn't usually given for smaller cancers that have not spread. It does not work for medullary or anaplastic thyroid cancers, because these types of thyroid cancer do not take up iodine.

### When to have RAI treatment

RAI is generally not given until weeks or sometimes months after surgery. You will wait until any contrast dye from CT scans has left your system and any swelling from surgery has gone down (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 if you are breastfeeding. If you are pregnant or breastfeeding, treatment will be delayed. In this case, you may be able to wait 6 months or even longer after surgery before starting RAI treatment. Ask your doctor for more information about the timing of your treatment.

## Preparing for RAI treatment

### Limit foods high in iodine

A diet high in iodine makes RAI treatment less effective, so you need to avoid high-iodine foods from 2 weeks before treatment. This includes seafood, iodised table salt, sushi, some dairy foods and certain food colourings. Your treatment team will give you more detailed instructions about what to eat.

### Discuss 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.

### Raise TSH levels

For RAI treatment to work, you need a high level of TSH in your body. There are 2 ways to increase your TSH levels:

- **Have rhTSH (Thyrogen) injections** – 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 2 injections of Thyrogen, usually into the muscle in your buttock (bottom). The first injection is given 2 days before RAI treatment, and the second injection the day before RAI treatment. Thyrogen allows you to continue taking your thyroid hormone replacement medicine.
- **Stop taking thyroid hormone replacement medicine** – In certain circumstances you may be told to stop taking your thyroid hormone replacement medicine for 3–4 weeks, though this is not common. You will have a blood test before RAI treatment to check that your

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. Some people may first be given T3 therapy (tri-iodothyronine) to reduce symptoms, and then stop taking it about 10–14 days before having RAI treatment.

The option recommended for raising your TSH levels will depend on your stage of disease and what is suitable for you. Your specialist will explain this, and when to start taking your T4 medicine after treatment.

## **Having RAI treatment**

You will be admitted to hospital on the day of the RAI treatment. After swallowing the RAI tablet, your body fluids will be radioactive for a few days and you will need to stay in hospital during this time. See the table on page 35 for an outline of the safety measures that will be in place while you are having treatment. It's a good idea to ask any questions about this before you go into hospital, so you are prepared.

Once the radiation has dropped to a safe level, you will be able to go home. If you had Thyrogen injections, this is usually within 2–3 days. It may be a day longer if you stopped taking your T4 medicine.

A few days after treatment, you will usually have a full body scan (see page 17) to check for any thyroid cells. It's normal to see an area of RAI uptake in the neck as small amounts of healthy thyroid tissue remain after surgery. RAI takes several months to destroy this tissue.

The scan may also show if cancer has spread to your lymph nodes or other areas of your body.

## Side effects of RAI treatment

Usually, being temporarily radioactive is the only major side effect of having RAI treatment. Drinking lots of water will help the radiation to pass out of your body faster and also reduce your 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. Sometimes you may have dry or watery eyes.

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. Nausea is rarely a side effect, but if it happens there is medicine to help.

## Fertility and treatment for thyroid cancer

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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 permanently affected by surgery or RAI treatment. If you or your partner want to have a baby after RAI treatment, talk to your doctor. In the short term, it is recommended that

you delay pregnancy for 6 months after treatment. This is because RAI may have a short-term effect on eggs and sperm, so you'll be advised to use contraception for a set amount of time. Women also need to check that their thyroid hormone levels are normal before trying to get pregnant. Talk about this timing with your doctor.

## 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 your 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 needed with you before treatment. These precautions usually include:

- sleeping alone
- washing your clothing separately
- washing your hands extra thoroughly before preparing any food
- taking care with body fluids for a certain period of time
- sitting down to urinate (pee or wee), and putting the lid down and flushing the toilet several times after using it.

Sometimes these safety measures can make you feel anxious or lonely. Discuss any concerns you have with your doctors, nurses or a counsellor. It's a good idea to take something to hospital to help occupy your time – perhaps a book, tablet device, craft or puzzles.

## Targeted therapy

Targeted therapy drugs attack specific features of cancer cells, known as molecular targets, 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 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. This drug is given as a tablet, which you take daily. You will usually keep taking the tablets for several years.

Other TKIs may be available on clinical trials, including the drug selpercatinib, which targets mutations in the RET gene (see page 11). In rare or aggressive thyroid cancers, genetic tests may help your doctor tailor targeted therapy to a specific genetic mutation.

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 fatigue, 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 while you are taking targeted therapy drugs.

## External beam radiation therapy (EBRT)

External beam radiation therapy (EBRT) may be called external beam radiotherapy or just radiation therapy. It directs high-energy radiation beams precisely to the affected area, to kill cancer cells or damage them so they cannot grow, multiply or spread.

Most thyroid cancer does not need EBRT, but it may be recommended in particular circumstances:

- 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)
- to help control medullary or anaplastic thyroid cancer (because these types do not respond to RAI)
- as ongoing or palliative treatment (see page 40) to relieve symptoms such as pain caused by cancer that has spread to nearby tissue or structures. This is very rarely needed.

**Planning treatment** – EBRT needs to be carefully planned to ensure that enough radiation reaches the cancer, while as little radiation as possible reaches healthy tissues and organs.

Before the treatment starts, 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 meshed mask, but it may feel strange and uncomfortable at first. The radiation therapy team can help you manage any discomfort, so let them know if you are having trouble or feel anxious about it.

**Having treatment** – EBRT is usually personalised. Most people will have treatment 5 days a week over a period of one to several weeks. However, treatment is different for everyone so this can vary, sometimes a lot. Treatment sessions usually take about 10 minutes, but it can take up to 30 minutes to position the machine correctly.

You will lie very still on a table as the machine moves around you but does not touch you. The radiation session is painless and you won't feel anything happening to you.

## **Side effects of EBRT**

Many people develop side effects during radiation therapy to the thyroid. Common side effects include feeling tired, difficulty swallowing, sore throat, dry mouth, and red, dry, itchy, sore or ulcerated skin. Most side effects will disappear within a few weeks or months. Your treatment team can help you prevent or manage any side effects if they happen.

## **Chemotherapy**

Chemotherapy is the use of drugs to kill cancer cells or slow their growth. It is not a very common treatment for thyroid cancer, but 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.

Chemotherapy drugs are usually given by injection into a vein (intravenously). The number of treatment sessions and length of treatment time varies from person to person. Your treatment team will work out the best schedule for you.



## Side effects of chemotherapy

The side effects of chemotherapy 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.

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.

## Immunotherapy and radionuclide therapy

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 drug treatment that uses the body's own immune system to fight cancer. In Australia, clinical trials are currently testing whether immunotherapy works for anaplastic thyroid cancer.

For advanced medullary thyroid cancer, a type of radioactive nuclear medicine known as radiopeptide therapy may be available through clinical trials. This is also known as peptide receptor radionuclide therapy (PRRT). PRRT 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 immunotherapy or radionuclide therapy and how to join clinical trials.

For more information about treatments and their side effects, see our resources *Understanding Surgery*, *Understanding Targeted Therapy*, *Understanding Radiation Therapy* and *Understanding Chemotherapy*. To find relaxation exercises and meditation, listen to our *Finding Calm During Cancer* podcast series. You may also like to listen to the podcast episodes “Tests and Cancer”, “Coping with a Cancer Diagnosis” and “Making Treatment Decisions”, from our podcast series *The Thing about Cancer*.

## Ongoing treatment

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Most people with thyroid cancer respond well to treatment and don't need ongoing treatment and services. However, some people with advanced thyroid cancer may benefit from ongoing treatment or help – called palliative treatment or palliative care.

Palliative treatment helps to improve people's quality of life by managing symptoms of cancer without trying to cure the disease. The treatment offered to you 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

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### Surgery

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

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### Additional treatments

- After a total thyroidectomy, you will need to take 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. It is usually suggested for papillary, follicular or oncocytic thyroid cancers that have spread to the lymph nodes or that have a high risk of coming back. RAI treatment is taken as a pill. You will need to stay in hospital for 36–48 hours in an isolated room to safely contain the radioactivity.

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### Less common treatments

- Targeted therapy (e.g. 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. It may be used for medullary or anaplastic thyroid cancers.
- Chemotherapy is rarely used for thyroid cancer, but may be 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.

# 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 for People Living with 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, may prevent successful treatment of the cancer and can be harmful. 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 whether any financial assistance is available to you by asking a social worker at your hospital or treatment centre or calling Cancer Council 13 11 20.

▶ See our *Cancer and Your Finances* and *Cancer, Work and 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. The experience of having cancer 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 thyroid 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

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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, because counselling or medication – even for a short time – may help. Some people can

get a Medicare rebate for sessions with a psychologist. 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](http://beyondblue.org.au). For 24-hour crisis support, call Lifeline 13 11 14 or visit [lifeline.org.au](http://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 the cancer hasn't come back or spread. During these check-ups, you may have a physical examination, blood tests, x-rays or scans. You will also be able to discuss how you're feeling and mention any concerns you may have.

**Blood tests to measure thyroglobulin (Tg)** – If you have been treated for papillary, follicular or oncocytic thyroid cancer, you will have blood tests to check the levels of Tg. This protein is made by normal thyroid tissue and it may also be made by certain 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 before having a Tg blood test. This improved the accuracy of the results. However, newer Tg tests are more sensitive, and most people won't need to do this now. If a certain level of Tg is found in your blood, your doctor may suggest having scans (see pages 16–17). A small number of people have Tg antibodies. These antibodies don't do any harm, but they make it hard to accurately measure Tg. They tend to be less detectable 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 usually only needed every 6–12 months, or when there has been a change in thyroxine dose.

**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.

**Other scans** – If your doctor needs more information, or if cancer cells are found elsewhere in your body, you may have a CT or PET-CT scan (see pages 16–17). Radioisotope scans are no longer commonly used.

## **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 be in the lymph nodes. You may be offered further surgery, or a repeat of 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, immunotherapy, external beam radiation therapy or chemotherapy may also be used. You may also be able to get new drugs through clinical trials (see page 22).



# 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 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](http://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 Australia** – Carers Australia provides information and advocacy for carers. Visit [carersaustralia.com.au](http://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.

# 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 thyroid 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 by location.

### Cancer Council 13 11 20



Our experienced health professionals will answer any questions you have about your situation and link you to local services (see inside back cover).

### Information resources



Cancer Council produces booklets and fact sheets on more than 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.

### 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.

### Practical help



Cancer Council can help you find services or offer guidance to manage the practical impacts of cancer. This may include helping you access accommodation and transport services.

### 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](http://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	<a href="http://cancer.org.au">cancer.org.au</a>
Cancer Council Online Community	<a href="http://cancercouncil.com.au/OC">cancercouncil.com.au/OC</a>
Cancer Council podcasts	<a href="http://cancercouncil.com.au/podcasts">cancercouncil.com.au/podcasts</a>
Australian and New Zealand Endocrine Surgeons	<a href="http://endocrinesurgeons.org.au">endocrinesurgeons.org.au</a>
Australian Thyroid Foundation	<a href="http://thyroidfoundation.org.au">thyroidfoundation.org.au</a>
Cancer Australia	<a href="http://canceraustralia.gov.au">canceraustralia.gov.au</a>
Carers Gateway	<a href="http://carergateway.gov.au">carergateway.gov.au</a>
Department of Health and Aged Care	<a href="http://health.gov.au">health.gov.au</a>
eviQ	<a href="http://eviq.org.au">eviq.org.au</a>
Healthdirect Australia	<a href="http://healthdirect.gov.au">healthdirect.gov.au</a>
Services Australia (including Centrelink and Medicare)	<a href="http://servicesaustralia.gov.au">servicesaustralia.gov.au</a>

### International

American Cancer Society	<a href="http://cancer.org">cancer.org</a>
British Thyroid Association	<a href="http://british-thyroid-association.org">british-thyroid-association.org</a>
Cancer Research UK	<a href="http://cancerresearchuk.org">cancerresearchuk.org</a>
Macmillan Cancer Support (UK)	<a href="http://macmillan.org.uk">macmillan.org.uk</a>
ThyCa: Thyroid Cancer Survivors' Association	<a href="http://thyca.org">thyca.org</a>

# Question checklist

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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.

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## 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?
  - Are there clinical guidelines for this type of thyroid cancer?
- 

## 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?
  - Do I need to take any safety precautions after this 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

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## **active surveillance**

When a person does not receive immediate treatment, but instead has their health monitored regularly with the option of future treatment if the cancer starts growing faster.

## **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.

## **anaplastic thyroid cancer**

A rare thyroid cancer that may grow quickly.

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## **benign**

Not cancerous or malignant.

## **biopsy**

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

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## **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.

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## **endocrine system**

The system of the body that is made of glands that produce hormones.

## **external beam radiation therapy (EBRT)**

Radiation therapy delivered to the cancer from outside the body.

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## **follicular cells**

One of the two main types of cells that make up the thyroid. They produce and store the thyroid hormones T4 and T3, and make the protein thyroglobulin (Tg).

## **follicular thyroid cancer**

The second most common type of thyroid cancer, developing from the follicular cells.

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## **Geiger counter**

Instrument used to measure radiation levels.

## **goitre**

An enlarged thyroid, from either nodules or an autoimmune disease, that is usually benign.

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## **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.

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## **I-131**

See radioactive iodine.

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### **immunotherapy**

Drugs that use the body's own immune system to fight cancer.

### **intravenous**

Injected into a vein.

### **iodine**

An element that allows the thyroid to produce hormones. Found in foods such as seafood, iodised salt, eggs and some breads.

### **isthmus**

The band of tissue that connects the 2 lobes of the thyroid.

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### **lymph nodes (lymph glands)**

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

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### **malignant**

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

### **medullary thyroid cancer**

A rare type of thyroid cancer that develops from the parafollicular cells (C-cells).

### **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.

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### **neck dissection**

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

### **nodule**

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

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### **oncocytic thyroid cancer**

A rare type of thyroid cancer. Also known as oxyphilic or Hürthle cell carcinoma.

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### **palliative treatment**

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

### **papillary thyroid cancer**

The most common type of thyroid cancer, developing from the follicular cells.

### **parafollicular cells (C-cells)**

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

### **parathyroid glands**

Four glands located behind the thyroid. They produce a hormone that helps to control the amount of calcium in the bloodstream.

### **PET-CT scan**

Positron emission tomography scan combined with CT scan. In a PET scan, 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.

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### **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 I-131.

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

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

### **radioisotope**

Radioactive liquid.

### **radiologist**

A specialist doctor who analyses x-rays and scans. An interventional radiologist may also perform a biopsy under ultrasound or CT, and deliver some treatments.

### **radionuclide therapy**

The use of radioactive substances that can be taken by mouth as a capsule or liquid, or given by injection (intravenously). Also called radioisotope therapy.

### **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. Also known by the brand name Thyrogen.

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### **staging**

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

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### **T3, T4**

See tri-iodothyronine and thyroxine.

### **targeted therapy**

Drugs that target specific features of cancer cells to stop the cancer growing and spreading.

### **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 at the base of the neck. It produces hormones to control 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 T4 and T3. 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/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 controls blocks enzymes involved with cell growth. A targeted therapy drug.

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### **Can't find a word here?**

For more cancer-related words, visit:

- [cancercouncil.com.au/words](http://cancercouncil.com.au/words)
  - [cancervic.org.au/glossary](http://cancervic.org.au/glossary)
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# 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 experienced health professionals 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.



If you need information in a language other than English, an interpreting service is available. Call 131 450.



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

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

For information & support  
on cancer-related issues,  
call **Cancer Council 13 11 20**

## Visit your local Cancer Council website

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**Cancer Council ACT**  
[actcancer.org](http://actcancer.org)

**Cancer Council NSW**  
[cancercouncil.com.au](http://cancercouncil.com.au)

**Cancer Council NT**  
[cancer.org.au/nt](http://cancer.org.au/nt)

**Cancer Council Queensland**  
[cancerqld.org.au](http://cancerqld.org.au)

**Cancer Council SA**  
[cancersa.org.au](http://cancersa.org.au)

**Cancer Council Tasmania**  
[cancer.org.au/tas](http://cancer.org.au/tas)

**Cancer Council Victoria**  
[cancervic.org.au](http://cancervic.org.au)

**Cancer Council WA**  
[cancerwa.asn.au](http://cancerwa.asn.au)

**Cancer Council Australia**  
[cancer.org.au](http://cancer.org.au)

*This booklet is funded through the generosity of the people of Australia.  
To support Cancer Council, call your local Cancer Council or visit your local website.*

