

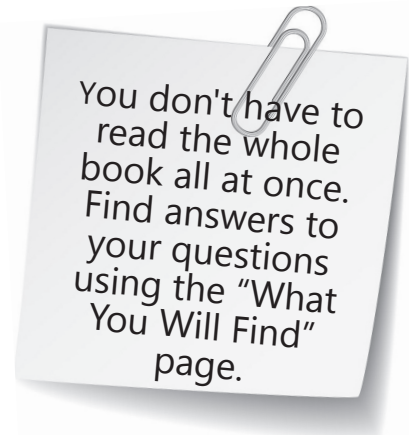
Thyroid Cancer Treatment in Alberta



This book will help you and your family understand basic information about thyroid cancer and its treatment.

This booklet includes information on:

- what thyroid cancer is
- how thyroid cancer is treated
- what comes after thyroid cancer treatment



Bring this booklet to your appointments.

Use this book as a workbook. Write down information and questions. If there is any information you don't understand, ask your health care team to review it with you.

Your health care team is here to help you and answer your questions.



For more information pick up a copy of these resources at your cancer centre:



Patient Guide (information and phone numbers for your centre)



Sources of Help (supports and resources)



<https://www.albertahealthservices.ca/cancer/Page9613.aspx>



Tell your health care provider if you:

- Are pregnant or think you may be
- Are breastfeeding
- Have recently fallen
- Have had a change to your medications

What You Will Find

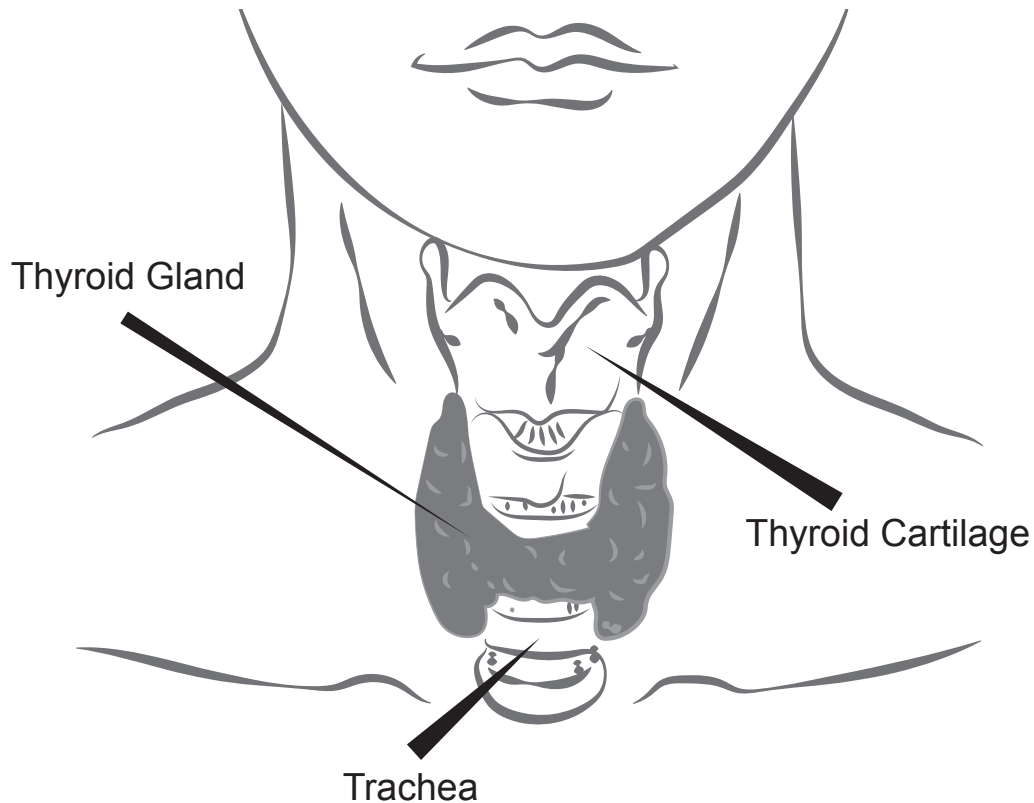
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A

Thyroid Gland General Information

Where is the thyroid gland?

The thyroid gland is located in the front of your neck close to your voice box. The gland is shaped like a butterfly — it has a right and a left lobe that is connected in the middle.



What does the thyroid gland do?

It makes hormones that help your body:

- Use energy
- Stay warm
- Keep the brain, heart, muscles, and other organs working normally

What is Hypothyroidism?

Hypothyroidism means that the thyroid gland can't make enough thyroid hormone to keep the body running normally. People are hypothyroid if they have too little thyroid hormone in the blood.

What is Hyperthyroidism?

Hyperthyroidism means there is too much thyroid hormone present in the blood. In other words, the thyroid gland is overactive and makes too much thyroid hormone.

B

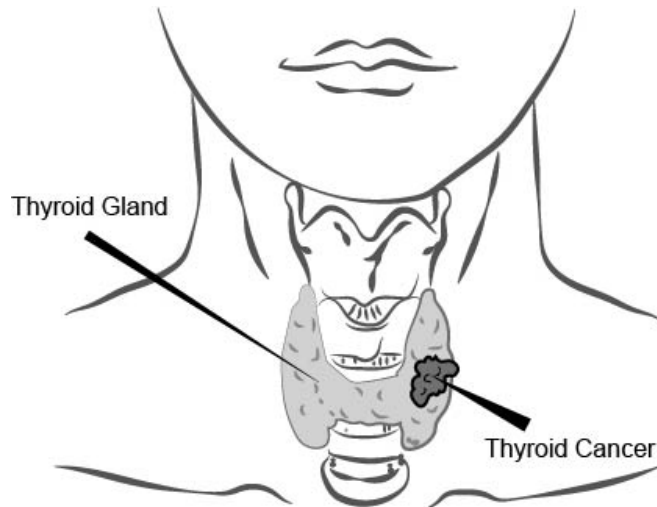
Thyroid Cancer

What is Thyroid Cancer?

Thyroid cancer develops from the cells in your thyroid gland.

The most common types of thyroid cancer are:

1. Papillary
2. Follicular



Questions to Ask After a Diagnosis

Being diagnosed with thyroid cancer can be a stressful and confusing time. Try writing your questions and their answers down.

You may want to ask your doctor:

- What kind of thyroid cancer do I have?
- Has my cancer spread beyond my thyroid gland?
- Do I need all, or part of my thyroid gland removed?
- What treatments are available, and which are best for me?
- What risks and side-effects can I expect from my treatment?
- How long will it take me to recover from surgery and treatment?
- How much time do I need to take off work?
- What are the chances that my cancer will return?

C

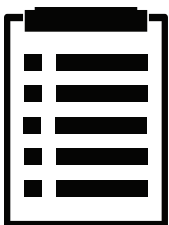
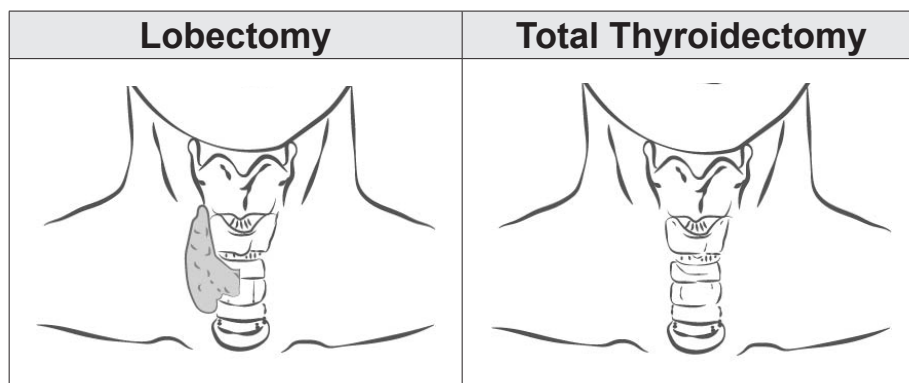
Treatment for Thyroid Cancer

Treatment for thyroid cancer usually begins with surgery to some or all of the thyroid gland. Hormone therapy is given to replace the hormones that the thyroid gland used to make. Radioactive iodine may be given after surgery to destroy any remaining thyroid tissue or area which the cancer may have spread to (metastasis).

Surgery

If your biopsy is positive for cancer, your doctor will recommend surgery. The amount of your thyroid that is removed depends on several things like your age, size of your nodule, number of nodules, and biopsy results.

- Removing one lobe is called a **lobectomy**.
- Removing both lobes is called a total **thyroidectomy**.
- Lymph nodes may be removed during surgery.



How do I prepare for surgery?

- Stock up on easy-to-prepare foods.
- Make arrangements for someone to drive you home.
- Lighten your household chores. Find a babysitter, or dog walker.
- Take time off work. It will take time to get back to normal activities. Talk to your doctor if you need special paperwork to get time off work.
- Get a special pillow. Some people find curved pillows help support the neck during recovery time.
- Some people use hot or cold packs to help minimize swelling.
- If you are having treatment in the hospital, pack for the hospital stay. Include your medications, pillow, toiletries, slippers, robe and sleepwear that opens in the front.



After your surgery

Most people will experience a stiff neck, sore throat, or a weak or hoarse voice when they wake up from surgery. This will be temporary and is caused by the position you were in for surgery, and by the tube used to help your breathe during surgery.

Patients who have more complex surgeries can experience more stiffness and discomfort and have a longer recovery. Talk to your doctor about how to manage your pain.



At home

- Take prescriptions given to you. You may need calcium or Vitamin D supplements if the **parathyroid glands** are removed or damaged during surgery.
- Eat soft foods at first if you find it hard to swallow.
- Don't sit hunched over.
- Keeping your surgical scar covered as directed.
- Rest — your recovery could take several weeks.
- Move your neck as much as you are able to, without causing pain. A physiotherapist can help if you are having trouble getting your range of motion back. Be sure to ask at your community physiotherapist clinic or local hospital if there is any provincial funding for your visits.
- You will have your stitches removed and a check up with your surgeon in about 7 to 10 days, or as instructed.



Parathyroid Glands*

Most people have four of these. Usually, they are separated from the thyroid gland and preserved if possible. Sometimes, the parathyroid glands are located inside the thyroid gland or attached to the thyroid capsule. This means that one or more of the parathyroid glands might be injured or removed when the thyroid is removed. Because the parathyroid glands regulate the body's calcium levels, your blood calcium levels are checked after surgery. If needed, we will ask you to take calcium and vitamin D supplements. Once the parathyroid glands heal and their normal function returns these supplements can often be stopped.

*Adapted from the American Thyroid Association



When can I return to work?

Talk to your doctor about your return to work. Your ability to go back to your work and normal activities depends on many things.



www.cancerandwork.com

Hormone Treatment

~ **Many thyroid cancer patients* take a daily pill of thyroid hormone.** ~

(*all patients who have had a thyroidectomy and some patients who have had a lobectomy)

How the Thyroid Pill Works

These pills work to do two things:

1) Replace your thyroid hormone

A normal thyroid gland produces thyroid hormone. Because the body needs thyroid hormone to function, people who have had their thyroid removed and/or treated with radioactive iodine need to take a pill form of this hormone because they can no longer produce it themselves. Thyroid hormone is important as it helps the heart, lungs, metabolism, energy, and mood. **Taking thyroid hormone daily decreases the chances of the cancer returning.**



Taking thyroid hormone is different from taking other medications, because its job is to replace a hormone that is missing. The only safety concerns about taking thyroid hormone are taking too much or too little. Your thyroid function will be checked regularly by your doctor to make sure you stay in the range that is right for you.

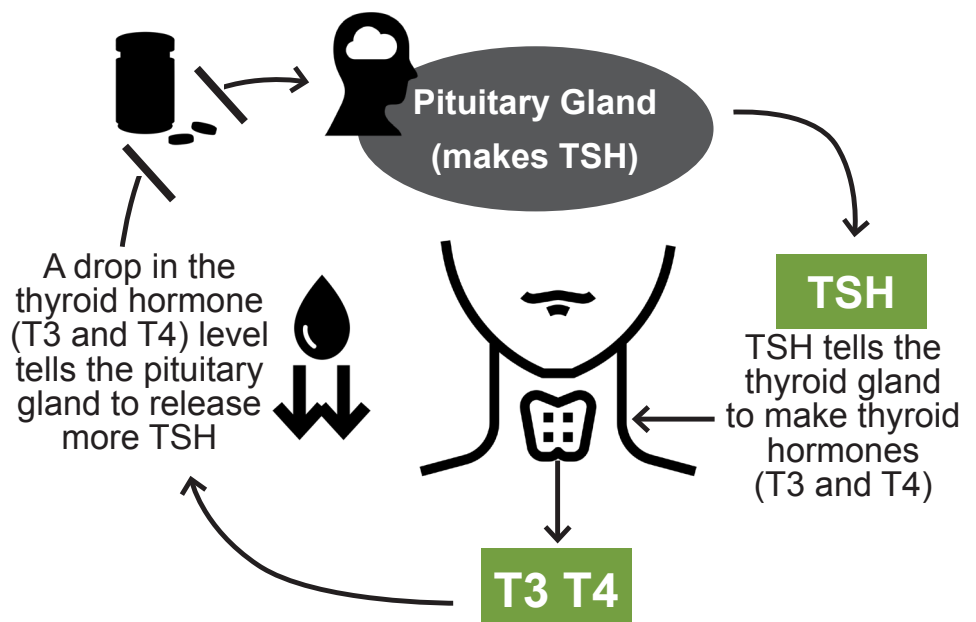
What do I need to know about taking thyroid hormone?

Take your thyroid pill:

- everyday at the same time, if possible (don't skip a dose)
- only with water
- on an empty stomach, 30 minutes before or 3 hours after meals
- without any food or drinks (including coffee), or other medications (especially calcium), as this can stop it from being absorbed by your body properly. Take your calcium supplements 4 hours after taking your thyroid hormone replacement pill.

2) Suppress your TSH (Thyroid Stimulating Hormone)

Part of treatment includes suppressing (stopping) the body from making too much TSH (thyroid stimulating hormone). TSH is the hormone that tells the thyroid gland to make more hormone and also tells the thyroid cells to grow. By giving you thyroid hormone, we suppress the TSH and stop the thyroid cancer cells from growing. The goal is to **break** the feedback loop, shown in the picture. Taking your pill everyday will do this.



My TSH Target Range

Your healthcare team will monitor your thyroid hormone levels closely, and try to keep you in a therapeutic range. This range changes for people depending on their diagnosis.

Write your range here:





Usually, when people have thyroid cancer, they are given a higher dose than someone who just needs to have regular thyroid hormone replacement. **It is important that you contact your cancer doctor if another doctor wants to decrease your thyroid hormone dose.**



Tell your doctor if you have heart disease or osteoporosis (weak and fragile bones).

What happens if my dose changes?

If your dose changes, it usually takes about 6 weeks for your lab results to reflect the change in dosage. A blood test should be done 6–12 weeks after the dose changes. When you start, it can take a while to get the dose right at first. Your doctor will adjust it as needed.

What are the possible symptoms of too much thyroid hormone? (Hyperthyroid)

This is when your TSH is too low.

• nervousness	• heart racing	• increased sensitivity to heat
• shakiness	• diarrhea	
• trouble sleeping	• tiredness (fatigue)	

What are the possible symptoms of too little thyroid hormone? (Hypothyroid)

This is when your TSH is too high.

• tiredness (fatigue)	• puffiness/bloating	• light-headedness
• weakness	• memory loss	• dry eyes, skin and hair
• trouble sleeping	• anxiety; depression	• muscle pain
• constipation	• intolerance to cold	• difficulty concentrating
• itchiness		



Be careful driving if you are off of your thyroid medication (hypothyroid). Your reaction time and ability to concentrate will be affected.

Radioactive Iodine (RAI)

After surgery radioactive iodine treatment (RAI) **may** be recommended to destroy any remaining thyroid tissue (both healthy and cancerous). RAI is the best treatment for destroying remaining cancer cells.



How does RAI work?

- The thyroid gland absorbs iodine from foods we eat or drink. After thyroid surgery, remaining thyroid tissue or thyroid cancer cells can still absorb iodine.
- This radioactive form of iodine **gives off radiation**. Cells that absorb the radioactive iodine are damaged or killed.
- It is TSH that stimulates the thyroid tissue (normal or cancerous) to take up the radioactive iodine. This is why your TSH level must be well above the normal range for this treatment to be the most effective.
- The iodine that is not absorbed by thyroid tissue is passed out of the body through saliva, sweat, bowel movements, and urine (see page 10 for safety precautions).
- Following the instructions we give you will prepare your thyroid cells to take up more iodine (see “How do I prepare?” page 8 & 9).

How is RAI given?

- Radioactive iodine is given as a liquid to drink, pill or injection. The most common way is as a liquid.
- You may need to fast (no eating or drinking) before and after the treatment. We will give you instructions if you need to do this.
- After drinking radioactive iodine, you will be temporarily radioactive and must stay away from other people (see Section D, page 10 for safety precautions).
- This treatment cannot be used during pregnancy. Women will be asked to take a pregnancy test 24-72 hours before treatment to confirm they are not pregnant.

Radioactive iodine treatment is usually given as an **outpatient** treatment. In certain circumstances patients will need to stay in hospital.

My treatment will be:

<input type="checkbox"/> As an outpatient	<input type="checkbox"/> In hospital
Usually: <ul style="list-style-type: none"> • you will go home shortly after drinking the treatment • at home you will need to stay away from other people and use your own washroom 	Usually: <ul style="list-style-type: none"> • you will stay in hospital for about 24 hours • you stay in a semi or private room, away from other people until your radiation level is low enough for you to go home



You will be given information and instructions for your treatment as an outpatient or in hospital. **Follow these carefully.**

Read **Section E Radiation Safety** for more information.

How do I prepare?

If you require a radioactive iodine treatment or a scanning dose of radioactive iodine, we will ask you to prepare in 2 ways by:

1. Following the Low Iodine Diet (LID), starting 1–2 weeks before your treatment (or as directed by your doctor) and for 1–2 days (24–48 hours) after the treatment. See **Section F** for more information.

2. ONE of the following procedures (your health care team will tell you which one; check off the box you should follow)

Going Hypothyroid
(thyroid hormone withdrawal)

- Stop taking your thyroid replacement pills (levothyroxine; Synthroid® or Eltroxin®) for the period of time your doctor tells you. You may also be asked to remain off hormone replacement until 24–48 hours after the radioactive iodine treatment or scanning dose has been swallowed.

I will stop taking my thyroid replacement on:

- You may experience some side-effects from being off your thyroid medications (see the hypothyroid symptom list on page 6).
- Most patients feel a worsening of symptoms in the 3–4 weeks they are not taking any thyroid hormone. Once they are back on hormone replacement, the symptoms gradually go away.

The goal is to have as much radioactive iodine as possible be taken into the thyroid cells. To do this you must allow your TSH hormone level to rise to a level of at least 30 mIU/L.

To know if this level has been reached, you may have your TSH level measured in the days before the treatment.

Write notes here:

– OR (see next page) –

Thyrogen® Injections
(to stimulate TSH)

- The injections stimulate the thyroid cells to absorb the radioactive iodine better.
- **Continue to take your thyroid replacement pills.**
- Thyrogen® is administered by a health care provider by 2 injections, 1 and 2 days before the radioactive iodine dose (one injection per day).
- Rarely, patients have mild headaches or nausea and vomiting after taking Thyrogen®.
- The injections are given at your family doctor's office or community pharmacy (not at the cancer centre). You will get the prescription and information telling you when you should go, in the mail. You must make your own appointment.

Write your appointments here.

I will go to _____ for my Thyrogen® injections.

First dose: _____

Second dose: _____

Write notes here:



Day of RAI Treatment

- Follow all of the instructions you were given by the Nuclear Medicine department.
- You **may** not be able to eat or drink for a period of time before and after your treatment.



I don't need to fast

I need to fast (no eating or drinking)

_____ hours before treatment

_____ hours after treatment

D

Side Effects from Radioactive Iodine (RAI)

Possible side effects:	Things you can do:
Neck pain and swelling of the thyroid	<ul style="list-style-type: none"> • Use Tylenol® • Use Ibuprofen, Advil®, Motrin® • In some cases, your doctor may prescribe a cortisone pill for a short period of time
Nausea, occasional vomiting	<ul style="list-style-type: none"> • Use Graval®
Soreness and swelling in the salivary glands (Salivary glands also take up the radioactive iodine; swelling may happen any time 6-12 months after treatment)	<ul style="list-style-type: none"> • Use Ibuprofen • Gently massage the area • Apply gentle heat (warm cloth) to the area • In severe cases, your doctor may prescribe cortisone
Dry mouth and decreased saliva (A greater risk with more than two RAI treatments)	<ul style="list-style-type: none"> • Increase fluid intake • Eat sour candies (as directed by your care team to help prevent dry mouth) • Pick up a copy of “Mouth and Dental Care for Cancer Patients” from the cancer centre.
Blockage of tear ducts (Not common. RAI is present in your tears and may cause scarring of this passageway, which then blocks the ducts, stopping the tears from draining properly).	<ul style="list-style-type: none"> • An eye doctor can put a tiny plastic tube into the tear duct passageway so tears drain properly
Fertility & Pregnancy	<p>Men:</p> <ul style="list-style-type: none"> • may cause a decrease in sperm count which usually recovers to normal • use protection to prevent pregnancy during and for at least 6 months after having RAI treatment <p>Women:</p> <ul style="list-style-type: none"> • must not be pregnant on RAI • use protection to prevent pregnancy during and for at least 6 months after having RAI treatment • the onset of menopause may be 1.5 years earlier
Drop in white blood cells and platelets	This may happen after several treatments with RAI
Risk of causing a different cancer	This is rare: it happens in less than 1 in 100 people



What if I am pregnant and need treatment? RAI must not be used during pregnancy. If you are pregnant you and your doctor will discuss other options. You cannot breastfeed during or after receiving this treatment.

What you should do to reduce radiation exposure to others:



Bodily fluid spill

In the 48 hours after treatment:

- Wear disposable gloves to clean up spills.
- Any spill of urine or vomit should be covered with paper towel or Kleenex.
- Make sure that no one goes in the contaminated area.
- The radiation safety officer will give you detailed instructions.



Candies or Gum

- You may be told to suck candies or chew gum. Follow any instructions you are given and throw away your chewed gum properly (see Garbage).



Dishes and utensils

- Regular dishes and utensils can be washed in the sink or dishwasher. Dishwasher is preferable, on a longer wash cycle. (You may rinse your plate first, if needed)
- If you don't have a dishwasher and use disposable utensils, throw them away in a separate garbage (kept away from others), along with any remaining food from plates.



Emergency and Medical Clinic Visits

- If you go to a medical clinic or hospital in the 7 days following your therapy, immediately inform the doctor or nurse of your radioactive iodine treatment.
- In case of emergency, go to the nearest hospital but when you arrive, tell them right away that you had radioactive iodine. You should also contact the radiation safety officer (but do not wait to go to hospital, if needed).



Food preparation

- Do not prepare food for others for the first 3 days.



Garbage

- Keep your garbage separate and away from others. If stored outside, make sure it is in a can with a lid to prevent animals from spreading it around.
- Put garbage with contaminated items into the trash for collection as directed by your health care team.



Kleenex and tissues

- Throw all Kleenex or tissue into a separate garbage and keep the garbage separate, away from others.
- We recommend using toilet tissue and flushing it down.



My clothes or linens

- Keep your linen and towels separate from others.
- Wear washable clothes. Do not wear clothes that require dry cleaning.
- Wash your clothes, towels and bed linens separately for the period of time recommended by your health care team.



My eyes

- Wear glasses instead of contact lenses.



My feet

- Do not go barefoot, wear socks, slippers or shoes at all times.



People

- Keep distance between yourself and others. **This depends on the amount of radioactive iodine you have.** Nuclear Medicine staff will tell you how long you must do this for.
- Keep the time you are in prolonged close contact to others to a minimum (prolonged time is a few minutes or more; close contact 2 meters (6.5 feet) or less.
- Do not have prolonged close contact with pregnant women or children under 12.
- If possible, travel home from treatment by yourself. If someone else is driving, stay as far away from the driver as possible, such as the back passenger seat.



Showering

- Take a shower everyday for the first 3 days.



Sleeping

- You will need to sleep separate for a period of time. How long you need to do this depends on your dose. The radiation safety officer will give you more detailed instructions.
- I need to sleep separate for _____ nights.



Toilet Use and Hand-washing

- You **must have your own bathroom** for the first 48 hours.
- With the lid down, flush the toilet 2-3 times after you use it and wash your hands afterwards.
- Men should sit to urinate to avoid splashing for the first 72 hours. Wipe up urine splatters with toilet paper and flush.
- Usually you can return to normal toilet routine 48 hours after the treatment, or as directed by your health care team.



Travelling

- If you will be travelling internationally within 3-4 months after treatment, ask for a letter from the staff giving you the RAI treatment. Small amounts of radiation can be detected by security scanners at airports and border crossings for international travel.



What is Nuclear Medicine?

Nuclear medicine is a medical specialty which uses safe and painless techniques to see what is going on in the body (imaging) and to treat disease. It uses small amounts of radioactive materials which are designed to be attracted to specific organs, bones, tissues or tumors. The radiation the materials give off can be detected by special cameras to get images of organs and tissues.

Common Imaging Tests

Common tests which **may** be done **before, during, or after** treatment for thyroid cancer include:

- Neck Ultrasound
- MRI (Magnetic Resonance Imaging)
- Chest X-ray
- PET (Positron Emission Tomography) scan
- Radioactive iodine scans
- CT (Computed Tomography) scan
- Bone scans
- PERT (Pertechnetate Thyroid) scan



Phone Numbers

Contact information will be given to you. Use this space to write other important phone numbers or staple a business card.

Name	Phone Number

G

Low Iodine Diet

A low iodine diet can help improve the success of radioactive iodine treatment. Iodine can be found in varying amounts in **all food and beverages**.

Avoiding iodine in your diet for 1–2 weeks before radioactive iodine treatment helps your thyroid gland absorb more of the radioactive iodine.

Visit the Thyroid Cancer Canada website to download or print a copy of the Low Iodine Diet booklet.



For a list of foods allowed and foods to avoid, along with diet ideas and tips visit:

www.thyroidcancercanada.org and search for the Low Iodine Diet booklet

Note: A low-iodine diet is **not** the same as a low-salt diet. Most salt in Canada and the United States **has iodine**, so low-iodine diets avoid iodized salt, but **non-iodized** salt is okay to eat.



H

After Thyroid Cancer Treatment

Hormone Therapy

Hormone therapy is lifelong. After a total thyroidectomy, you will need to take thyroid hormone medicine to replace the hormones that your body no longer makes.

- At the right dose, thyroid hormone therapy rarely causes side effects. Too much or too little thyroid hormone can cause side effects (see page 6).
- High doses of thyroid hormone can cause a rapid or irregular heartbeat, and over time can cause weakness in your bones (called osteoporosis).

Follow Up

You will have follow-up visits with your doctor. Ask your doctor how often you will be seen.

- You will have a physical exam of your neck and thyroid area
- Your doctor will order: blood tests (such as thyroglobulin), a neck ultrasound, and other tests or scans

Tell your doctor if you notice another lump in your neck or have trouble swallowing.

Neck Exercises

Neck tightness is common after surgery or radiation treatment. You may notice that it is more difficult to turn or tip your head, or look up at the ceiling. It is important to exercise your neck to stop the tightness from developing. Ask for a copy of the Jaw and Neck Exercises and practice the neck exercises on the handout. If you notice tightness developing, ask for a referral to a physiotherapist.


Cancer Recurrence

Thyroid cancer can come back. If thyroid cancer does come back, it may be found during a physical examination, on an ultrasound, or from your blood work.

Unlike other types of recurrent cancer, **recurrent thyroid cancer is often cured**, especially if it has spread only to the lymph nodes in the neck.

Recurrent thyroid cancer or thyroid cancer that has spread (metastasized) to other parts of the body may be treated with surgery, radioactive iodine, radiation therapy, or systemic therapy.

Clinical Trials

Your doctor may talk to you about being in a clinical trial. For some people with thyroid cancer, taking part in a clinical trial may be the best treatment choice. Clinical trials for thyroid cancer are looking at targeted therapy with tyrosine kinase inhibitors.  www.albertacancerclinicaltrials.ca

Pregnancy & Breastfeeding


Do not become pregnant for 6 months after radioactive iodine treatment. You cannot breastfeed during or after RAI treatment.

I

Resources for Support

Psychosocial Oncology

Provide patient and family counselling and emotional, psychological and spiritual support. Resources and programs can vary. Contact the closest centre, to find out more.


 403-355-3207 (Calgary)

 780-643-4303 (Edmonton)

Support Groups

Thyroid Cancer Canada

The Thyroid Cancer Canada website has information for people who have been diagnosed with thyroid cancer and their families, including email and telephone support, and an online question forum.

 1-416-487-8267

 www.thyroidcancercanada.org

 info@thyroidcancercanada.org

Support groups give those living with cancer an opportunity to interact with others in similar situations. Some are led by health care professionals while others are led by community members. They can be held in person or online.




Look for more
resources in
Sources of Help

Community Support

Canadian Cancer Society

It can be helpful to talk with someone who has also had thyroid cancer and finished treatment. The Canadian Cancer Society's Cancer Connection program is a support network that offers peer-to-peer support to cancer patients and their caregivers. You can talk with caregivers or current and former patients with your same type of cancer. Call 1-888-939-3333 or visit

 1-888-939-3333

 www.cancerconnection.ca

Wellspring

Wellspring is a community organization that offers one-on-one sessions for those diagnosed with cancer, their caregivers, or both, to meet with trained volunteers who have experience with cancer. Wellspring also hosts meetings for several support groups. People who live out of town are welcome to attend.

Calgary  403-521-5292

 wellspringcalgary.ca

Edmonton  780-758-4433

 wellspring.ca/edmonton



Alberta
Cancer
Patient
Education

