

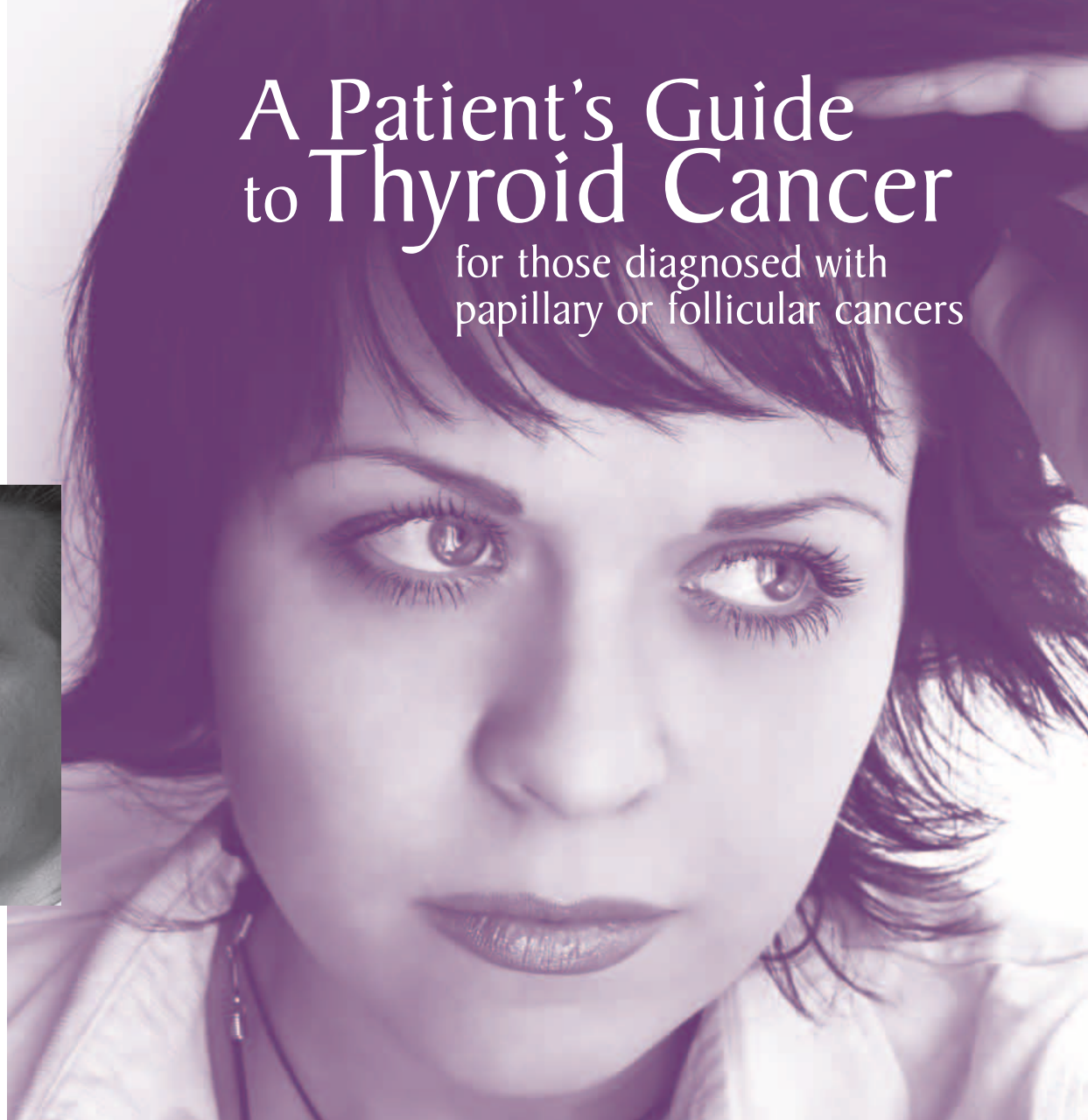
A Patient's Guide to Thyroid Cancer



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A Patient's Guide to Thyroid Cancer

for those diagnosed with
papillary or follicular cancers



www.thyroidcancercanada.org

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This guidebook was written and published by *Thyroid Cancer Canada* and reviewed by members of its Medical Advisory Panel. The information herein is offered as a general guideline and is not intended to replace the medical care and advice of your physician.

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

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www.thyroidcancerCanada.org

This booklet is available in French by request and a PDF copy is available at www.cancerdelathyroideCanada.org

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Introduction

I have found the mental challenge of dealing with cancer harder than the actual physical problems ... Do not under-estimate the toll that the cancer diagnosis takes on your mental health. It's not just a physical problem, especially because the thyroid controls overall physical and mental chemical processes.

Jean, Kelowna, BC

This booklet, prepared by thyroid cancer survivors, is intended as a guide for those diagnosed with the disease. While it is written from the patient's point of view – by patients for patients – it has also been reviewed by members of *Thyroid Cancer Canada* Medical Advisory Panel (See our website for list of MAP members www.thyroidcancercanada.org). This booklet will complement the medical information you will receive through your physician and other resources, and provide you with practical tips and questions to ask your doctor(s).

Thyroid Cancer Canada is an incorporated non-profit group and federally registered charitable organization led by thyroid cancer survivors. Our goal is to connect with patients and their families who want support and information about the disease.

For more detailed information about thyroid cancer and its treatment, view detailed information on our website at www.thyroidcancercanada.org

We welcome your comments. Information on how to contact *Thyroid Cancer Canada* or become a member of our group is available on the first page of this booklet.





Diagnosis of Thyroid Cancer

Frequently there are no symptoms associated with thyroid cancer. Initially, a lump in the neck may be noticed by the doctor or the patient. For others, the diagnosis may be made following the exploration of a seemingly unrelated health issue such as trouble swallowing or a hoarse voice. For most people, what follows next is a neck ultrasound or a fine needle aspiration biopsy (FNA). Sometimes these diagnostic techniques are done together.

Neck Ultrasound (U/S)

The usual procedure for a neck ultrasound is that you are asked to lie on your back, extending your head backwards. With the help of some gel, the attending ultrasonographer rubs a wand-like probe over the neck area, stopping to click on a computer keyboard in order to take still pictures of specific areas of interest.

Fine Needle Aspiration Biopsy (FNA)

The fine needle aspiration biopsy is performed by a specialist such as an endocrinologist; ear, nose and throat doctor (ENT); radiologist or surgeon. When a nodule can be palpated (felt by touch), the doctor inserts a needle into the lump to remove a sample for analysis under a microscope (biopsy). In the case where the nodule(s) are very small, the doctor may use ultrasound to guide the needle.

Freezing can be used to minimize discomfort, although it is not usually necessary. Many doctors explain that the needle used for the freezing can be more uncomfortable than the biopsy needle. The samples obtained are sent to the pathology department of the hospital for analysis. In most cases, if the pathology report indicates that the sample contains cancerous cells, the physician will recommend a total thyroidectomy.

However, FNA biopsy results can be inconclusive. If so, the doctor will likely recommend that the biopsy be repeated.

Getting the Results

The hardest part of dealing with thyroid cancer is the unknown, and the waiting for the known. Once I know what's going to happen, I handle it well.

Lynda, Toronto, ON

It may take a week to ten days to get the results of a biopsy. If a diagnosis of thyroid cancer is made, then surgery is the next step. In some instances surgery is recommended even when the biopsy has come back normal or inconclusive, because of the suspicious nature of the nodule. The post-surgery report and pathology report will provide much more detailed information about the type of cancer and where it was located.

The Diagnosis and Prognosis

Questions you may want to ask your doctor after being diagnosed with thyroid cancer:

- 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 recur?
- What will the regular follow-up be for my condition and which doctor will I see?



Tips for Visits with Your Doctor

1. Write down your questions in advance.
2. Take a friend or relative to the appointment to help you remember what was said.
3. Ask for copies of your reports and keep them in a binder or folder along with any subsequent reports.
4. Maintain a log or journal of appointments and record results such as blood test results and hormone replacement dose.

Educating yourself and your family about your disease will make it more manageable and less frightening.

Thyroid Cancer and Your Emotions

Patients feel a range of normal emotions upon receiving a diagnosis of thyroid cancer. They include:

- Fear, worry and uncertainty leading up to the cancer diagnosis, especially if you have to wait a long time for diagnosis and/or treatment.
- The feeling of being on an emotional rollercoaster.
- Loss of security about your health often experienced as a form of grief.
- Unusual fears related to possible recurrence following your treatment(s). Many people imagine every ache and pain to be something more serious than it is. It takes time to regain your emotional equilibrium.
- Strained relationships: Sometimes children act out their emotional turmoil in negative ways. Occasionally a friendship is lost, or you may experience strains in your relationship with a partner. Some experience depression and/or mood swings especially during the time of adjusting to thyroid hormone replacement medication.

All of these adjustments can be painful, and can cause sadness and stress in the short term. It is not uncommon to feel isolated by your diagnosis, afraid to burden family and friends. Don't be afraid to ask for help if you need it.

Communicate your needs clearly with loved ones. Let them know what they can do to help. Be patient — it takes time to heal, both physically and emotionally. Besides friends and family, support groups such as *Thyroid Cancer Canada* and/or community or church counsellors are often available to help. Professional psychologists and social workers are often accessible on-site at cancer treatment centres or by referral. Others may be able to avail themselves of Employee Assistance Programs (EAP).

Surgery

The main form of treatment for thyroid cancer is a total thyroidectomy. Occasionally, partial or hemi-thyroidectomies are performed when FNA biopsy results are inconclusive – that is, when it is not known for sure if the nodule is cancerous or not. If the diagnosis is made after a partial thyroidectomy, completion surgery is usually performed to remove the remaining part of the thyroid.

It is common that a total or partial thyroidectomy includes dissecting (removing) adjacent neck lymph nodes for examination. In some cases, where neck metastases are known to exist or are apparent during the surgery, a more radical surgery may be performed to remove left or right neck lymph nodes. This is known as a neck dissection surgery. For a simple surgery a small incision is made at the front or bottom of the neck. For a neck dissection surgery, a longer incision may be necessary both in the front and side(s) of the neck.

Thyroid surgery requires skilled, experienced hands, as the thyroid gland is adjacent to the larynx (voice box) and important parathyroid glands. Results are better when surgery is done by a specialist trained and experienced in thyroid surgery. In some centres this may be a head and neck surgeon; in others, a general surgeon.

Sometimes the tumour has grown outside of the thyroid (extra-capsular extension). Every effort must be made to keep intact the four small parathyroid glands which lie adjacent or attached to the thyroid. If the tumour surrounds the parathyroid gland(s), one or more of them may need to be



removed. In some cases, the surgeon transplants one or more of the parathyroid glands onto adjacent muscle tissue. It is very important that at least one parathyroid gland is in 'working order' after the surgery, as the glands have the vital function of controlling calcium levels in the body. After the surgery, patients' blood calcium levels are carefully checked to ensure that the parathyroid glands are in working order by performing periodic blood tests. As well, nurses may occasionally check your parathyroid function by tapping your cheek.

Patient recovery from a total thyroidectomy is usually relatively easy. You will probably stay in hospital for one or two nights. Initially drainage tube(s) may be left in at the surgical site, and they are usually removed before discharge from the hospital. Sometimes, patients go home with a drainage tube and return a few days later to have it removed. Occasionally patients are referred to a home care organization for a few days of follow-up care after discharge.

Some patients may experience a stiff neck, sore throat or a weak voice upon waking up from surgery. These are temporary conditions caused primarily by the position the patient was in for surgery and by the intubation tube, used to support breathing during surgery. Patients who have more involved surgeries, such as a neck dissection, may experience more stiffness and discomfort and have a longer recovery period. Discuss your pain management needs and options with your doctor prior to surgery.





Making Your Hospital Stay Comfortable

1. **Prepare.** Stock up on easy-to-prepare foods and comfort foods for your return home after surgery.
2. **Find a driver.** Make arrangements for someone to drive you home.
3. **Lighten your workload.** Make arrangements for a babysitter, dog walker, etc. Be aware that it may take a few weeks or months to resume your employment.
4. **Use a special pillow.** A 'dog bone' or curved pillow may be helpful. Some people find these pillows comfortable to support the neck during recovery time. Others use hot or cold packs to minimize the swelling.
5. **Pack for the hospital stay.** You may need: medications, curved and/or regular pillow, toiletries, slip-on slippers, rope and sleepwear (pyjamas or nightgowns that open in the front).
6. **When you are released,** keep track of the notes and prescriptions given to you. Eat soft high-fibre foods. Don't sit hunched over.
7. **Minimize your scar.** Follow your doctor's instructions for keeping your incision covered and/or the use of ointments.
8. **Rest.** Recovery usually takes several weeks.

Possible Complications

Complications from thyroid surgery are generally rare but can happen, including:

- Potential problems associated with any operation (your doctor will summarize these)
- Change in voice due to injury to one of the laryngeal nerves beside the thyroid. The likelihood of a permanent injury to the nerve is approximately 1% (the voice box often adjusts, resulting in gradual improvement in voice quality over time).
- Damage to one or more of the four parathyroid glands. The parathyroids are four tiny rice-sized glands located adjacent to the thyroid that control the blood calcium level. Following a total thyroidectomy, approximately 30% of patients will have temporary injury to these glands, resulting in a drop in blood calcium level, called hypocalcemia. Approximately 2% of patients have permanently low calcium following a total thyroidectomy, even when careful steps are taken to preserve

and protect the parathyroids during surgery. Hypocalcemia (low calcium) is treated with calcium supplements and a high-dose vitamin D available by prescription.

Treatment and Monitoring After Surgery

Within a week to ten days after surgery you will see your surgeon for removal of stitches or staples. This is a relatively painless procedure.

A few weeks after surgery, your doctor will review the results of your final pathology report with you and give you the final diagnosis. The information from the pathology report helps the doctor to determine whether or not you need additional treatment, such as radioactive iodine (RAI).

For most patients, the main form of thyroid cancer treatment is surgery. If the malignancy was small, removed by surgery and the patient has a low risk of recurrence, radioactive iodine treatment is usually not needed. In such cases, the doctor will outline a schedule for future monitoring and will decide upon the recommended level of the patient's thyroid hormone replacement (taken by a daily pill). Taking the proper dose of hormone replacement **is a form of follow-up treatment**, as a suppressive dose is associated with low recurrence.

Radioactive Iodine Treatment (RAI)

Radioactive iodine treatment is recommended for some thyroid cancer patients by their physicians. Usually those who receive this treatment do so because they are at a higher risk of recurrence based on factors that may include: the age of the patient, the variant or sub-variant type of their disease, the number of initial tumours in the thyroid gland, the size of the tumour(s), spread beyond the thyroid capsule and/or metastases.

Note: Women who are breast-feeding are usually asked to stop nursing at least two months prior to treatment in order to reduce the exposure of the breast to the radioactive iodine.



If required, RAI has two purposes:

- To destroy any remaining thyroid cancer cells and minimize the risk of recurrence.
- To destroy any remaining normal remnant thyroid tissue and/or thyroid cancer cells left behind after the surgery so that a unique protein, called Thyroglobulin (Tg) can be very accurately measured to indicate thyroid cancer recurrence in future blood tests.

The treatment:

- Is usually in the range of 3.7-5.5 GBq (100 or 150mCi), but can vary based on the size of the initial tumour and other risk factors;
- May occur anytime from six weeks to six months post-surgery;
- Or, another approach is to closely follow patients in the post-surgery months using ultrasound and blood tests, keeping the radioactive iodine treatment an option if the test results indicate its necessity.

“Going Hypo”

Our bodies require thyroid hormone. Once the thyroid gland has been removed, thyroid hormone is taken in synthetic form as a daily pill. Without thyroid hormone, the body produces an increasing amount of thyroid stimulating hormone (TSH). An elevated TSH of at least 30 mIU/L is needed for RAI treatment to be effective. To achieve this rise in TSH, patients must stop taking their thyroid hormone replacement pills creating a hypothyroid state (‘go hypo’), or have their TSH stimulated by taking Thyrogen, a medication given by injection (see section below).

Becoming hypothyroid by hormone withdrawal involves stopping levothyroxine, also known as T4 (brand names are Synthroid and Eltroxin) for approximately 4-6 weeks prior to RAI treatment. During the time that levothyroxine is stopped, Cytomel (T3) may be prescribed. Cytomel is a fast-acting (and fast dissipating) form of thyroid hormone used to minimize the symptoms of hypothyroidism during hormone withdrawal. Cytomel is stopped approximately 2 weeks prior to RAI treatment.

‘Going hypo’ is a gradual process with the thyroid hormone changes occurring slowly over the six-week period. The longer the patient is off of thyroid hormone, especially during the last two weeks prior to RAI treatment when no thyroid hormone is taken, the more likely the patient will experience symptoms of hypothyroidism.

Some Symptoms Associated with Hypothyroidism:

- Tiredness, loss of energy, weakness
- Light-headedness, instability on your feet
- Trouble sleeping, nightmares or excess sleep
- Puffiness and bloating especially in the face
- Loss of ability to concentrate, memory loss, absentmindedness
- 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
- Tingling or numbness in arms or legs
- Ringing in ears
- Slight changes in eyesight





Helpful Hints for “Going Hypo” and Preparing for RAI

1. Identify people you can count on for support and help before and after your treatment.
2. Obtain information from your Nuclear Medicine department or doctor regarding precautions and preparation for your return home from the hospital. Make sure your family and friends understand the necessary precautions.
3. Consult with your doctor about your daily activities including driving, and learn when you should restrict your activities. (Note that hypothyroidism is a form of physical impairment, thereby restricting you from driving in the final days or weeks before treatment.)
4. Prepare Low Iodine Diet (LID) meals and have your pantry stocked with low iodine foods (see LID section).
5. Take naps as needed.
6. Watch alcohol consumption while hypo as the impact will be much greater than what you normally experience.
7. Keep your sense of humour.
8. Don't expect immediate recovery right after your scan is complete. While patients feel much better in 2–3 weeks, it takes approximately 8 weeks for the thyroid hormone levels to normalize once thyroid hormone pills are resumed.





Thyrogen

Doctors have the option of prescribing Thyrogen (rhTSH) to increase TSH levels in order to prepare for RAI treatment, scanning, or stimulated Tg measurements. Thyrogen replaces the need to have patients withdraw from their hormone replacement ('go hypo') as described above.

Thyrogen is a fast-acting way to raise the TSH in preparation for a treatment, scan or Tg blood test. It requires two visits to a doctor (or alternate) for injections. Where a test-dose (scanning dose) of RAI is given, patients are typically given two doses by injection on a Monday and Tuesday, having their test-dose RAI on Wednesday and scan on Friday. A similar schedule is followed for a treatment (ablative) dose, although the Whole Body Scan (WBS) may be delayed for a week or so. During the treatment week, a blood test is also required at least once.

Most patients have mild (if any) side-effects from Thyrogen and are delighted to avoid hypothyroid withdrawal.

The current cost of one patient kit of Thyrogen (two injections) is approximately \$1,600. The actual consumer cost can vary per pharmacy and you may call ahead of time and request cost quotations to determine where you can obtain the best price. The cost of Thyrogen may be covered by your provincial or private health insurance. (To view whether the costs may be covered in your province, visit www.drugcoverage.org. Enter the word 'Thyrogen' and the DIN# 02246016.)

The manufacturer of Thyrogen, Genzyme Canada Inc., has set up a helpline to assist you with determining if the drug is covered by your insurance plan, and how to go about being reimbursed. As well, in some parts of the country a 'Thyrogen Support' program is available, whereby a nurse may be made available to administer the dose. The number to call is:

1-866-401-8323

The Thyrogen Reimbursement Helpline is open from 8:00 am until 8:00 pm EST, Monday through Friday.

For Thyrogen-specific inquiries patients may contact Genzyme Medical Information at 1-800-745-4447 option #2 or medinfo@genzyme.com

Thyrogen Schedule

(For Tg Testing and/or RAI Treatment and/or Whole Body Scan)

Monday

Thyrogen Injection #1

Tuesday

Thyrogen Injection #2

Wednesday

Swallow RAI capsule or liquid (Nuclear Medicine department)*

Thursday

Off

Friday

1. Have a blood test for TSH and Tg
 2. Have a RAI scan (Nuclear Medicine department).**
-

* Optimally the injections, ingestion of RAI, and scan should all be performed at the same time of day for each.

** If a treatment dose of RAI is given, the Whole Body Scan (WBS) will be delayed for 5-10 days after treatment



Low Iodine Diet (LID)

A LID is prescribed for thyroid cancer patients for a short period of time before (approximately 14 days) and 2 days after receiving RAI. The reason is that thyroid cells (both healthy and cancerous) uniquely “crave” iodine. A LID starves the body of iodine, causing increased RAI uptake, thus increasing effectiveness of the treatment or scan.

Iodine occurs naturally in many foods — especially in foods originating from the sea. It is also added (by regulation) to all table salt sold in Canada. The primary sources of iodine in foods are: table salt, dairy products, egg yolks, foods originating from the sea and food prepared in restaurants. The diet requires you to make your best effort to limit or exclude foods with naturally occurring or added iodine.

A LID is generally defined as a diet providing less than 50 micrograms of iodine per day. *Thyroid Cancer Canada* has developed resources to help patients to prepare for and follow a low iodine diet, with the help and advice of more than 50 experts including Canadian physicians, Registered Dietitians, and food and packaging officials. The *Thyroid Cancer Canada* resources include a full-colour patient pamphlet, a list of references and reviewers and LID recipes. Copies of the full-colour LID pamphlet are available upon request (see first page of this booklet for contact information).

As a general rule of thumb, it is best to cook all foods yourself from scratch — avoiding take-out, restaurant and pre-packaged foods. Choose fresh fruits, vegetables and meats. You may want to prepare and freeze stews, soups, and roasted dinners a few weeks in advance, so that they will be on hand when you are feeling “hypo.”

For the full diet details and meal ideas visit
www.thyroidcancerCanada.org





Administration of Radioactive Iodine (RAI)

Radioactive iodine treatment is administered by staff in the Nuclear Medicine department of hospitals. Treatment doses are approximately 3.7-5.5 GBq or 100-150 mCi. Physicians usually offer printed instructions to follow after the treatment and they may differ slightly from place to place. As the iodine is radioactive, hospitals must follow specific procedures in administering the treatment. Patients are given the iodine (¹³¹I) in pill or liquid form. For those given the liquid form, they are asked to drink it through a small straw. Once a treatment dose is administered, you are isolated – sometimes in a special hospital room, to protect others from the radioactivity you will be emitting. Patients receiving a treatment dose of RAI are typically kept in full isolation for two to three days. Alternatively, where domestic circumstances permit, and according to the guidelines of some treatment centres, patients may be asked to or allowed to go home with instructions on self-isolation.

The RAI is tasteless and there is usually no physical reaction — although with high dose treatments (over 5.5 GBq or 150mCi), patients may experience nausea and, in rare cases, vomiting.

Patients who are admitted to hospital remain in an isolation room for one to three days in order for the level of radioactivity to diminish to an acceptable level. Because of the initial relatively high level of radioactivity, visitors are either not permitted or limited in the duration of their visits. You will be in contact with the nursing station usually by telephone, and in some instances nursing staff may check on you for short periods of time, but remaining at an appropriate distance. Food will be delivered to your door. Patients are advised to take frequent showers and remember to drink fluids. Special instructions in regards to bathing and disposing of your waste are usually given. It is often the case that everything stays in the room with you (including food trays and used towels) until you are discharged.

A doctor or technician from the Nuclear Medicine department administers the RAI and returns to your room at the end of the isolation period to

measure the degree of radioactivity you are emitting with an instrument similar to a Geiger counter. When the measure is low enough, you are discharged.

Excess radioactive iodine exits the body primarily via urine with lesser amounts leaving in saliva, sweat and feces. The amount of RAI in your body decreases rapidly and the possibility of harmful radiation exposure to the patient and others decreases quickly after the first few days. The tiny amount of RAI remaining in the body is “absorbed” only by thyroid cells. Over time this small amount of RAI continues to ablate (destroy) remaining normal thyroid tissue and thyroid cancer cells.

Most hospitals are not prepared to provide low iodine meals while patients are in RAI isolation. Therefore, it is a good idea to steer clear of any high iodine foods they may provide (e.g. fish, milk, egg yolk) and/or to bring some appropriate foods from home. Some easy-to-pack and wholesome foods include unsalted nuts, fruits and rice cakes. As the duration of the hospital stay can vary, check with your doctor to confirm when you start and stop the Low Iodine Diet.

The isolation experience is not painful, but it may be lonely so it is important to be prepared.





Helpful Hints for Isolation Following RAI Ablation

- As some hospitals do not offer low iodine meals, you may want to take a supply of fruit, juices and LID treats with you.
- RAI treatment may cause changes to the salivary glands. To help minimize this you may be asked to:
 - keep hydrated by drinking water several times during the first night after your RAI treatment.
 - occasionally suck on something sour, such as sour candy or fruit to encourage saliva flow. You may want to bring your own supply of lemon wedges or candies to suck on. Hospitals may supply you with lemon wedges for the same purpose.
 - salivary gland massage is thought by some to promote drainage of radioactive saliva.

You may want to bring anti-nausea medication such as Gravol. If you do take a dose of your own medication, let the nursing staff know.

You are strongly advised to use the toilet if you need to vomit. Remember, you are producing radioactive waste and it is safest diluted in the sewer system.

Some hospital guidelines for RAI require that all patients, males included, sit to urinate. You should flush twice and wash your hands thoroughly with soap and plenty of water after using the toilet; then rinse the sink.

It is suggested that you take showers throughout the day and wash your hair to remove radioactivity from your skin and scalp. Bring small bottles of shampoo, conditioner, skin lotion, etc. and leave the containers behind when you leave.

You might want to bring a supply of magazines or paperback books that can be left behind, if need be, when you leave the isolation room. Another suggestion is to bring a list of phone numbers and a long-distance phone card, so you can catch up with friends and family by phone.

Home Isolation

Upon release from hospital isolation, you may be asked to follow some special instructions to continue semi-isolation at home for a few days. This includes keeping a distance from others, especially young children and pregnant women. You will probably be requested to sleep in a separate bed from your spouse, wash your clothes and bed linens separately, and keep your distance from people and pets (e.g. only sit close to people for short periods of time).

As noted above, it is now common for patients to spend their full isolation period at home (i.e. no hospital isolation following the administration of the RAI treatment). This may be possible for those who can have a bedroom completely to themselves for the first three to seven days post-RAI treatment. The number of days may vary according to the dose you received. The nuclear medicine department of your hospital will give you full instructions for this process.

After RAI Treatment

RAI often affects the taste buds for a short period of time and you may notice some changes in how food and drink tastes. These changes are temporary and usually improve within a few weeks of RAI treatment.

If dry mouth symptoms persist for a time, patients could ask their pharmacist for gel and spray products to ease them.

Sometimes the salivary glands are affected and may swell and cause pain. Rarely, there may be blockage in the tear ducts. If these symptoms occur, you should notify the physician who treated you because a short course of Prednisone may quickly reduce the swelling and may also help to reduce the likelihood of a problem later on. Keeping well hydrated by drinking regularly may help minimize the symptoms. Heat and massage may also help.

Regular brushing and flossing of the teeth will help maintain dental health as there will be a decrease in saliva production.



Sometimes these side-effects do not manifest until several months after the treatment. Patients should speak with the treating doctor or other specialist(s) for his/her recommendations regarding these issues.

Whole Body Scan (WBS)

Approximately five to ten days after RAI treatment, patients are asked to come back to the hospital for a Whole Body Scan (WBS), also known as a ¹³¹I scan. The scan is performed in the Nuclear Medicine department of the hospital. Usually the scan takes between 30 minutes to one hour to perform.

Patients are asked to lie very still on a narrow bed that moves slowly through or under the scanner, which continuously takes a digital picture of the entire body. Patients may feel cold, either because of the low temperature in the room, or because they are lying very still and a blanket may be provided. While it is not necessary to remove your clothing for scanning, all metal should be removed such as jewellery or clothing with metal clips or buttons. It is also a good idea to use the washroom before scanning.

The scanner moves very close to the body, and many patients find it more comfortable to close their eyes while the top section of their body is being scanned. The WBS is not painful or uncomfortable in any way, although some may feel impatient or claustrophobic with the procedure. Patients who know they are claustrophobic should tell the technologist before the examination begins so that steps can be taken to help manage the situation.

Once the scan is completed and the technician ensures that a “good picture” has been obtained, the patient is released. In some cases, a Nuclear Medicine doctor meets with the patient after the scan to review the results. In other hospitals, patients have to wait until the written report is available before they can get the results of the scan from their doctor.

A small amount of thyroid remnant tissue will show up on the scan in at least 98% of cases since it is extremely difficult for surgeons to remove every microscopic bit of thyroid tissue from the neck. The nuclear medicine

report may refer to this as “normal uptake in the neck.” The RAI dose continues to ablate those remaining thyroid cells over the next few months, and it is likely that any subsequent scan (months or years later) will indicate a great reduction or elimination of this remnant tissue.

Thyroid Hormone Replacement

In order to replace the hormones once produced by the thyroid, thyroid cancer patients take a synthetic hormone called Levothyroxine or T4. Synthroid and Eltroxin are the brand names for Levothyroxine in Canada.

Things to remember about taking Levothyroxine/T4:

- It is extremely important that you take your thyroid hormone every day, at the same time and under similar circumstances. You can take your pill first thing in the morning, an hour before eating. Alternatively, you can take your pill at bedtime.
- Swallow the pill with water only. Food, minerals, and other medications will bind with the hormone and interfere with its absorption.
- If you have trouble remembering to take your pill, buy a day-of-the-week pill dispenser and use it faithfully.
- Some products will bind to Levothyroxine and interfere with absorption: iron-containing medications, sucralfate (Carafate), cholestyramine, large doses of aluminium hydroxide gels (Maalox, etc.), and soy protein supplements. Calcium and food containing calcium (milk, cheese, etc.) may also interfere. If any of these items must be consumed, they should be taken five hours away from the hormone replacement pill. Upon request, the pharmacy that fills your prescription can provide you with written instructions on how best take your pills. Note that estrogens and birth control pills do not interfere with Levothyroxine absorption.
- Levothyroxine will lose potency if exposed to heat. Store your pills at a controlled room temperature between 10-15° C and protect them from light and moisture. Take only the number of pills you require while travelling, as a hot car or warm climate will quickly reduce the potency of your pills. If they are exposed to heat, they should be discarded once you return home.



Understanding your Blood Test Results

The thyroid cancer specialist managing your care will order blood work several times during the course of your treatment and in the months and years following. As you will be on a synthetic form of thyroid hormone for the rest of your life, it is important to continually gauge whether the dose you are on is creating the desired effect in your body. You and your physician will work towards finding the correct dosage for you, and you will likely remain on it for long periods of time.

Weight gain or loss, pregnancy and menopause are some events that may affect your dosage.

After the first year post-surgery, your doctor may order blood tests on a yearly or bi-yearly basis. There are three main blood tests that will be monitored:

1. **Thyroid Stimulating Hormone (TSH):** Once your thyroid has been removed, TSH is regularly monitored. As the presence of TSH may stimulate the growth of thyroid cancer cells, it is important for thyroid cancer survivors to be given enough thyroid hormone replacement to keep the TSH level lower than normal.

Patients at low risk for thyroid cancer recurrence may be allowed a TSH in the range of 0.1 – 3.0 mIU/L or more. All other patients may be required to keep their TSH as suppressed as they comfortably can (0.1 mIU/L or less). The recommended target TSH level needs to be identified per patient and will depend on a number of factors that your doctor will need to take into consideration. Adjustment to the dose of hormone replacement (i.e. T4 - Synthroid or Eltroxin) helps to achieve the desired TSH level. Raising the dose of hormone replacement has the effect of lowering the TSH.

2. **Thyroglobulin (Tg):** Thyroglobulin is the “cancer marker” for thyroid cancer. As such, this number should be as low as possible (sometimes expressed as “undetectable”). It may take several months (even years)

for the measure to come down to the desired level following surgery and if need be, RAI treatment.

3. **Anti-thyroglobulin antibodies (TgAb):** Some patients produce antibodies which, while not harmful, mask the reliability of the Tg value. Sometimes the anti bodies disappear over time and that is a valuable secondary sign that all cancer has been eliminated.

As well, some patients (especially those with parathyroid loss or damage) will have their blood calcium levels periodically measured.

It is important to use the same laboratory for your blood tests each time, for comparative consistency.

Post-Treatment Monitoring

A diagnosis of thyroid cancer requires life-long monitoring for possible recurrence. A regular monitoring program is important and can be reassuring.

Monitoring may include regular neck examination (including palpating the thyroid area), neck ultrasound and blood tests. For some (depending on their circumstances) follow-up may include chest X-ray, CT scans of neck and/or chest, or PET/CT scans.

In some cases, patients are also followed one or more times with a test-dose of RAI in order that a scan can be performed and compared to previous results. In that case, the patient follows the same procedure for becoming hypothyroid or is prepared with Thyrogen. With either preparation it is necessary to follow the LID as described above. A RAI scanning dose is usually in the range of .15 to .30 kBq (4-8 mCi).

The American Thyroid Association recommends that in most cases patients can be followed up with physical examination, periodic Thyroglobulin monitoring and neck ultrasounds.



Last Word to Patients

Sometime during your diagnosis and treatment, someone will likely tell you that you have the “good cancer.” We don’t think any cancer can be described as “good,” but for the vast majority of patients diagnosed with well-differentiated thyroid cancer, the prognosis is very good. Diagnosis, surgery, and treatment usually follow a fairly routine course as described in this booklet.

Patients with more advanced disease at diagnosis, or patients with more aggressive variants may need additional forms of treatment (such as External Beam Radiation) and more frequent monitoring.

While it’s not uncommon to feel isolated and alone with a cancer diagnosis, there is help and support available when you need it. Regular follow-up monitoring with your physician will help detect recurrences early, putting you back on the road to a healthy future.



Glossary

Common Short Forms Used by Thyroid Cancer Patients

CT	computed tomography
DX	diagnosis
EBR	external beam radiation
Endo	endocrinologist
FNAB	fine needle aspiration biopsy
Hypo	hypothyroidism
MRI	magnetic resonance imaging
PET	positron emission tomography
PT	partial thyroidectomy
Thyrogen	recombinant human TSH (rhTSH)
RAI	radioactive iodine
TCC	Thyroid Cancer Canada
thyca	thyroid cancer
TT	total thyroidectomy
TX	treatment
U/S	ultrasound
WBS	whole body scan (131-I scan)

Radioactive iodine doses are measured in GBq (gigabecquerel) or mCi (millicurie) (100 mCi = 3.7 GBq)



Thyroid Cancer Resources

Check our website regularly for our newsletters, new patient resources, and *Ask Thy'vors* – questions and answers between our members and medical advisory panel. www.thyroidcancerCanada.org

Books

Thyroid Cancer: A Guide for Patients, Douglas Van Nostrand MD, Gary Bloom and Leonard Wartofsky MD (Keystone Press, 2004) ISBN 0-9746239-0-3

The Complete Thyroid Book, Kenneth B. Ain MD and M. Sara Rosenthal, 2005 (Toronto: McGraw-Hill, 2005) ISBN 0071435263

The Thyroid Solution, Ridha Arem (New York: Ballantyne Books, 1999) ISBN 0-345-42919-2

Thyroid Cancer: A Comprehensive Guide to Clinical Management, Leonard Wartofsky (Totowa, N.J. Humana Press, c1999) ISBN 0896034291

The Thyroid Cancer Book, M. Sara Rosenthal, 2nd Edition (Trafford Publishing, 2002 catalogue #02-0771 www.trafford.com); ISBN 1-55395-059-3

The Low Iodine Diet Cookbook, Norene Gilletz, (Toronto: Trafford Publishing, 2005, www.trafford.com) ISBN 1-4210-6691-3

Websites

www.thyroidcancerCanada.org

www.mythyroid.com

www.endocrineweb.com/thyroidca.html

http://www.thyroid.org/patients/brochures/ThyroidCancer_brochure.pdf

Thyroid Cancer Canada
Dr. Drucker, Toronto, Ontario
Endocrineweb
American Thyroid Association





Support Resources

Wellspring is a network of community-based centres that provide support, education and coping skills, at no charge, to individuals and families. To find out if there is a Wellspring centre in your area, visit their website at www.wellspring.ca

Cancer Information Service (Canadian Cancer Society) is a national, bilingual service offering credible, comprehensive information about cancer and community resources. www.cancer.ca
Call 1-888-939-3333 (toll-free), Monday to Friday,
9 a.m. to 6 p.m., anywhere in Canada or e-mail info@cis.cancer.ca

Thyroid Cancer Canada/Cancer de la thyroïde Canada
550 Eglinton Ave. W
PO Box 23007
Toronto, ON M5N 3A8

Note the above is a mailing address; not an office.

E-mail: info@thyroidcancercanada.org
Visit our website: www.thyroidcancercanada.org





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