

Patient's Guide to Thyroid Cancer

for those diagnosed with papillary or follicular cancer



INFORM. SUPPORT. EMPOWER.

For more information about this booklet or to obtain copies, contact us at:

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Introduction



INFORM. SUPPORT. EMPOWER.



This booklet provides an overview of thyroid cancer, its management and what to expect, from a patient's perspective. It was written by thyroid cancer patients and reviewed by members of the Thyroid Cancer Canada Medical Advisory Panel. For detailed medical information, please consult your doctor. There are also some helpful websites listed at the end of this booklet.

More than 85% of thyroid cancer cases are known as "well-differentiated thyroid cancer" (WDTC). Only WDTC is covered in this booklet. Whenever you see "thyroid cancer", we are referring to WDTC.

For information about other forms of thyroid cancer, please visit **thyroidcancercanada.org**

Thyroid Cancer Canada provides a wide variety of helpful support and resources which can be found at **thyroidcancercanada.org**

What is thyroid cancer?

The thyroid is a butterflyshaped gland at the front of
the neck, just below the larynx
(voice box) and on top of the
trachea (windpipe).

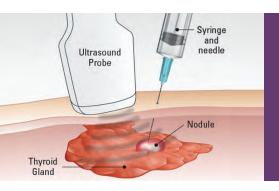
The thyroid gland produces hormones, called T4 and T3, which are vital to the normal functioning of your body. Too much or too little can result in bothersome symptoms, so keeping a steady level is important to feeling well.

The thyroid gland tends to develop nodules (small lumps). In fact, at least half of the population has nodules – 95% of which are benign (noncancerous). Sometimes though, nodules are not benign – and are cancerous. This happens when cells mutate, or become 'abnormal'. Why this happens is not completely understood. Thyroid cancer is normally slow-growing, and it may take many years for a nodule to become apparent on touch. People may also have other symptoms, like a hoarse throat or a feeling of fullness in the neck.

As a patient with thyroid cancer, know that you're not alone. AND, it's often curable. What's important is to be engaged in your own care, which includes:

- Being informed. This brochure is one way to learn about your condition and treatment options.
 ThyroidCancerCanada.org is another valuable resource.
- Asking for help. Don't be afraid to reach out for support. Thyroid Cancer Canada provides support by telephone, email, and on our online forum. Your family and friends, as well as other community resources, may also be helpful.
- Working with your doctor. Ask questions, get copies of your results/ reports, and follow-up if you don't have the answers you need.

How is thyroid cancer detected?



Thyroid cancer is detected by a procedure called Fine-Needle Aspiration Biopsy (FNAB or FNA).

Thyroid cancer is detected by a procedure called Fine-Needle Aspiration Biopsy (FNAB or FNA), also referred to as fine-needle aspiration cytology (FNAC). Nodules greater than 1 or 1.5 cm are usually examined with an FNA.

What does an FNA feel like?

A specialist (usually a surgeon or radiologist) will insert a needle into one or more nodules in your neck area and withdraw cells. He/she may put the needle in the same nodule more than once and take several samples to

be sure the samples were withdrawn from the right places. The doctor will ask you to put your head back for the procedure and you will feel a poking and pulling sensation. Most people feel that the process is somewhat uncomfortable and may feel anxious, but it's usually a very short procedure. It is not uncommon to have some soreness from the FNA for a few days afterwards, feeling a bit like a bruise. The procedure is very safe and does not cause spread of cancer.

Did you know?

80% of thyroid cancer patients are women. Thyroid cancer has a 98% cure rate. The rate of thyroid cancer is rising faster than any other cancer – yet it receives only 0.2% of cancer research dollar.



Why did I get thyroid cancer?



It's common for patients to ask: "Why me?"

Know that there is nothing you did that caused your thyroid cancer. Thyroid cancer can affect anyone. But, certain people appear to be at greater risk.

Risk factors include:

- **History** (if you've had it before, or if a family member has)
- Age (higher risk in people over 45 years old)

- **Gender** (80% of those with thyroid cancer are women; but, men tend to have more aggressive forms)
- External beam radiation (i.e., if you've received radiation for other cancers)

For the vast majority of individual patients, the cause of thyroid cancer is unknown.

How is thyroid cancer treated?



There are many treatments available for thyroid cancer, with excellent success rates. If you have thyroid cancer, your doctor will determine a treatment plan based on your

symptoms, disease characteristics and individual needs. Treatment may include the following, which are discussed in detail in the next several pages:

Treatment options	Who it's recommended for
Surgery	All cases*
TSH suppression with thyroid hormone replacement	Some cases
Radioactive Iodine treatment (RAI)	Some cases
External Beam Radiation (EBR or XRT)	Rare
Chemotherapy	For medullary thyroid cancer and cancer that does not respond to RAI
Tyrosine Kinase Inhibitors (TKI)	Usually reserved for anaplastic thyroid cancer or other aggressive forms
Follow-up	All cases

^{*}Some micro-tumours (< 1cm) may be followed regularly and not require surgery.

Surgery

Surgery is the most common treatment option.



Almost all forms of thyroid cancer are treated with surgery (**thyroidectomy**), in which some (partial thyroidectomy) or all of the thyroid (total thyroidectomy) is removed. This is done to remove the cancerous cells. If your tumour is very small (< 1 cm), your doctor may recommend routine follow-up instead of surgery.

How much of your thyroid is removed can vary based on several factors, including:

- Age
- Gender
- Size/number of nodules
- Lab results
- Genetics (i.e., if you have a gene for thyroid cancer)

Sometimes, a more complete diagnosis is made after a partial thyroidectomy, and a total thyroidectomy is needed.

If you have a more aggressive form in which cancer spreads to the lymph nodes, these will likely be removed during your thyroidectomy. How much is removed depends on the extent of spread. If you have questions or concerns about the possibility of lymph node removal and what this means, ask your doctor.

What should I do to prepare for surgery?



There are several things you can do to prepare for surgery.

- **1. Plan meals.** Stock up on easy-to-prepare or pre-made meals for your return home after surgery. Soft, high-fibre foods are recommended (e.g., oats, brown rice).
- **2. Pack for your hospital stay.** Things you may need: medications you're taking, a pillow, toiletries, slippers, a robe and sleepwear (choose pajamas or nightgowns that open in the front).
- **3. Find a driver.** Make arrangements for someone to drive you home on the day of surgery.
- **4. Lighten your workload.** You may need a few weeks off work to recover, so you may wish to notify your employer in advance (if applicable). Make needed arrangements (e.g., babysitter, dog walker) to ensure you get the rest you need.

- **5. Use a special pillow.** A 'dog bone' or curved pillow may be helpful. Some people find they help support the neck during recovery. Hot or cold packs may also be used to minimize any swelling.
- **6. When you are released**, keep track of the notes and prescriptions given to you.
- **7. Care for your incision.** Follow your doctor's instructions for keeping your incision covered and/or the use of ointments to minimize or prevent scarring.
- **8. Rest.** Be sure to get the rest you need, and lean on loved ones for help. Recovery usually takes several weeks.

What can I expect after surgery?

Most patients feel back to normal within a few weeks of surgery.

Although it can vary, most patients feel "back to themselves" within a few weeks of surgery. The incision scar can remain red for about 6 months, but usually fades – or disappears – in time. Those who have a lateral or bilateral neck dissection tend to have a longer recovery time, and may experience numbness or weakness in the neck and shoulders, which typically resolves. Physiotherapy can help ease these symptoms.

In rare cases, the parathyroid glands need to be removed during surgery.

These glands help regulate the amount of calcium in your body. Your doctor will tell you if this was needed in your particular case. If so, you will need to take calcium and vitamin D supplements. Talk to your doctor to learn more.

Very rarely, people experience some degree of voice loss or hoarseness, which typically resolves within weeks. If it doesn't, talk to your doctor to see what can be done, such as working with a speech pathologist.

Questions to ask your surgeon post-surgery



- What type of thyroid cancer do/ did I have?
- How many thyroid cancer nodules did I have and how big was each?
- How many lymph nodes were removed during the surgery, and from which part of the neck? How many of those were cancerous?
- What are my chances for recurrence?
- Which follow-up procedures will I require?
- Which doctor are you referring me to see for follow-up on a regular basis?
- What is my initial dose of hormone replacement?

Tips

- Write your questions down in advance and bring a friend/relative to help you absorb the information as it can be a lot to take in.
- Ask for a copy of the pathology report from your surgery and start a file for all your reports/tests.

Radioactive Iodine treatment (RAI)



Radioactive Iodine treatment (RAI) is a common way to treat thyroid cancer. It's not the type of radiation you may think of when you think of cancer treatment. RAI is taken by pill — once swallowed, the radioactive iodine gets to work by destroying cancer cells.

RAI is usually only considered for those with stages 2-4 of thyroid cancer, which is considered higher risk. Those

at a low risk of recurrence generally do not need RAI.

This includes patients:

- Who have only one cancerous nodule without 'aggressive features'
- Less than 45 years old
- With no family history of thyroid cancer
- With stage I thyroid cancer

What does RAI do?

RAI is taken by pill – once swallowed, the radioactive iodine gets to work by destroying cancer cells.

RAI treatment destroys any remaining thyroid cells (both normal and cancerous) after surgery, minimizing the risk of the cancer coming back. It is also called ablation therapy.

The initial RAI treatment may be given anytime, but usually 6 weeks to 6 months after surgery. The reason for a delay may be because your doctor wants to see how you're doing after surgery before deciding if RAI is necessary.

How can I prepare for RAI?

One way to maximize the effects of RAI is by raising your TSH level.

There are 2 ways to do this:

- Stop hormone replacement ("Going Hypo"; see page 15)
- Receive Thyrogen® (see page 16)

For either, it is also recommended that you go on a Low Iodine Diet. (see page 18)

Because you are receiving a radioactive substance, there are some precautions you should be aware of, as discussed in the following page.

RAI: Frequently asked questions

When can I go back to my regular routine?

1. Can I isolate myself in a hotel room?

No, this is not recommended as there is a chance the housekeeping staff will come into contact with the RAI you discharge from your body.

2. How do I protect my children? If you have young children, it is best that they stay with a relative for the first few days, or that you stay in hospital isolation. You may also consider other suitable alternatives (e.g., a cottage, a friend's place if they are away).

3. What side effects can I expect?

Most people have few side effects or they are very temporary. Almost all have an altered sense of taste for the first few days or weeks (e.g., food tastes like "Styrofoam"). Rarely, this effect lasts longer. In some cases, patients experience damage to their salivary glands and/or tear ducts (30%), which is usually temporary. Some people experience mild pain in

their cheeks, mouth dryness and/or blocked tear ducts, which may require treatment from specialists.

Occasionally, months after RAI treatment, patients feel soreness or swelling in glands of the face or neck. This usually lasts less than two weeks.

4. When am I "good to go" (be with other people and go back to work)?

After RAI treatment, you will have a Whole-Body Scan (WBS) about 5 to 7 days later. After this, patients are typically given the "go ahead" to resume normal activities. You should be aware that a tiny amount of radioactivity remains in your body for months afterwards, which could set off alarms at border crossings and airports. Border security systems have precision and can usually recognize that you have ingested a harmless medical isotope (I-131). But, if you are travelling within two months of treatment, you may want to have a note from the hospital explaining that you had medical treatment with radiation.

Tips for hospital-based isolation



- Bring a supply of Low lodine Diet snack foods as you are advised to remain on LID for 24-48 hours after treatment.
- Bring comfortable clothing or night wear, anti-nausea medication (some patients feel nauseated after treatment), other medications you normally take, toiletries, and something to keep you busy. Check with your hospital if you are allowed to bring in electronic devices.
- You may be advised to suck on sour fruit or candy every few hours to increase your saliva flow and decrease the chance of salivary damage. So, it's a good idea to bring some lemon wedges or grapes.
- Keep in mind that you will also be asked to drink a little more water or juice than usual. Some hospitals also advise their patients to take a laxative
- Bring something like an electronic device or book to keep yourself occupied.

What does a Whole-Body Scan (WBS) feel like?



All patients who have RAI treatment return to the hospital to have a **WBS** about a week later. Most WBS machines look like a box-like object that moves over your body one section at a time, or continuously, while you lie on a narrow bed. The machine is silent. Usually you are only asked to remove your glasses and jewellery. The procedure takes about 45 minutes. When the machine is over your head area, it is extremely close to your face, so it may help to close your eyes.

Remember that the procedure is not painful or uncomfortable. However, you must lie completely still for a clear

image to be produced. The procedure does not subject you to radiation exposure, but rather, produces images of the RAI you took. You may see an image of your body on a nearby computer monitor as you are being scanned. In some facilities, the radiologist immediately reports the results to patients, but typically, a report is sent to your doctor, who gives you the results a few days later.

Occasionally, the WBS image is not as clear as they hoped and the radiologist may ask you to come back and repeat the procedure a few days later.

What does "Going Hypo" mean?

Our bodies require thyroid hormone to function normally.

Our bodies require thyroid hormone (T4) to function normally. This is why people need to take a synthetic (man-made) form of the hormone, by pill, once the thyroid has been removed. **Synthroid**® and **Eltroxin**® are brands of thyroid (T4) pills in Canada.

Without thyroid hormone, the body produces more and more thyroid stimulating hormone (TSH). A high level of TSH is needed for RAI treatment to be effective. This is why your doctor may instruct you to stop taking your thyroid pills 4-6 weeks before starting RAI treatment.

Temporarily stopping your thyroid pills

may cause symptoms of hypothyroidism (low thyroid levels). Symptoms tend to be more common in the 2 weeks leading up to your RAI treatment.

They include:

- Tiredness
- Trouble sleeping
- Puffiness in the face; bloating
- Poor concentration
- Weight gain

Your doctor may prescribe a drug called **Cytomel®** to help ease these symptoms of hypothyroidism.

Thyrogen[®]



As an alternative to 'going hypo', patients can receive a drug called **Thyrogen®** before RAI treatment. Thyrogen® raises TSH levels – so patients can continue taking their daily thyroid pills. So, there is no risk of having the symptoms of hypothyroidism.

You need to visit your healthcare provider twice to receive Thyrogen® injections in the 2 days before starting RAI. Thyrogen is associated with mild side effects, if any.

Thyrogen® is provided as a kit. The kit does not come with sterile water which is a necessary ingredient, so if you are filling your prescription themselves at a pharmacy, you will need to purchase sterile water from the pharmacist (cost can be up to \$10).

Thyrogen tips

You may or may not be covered for Thyrogen® depending on your province. In provinces where the cost of Thyrogen® is not covered under the provincial health plan, it is covered by most private plans so you may want to check with yours (if applicable).

For additional information, contact Genzyme (who manufacturers Thyrogen®) at 1-800-745-4447 or medinfo@genzyme.com.

Thyroid Stimulating Hormone (TSH)



In patients with papillary or follicular thyroid cancer, surgery is the usual form of treatment. In addition, **Thyroid Stimulating Hormone (TSH)** treatment is given. TSH helps regulate the levels of thyroid hormones in the body.

In healthy people (with normally functioning thyroid glands), TSH should be to be about 0.4 to 5.0 μIU/mL.

In people with thyroid cancer, TSH drops to 0.01 to 3.0 μ IU/mL. This is because thyroid hormone replacement pills suppress the production of TSH. Low TSH helps prevent cancer recurrence, but a careful balance of hormone levels is important.

When a person's thyroid gland is removed, they can no longer produce thyroid hormone (T4), which is important for the body to function normally. For this reason, they take a man-made form of thyroid. In Canada, thyroid pills go by the names **Synthroid®** and **Eltroxin®**.

A balance between TSH and thyroid hormone is needed so that you can feel at your best. While a low TSH helps reduce recurrence risk, too much or too little thyroid hormone can result in bothersome side effects.

Low Iodine Diet



Another important part of RAI treatment is to reduce your iodine intake by following a **Low Iodine Diet (LID)**. This helps maximize the absorption of the radioactive iodine in your body. It is normally recommended you start on a LID 2 weeks before RAI.

Quick facts on the Low lodine Diet:

Designed so you consume less than 50 mcg iodine per day. Foods high in iodine that should be avoided: table salt, dairy products, egg yolks and sea foods of all types. Soy is also restricted because it interferes with RAI.

Most patients are advised to stay on a LID for 48 hours after RAI treatment. Since LID meals are usually not available in the hospital, you should bring appropriate foods with you (or have a family member or friend do so).

Visit ThyroidCancerCanada.org to download Thyroid Cancer Canada's Low Iodine Diet pamphlet, which contains useful information on the diet, including a shopping list and menu samples.

Our diet has been officially endorsed by the Canadian Association of Nuclear Medicine and is approved by the "Practice-based Evidence in Nutrition" project of the Dietitians of Canada.

Hypothyroidism

Hypothyroidism and hyperthyroidism...

Symptoms of hypothyroidism (low thyroid levels)

- Fatigue, weakness
- Trouble sleeping, nightmares or excess sleep
- Puffiness especially in the face, bloating
- · Poor concentration, memory loss
- Weight gain
- Anxiety, panic attacks, irritability, mood swings
- Depression
- Dry eyes, skin and hair; hair loss
- Change in menstrual cycle
- Joint pains and stiffness, muscle cramps
- Intolerance to cold
- Constipation and/or nausea
- Tingling or numbness in fingers or toes
- Itchiness
- · Ringing in ears
- Slight changes in eyesight

Symptoms of hyperthyroidism (high thyroid levels)

- Fatigue
- Trouble sleeping, nightmares
- Shakiness, nervousness, restlessness
- Weight loss, increased hunger
- Anxiety, panic attacks, irritability, mood swings
- Increased sweating, warm/ moist hands
- Hair loss, brittle nails
- Change in menstrual cycle
- Increased thirst
- · Itching, hives
- Joint pains and stiffness, muscle cramps
- Diarrhea
- Increased heart rate, palpitations, shortness of breath

Taking your medication



Your doctor will determine the right dose of thyroid pills to help achieve the right hormonal balance, and regularly monitor your thyroid levels. It may take a few dose adjustments along the way. It's important to talk to your doctor about the optimal hormone level he/she has set for you, and how often you need to be tested.

Taking your pills correctly is a key part of your treatment.

Here are a few tips:

DO take your pills

- At the same time each day.
- With a glass of water. Do not take them with hot drinks, especially coffee.
- On an empty stomach (1 hour before eating or drinking anything other than water, or 3 hours after).

DO NOT take your pills

- With vitamins or minerals, especially calcium and iron (if you do, wait 5 hours).
- With laxatives or high-fibre foods.

DO NOT allow your pills to become heated

- In the summer, take precautions to not expose your pills to the sun/heat
- Avoid storing pills in places that can overheat (e.g., a cupboard over the oven or stove, a hot car). If your pills are exposed to heat, dispose of them and get a fresh supply from the pharmacy.

Radiation and chemotherapy



Radiation is not commonly used for thyroid cancer, but it may be required in special circumstances. Your doctor will determine if this is needed based on your specific situation. Radiation is administered by a radiation oncologist, usually in a specialized centre.

Although rarely used, some forms of thyroid cancer may be treated with **chemotherapy**. This is a new area of research for thyroid cancer, with exciting new findings showing promise for future treatment of this disease.

Tyrosine Kinase Inhibitors (TKIs)



A small percentage of patients with metastatic (cancerous cells that have spread) differentiated thyroid cancer do not respond to radioactive iodine (RAI) treatment and TSH suppression. In these patients, there is still an option: targeted tyrosine kinase inhibitors (TKIs). TKIs target a group of proteins, called tyrosine kinases, that are involved in the growth and spread of certain cancers. Below are medications approved for use in Canada. Many more are in development.

Lenvima™

Lenvima[™] (levatinib capsules) is used to treat a type of thyroid cancer that can no longer be treated with RAI. Lenvima[™] works by blocking the creation of certain proteins in tumour cells, slowing down the growth of new blood vessels in these tumours. This

cuts off the supply of nutrients and oxygen to the tumour, which slows or prevents its growth. LenvimaTM also acts directly on cancer cells in other ways to kill them or slow down their rate of growth.

Caprelsa®

Caprelsa® (vandetanib tablets) is used to treat medullary thyroid cancer in adult patients whose tumour cannot be removed by surgery or has spread from the thyroid to other parts of the body. Like LenvimaTM, Caprelsa® works by blocking the production of certain proteins in tumour cells, which slows down the growth of new blood vessels, cutting off the supply of nutrients and oxygen to the tumour to slow or prevent its growth. Caprelsa® also acts directly on cancer cells to kill them or slow down their rate of growth.

Follow-up

- Routine blood tests
- Regular check-ups
- Ultrasounds or whole-body scans



Follow-up

All thyroid cancer patients need to be "followed" for the rest of their lives and includes:

- Routine blood tests
- Regular check-ups, including examination of the neck
- Ultrasounds or whole-body scans for a more detailed view of the body (to detect for cancer recurrence)

You may fear that your cancer will 'come back.' Know that the vast majority of thyroid cancer patients do not have a recurrence. And even in the small amount of cases where it does happen, it is often curable.

What do blood tests monitor?

Blood tests are needed to monitor Thyroid Stimulating Hormone (TSH) levels, which tells your doctor about your hormone levels. Blood tests also measure a substance called **thyroglobulin (Tg)**, which is only produced by thyroid cells.

A person who had their thyroid gland removed should have very low or undetectable Tg levels. If too much Tg is detected, it may be a sign of cancer recurrence. In this case, RAI treatment may be prescribed, or in rare cases, radiation therapy. Tg is tested regularly as part of your follow-up.

Questions for your endocrinolgist or cancer care specialist

Ask for a copy of all reports and add them to your file.



- What is the target range for my TSH blood level?
- What dose of replacement hormone will I take to try to achieve the desired TSH?
- When will I have my next TSH blood test, and how frequently after that?
- How often will I have appointments with you?
- What should I do if I do not feel well (i.e. have hypo- or hyperthyroid symptoms) and how should I let you know?
- When and how often will I have follow-up testing such as a thyroglobulin (Tg) test and neck ultrasound?

Tips

- Write down your questions in advance to take to your appointment (some doctors like them faxed or emailed in advance).
- Ask for a copy of all reports and add them to your file.
- Write down your tested level of TSH that your doctor reports to you and the date of the blood test, and continue to do so in the future.
- Keep a diary or spreadsheet of symptoms by date and dose if you think you may have hypo- or hyper- thyroid symptoms, or symptoms of hypoparathyroidism.
 If they bother you, report them to your doctor so you can determine a plan.
- Ask for a copy of a TSH blood test requisition form and have a TSH blood test one week before your next appointment with your specialist. Keep a record, by date, of all Tg blood test results.

Can thyroid cancer affect pregnancy or fertility?

Thyroid cancer does not have lasting negative effects on male or female fertility.

Thyroid cancer does not have lasting negative effects on male or female fertility. However, if you have had RAI treatment, you should wait 6 months to a year to conceive. This is to allow time to see if further treatment is needed during this

time, not because of any effects of RAI on you or your child. Women may need to adjust their thyroid pill dose if they decide to try and become pregnant. Some women notice changes in their periods after surgery or treatment.

The emotional impact

Ask for help and clearly communicate your needs.



Being diagnosed with thyroid cancer can have a **profound emotional impact**. Everyone's response is different. Fear, worry and uncertainty about surgery and/or treatment, and the possibility of a recurrence, are common. Some patients may have mood swings when adjusting to thyroid replacement treatment. This can, in turn, strain relationships with your loved ones.

Here are some ways to help you cope:

 Ask for help and clearly communicate your needs (e.g., help with everyday tasks, or just a shoulder to cry on).

- Join a support group. Often times, the best support is from someone who has gone through what you are going through.
- Seek out professional help if your symptoms don't improve. This can include social workers, psychologists or counsellors.
- Know that if you are feeling down, scared or anxious, this is completely normal. Living with thyroid cancer is a journey, but there is support available every step of the way. Visit

ThyroidCancerCanada.org for more information on support groups, helpful resources, and coping tips.



Thyroid Cancer Canada informs, supports and empowers a community of those impacted by thyroid cancer.



INFORM. SUPPORT. EMPOWER.

Notes

References

"Recent Research Studies & Guidelines", a listing of medical links and articles about thyroid cancer, provided by Thyroid Cancer Canada at: http://www.thyroid-cancercanada.org/recent-research-studies-and-guidelines.php

American Thyroid Association: www.thyroid.org Canadian Cancer Society: www.cancer.ca Negotiating the Emotional Ups and Downs

This booklet is dedicated to our volunteers, patient members and the thousands of Canadians affected by thyroid cancer.

To join our support group, please visit:

thyroidcancercanada.org

As an incorporated non-profit group and federally registered Charitable Organization, Thyroid Cancer Canada welcomes donations at the above mailing address and acknowledges them with a receipt for tax purposes.

Online donations to benefit Thyroid Cancer Canada are also welcome via canadahelps.org

Charity #: BN 86306 9464 RR0001

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Thyroid Cancer Canada informs, supports and empowers a community of those impacted by thyroid cancer.

