



What you need to know about

Differentiated Thyroid Cancer and its Treatment



This booklet has been designed as a resource for information about thyroid cancer and the complications associated with hypothyroidism.

In addition to reading this brochure, it is recommended that you consult your doctor or nurse for more information.

THE THYROID GLAND

What does your thyroid gland do?

Your *thyroid* gland is a butterfly-shaped *endocrine* gland located at the base of your neck. Each wing, or lobe, of your thyroid lies on either side of your windpipe. The function of the thyroid gland is to make, store and release thyroid hormones into your bloodstream.

Your thyroid hormones, thyroxine (T_4) and triiodothyronine (T_3), control your body's metabolism and organ functions. These hormones affect your heart rate, cholesterol level, body weight, energy level, muscle strength, memory and many other conditions.

In some cases your thyroid gland does not function properly due to either internal or external factors. If your thyroid gland is not able to produce enough thyroid hormone your body will become less active. The thyroid gland is then referred to as under-active and this is called being **hypothyroid**. On the other hand, your thyroid gland can be over-active, meaning that it produces too much thyroid hormone, speeding your body up. This is called being **hyperthyroid**.

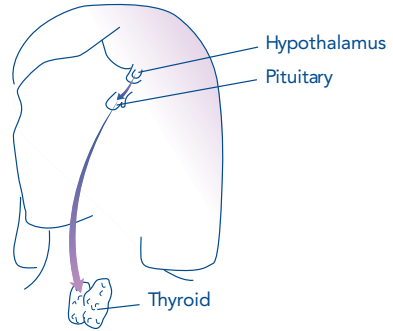
The amount of thyroid hormone made by your thyroid gland, is adjusted by thyroid stimulating hormone (TSH) released by a gland in the brain called the pituitary. These form a negative feedback loop, so that TSH production is suppressed when the thyroid hormone levels are high, and vice versa. With the pituitary controlling most of the action, these organs work similarly

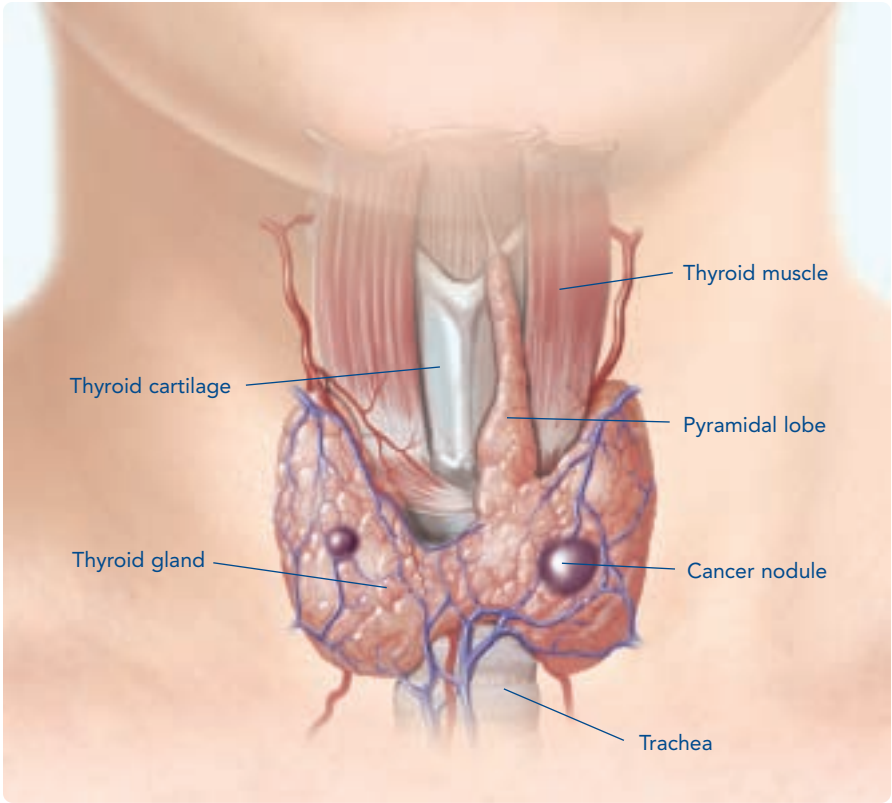
to the way a thermostat controls the temperature in a room. For example, just as the thermometer in a thermostat senses the temperature of a room, your pituitary gland constantly senses the amount of thyroid hormones in your blood. If there is not enough thyroid hormone, your pituitary senses the need to "turn on the heat." It does this by releasing more



The thyroid gland

thyroid-stimulating hormone (TSH), which signals your thyroid to make more thyroid hormone. Your thyroid gland then makes and releases the hormones directly into your bloodstream. Your pituitary gland then senses that there is just the right amount of thyroid hormones in your blood. With your thyroid hormone levels now restored to a normal level, your pituitary slows its production of TSH back down to normal.





Together, the right level of TSH and thyroid hormones play a central role in ensuring that your body functions normally, allowing you to be energetic and feel good.

THYROID CANCER

What is thyroid cancer?

Thyroid cancer is a cancerous tumor or growth located within the thyroid gland. In Canada thyroid cancer is fastest growing diagnosed cancer, and is the 6th most common cancer diagnosed in women. In 2006, it's estimated there will be 2,600 new cases diagnosed in women, 750 new cases diagnosed in men and 160 deaths, due to thyroid cancer.* It is estimated that approximately 30,000 Canadians are living with thyroid cancer.

There are several types of thyroid cancer. The most common are papillary carcinoma and follicular carcinoma, which are often grouped together and referred to as well-differentiated thyroid cancer. Medullary carcinoma, Hürthle cell carcinoma, anaplastic carcinoma and thyroid lymphoma are less common types.

If you or someone you know has been diagnosed with thyroid cancer, you will be glad to know that the outlook with treatment is very good. Most thyroid cancers can be totally removed with surgery and managed with regular follow up.

However, this type of cancer can sometimes come back or spread to other parts of the body, even many years later. For this reason, doctors recommend that patients who have had thyroid cancer, receive routine checkups for the rest of their life, especially within the first 5 to 10 years after surgery.

What causes thyroid cancer?

Thyroid cancer is more likely to occur in people who have undergone extensive radiation therapy at a high dose during childhood, in the areas of the head, neck, or chest. Radiation was commonly used before 1960 to shrink enlarged tonsils, to treat various skin problems (such as acne), and to reduce an enlarged thymus gland (an organ inside the chest) in infants. Thyroid cancer is also more likely to occur if you have a family member who has had thyroid cancer. However, thyroid cancer can occur in anyone.

Note: Radiation that is used in diagnostic x-rays (for example, x-rays used by dentists) is not connected with thyroid cancer.

* www.cancer.ca Canadian Cancer Statistics

DIAGNOSIS

How is thyroid cancer diagnosed?

Thyroid cancer is often discovered when you see or feel a lump or **nodule** on the front of your neck, or your doctor may notice a nodule during a routine physical examination.

Fortunately, most of the time, nodules are **benign**, which means they are not cancerous or life threatening. Only about 1 out of every 20 nodules ever turns out to be cancerous; benign thyroid nodules are extremely common. By feeling or gently pressing around the thyroid gland, your doctor can usually make a diagnosis of a thyroid nodule with little risk or discomfort to you.

After completing the physical examination taking your medical history, and inquiring as to your general health, the doctor will likely do more tests, including:

- Blood tests (to measure the level of thyroid hormones)
- Thyroid imaging tests or scans (to take a picture of your entire thyroid gland)
- Thyroid biopsy (to take a small sample of the thyroid gland and see if it contains cancerous cells)

TREATMENT

Thyroid hormone treatment

Once your thyroid gland has been removed, called a thyroidectomy, your doctor will start you on thyroid hormone replacement (T₄:L-thyroxine). This is to replace the primary hormone your thyroid gland used to make. Another reason to take thyroid hormone after thyroidectomy is that as time goes on, TSH (made by the pituitary gland) may cause any existing thyroid cancer cells to grow. Thyroid hormone medication sends a signal to the pituitary gland to make less TSH. So taking the thyroid hormone medication helps in two ways; one, it replaces the thyroid hormones that your body used to make on its own, so that you will not become hypothyroid; secondly, it tells the pituitary to make less TSH, to suppress the growth of thyroid cancer cells that may be present.

Once my surgery is over, is my cancer gone forever?

Sometimes thyroid cancer can come back or spread to other parts of the body – even many years after surgery. Differentiated thyroid cancer has a high recurrence rate: 20% at 10 years and 26% at 20 years.* That's why your doctor needs you to come in for regular checkups, especially in the first 5 to 10 years after your surgery.

How are you tested?

If you have had surgery to remove all or part of your thyroid gland because of thyroid cancer, your doctor will use two primary tests to check if the cancer has come back or spread to other parts of your body. One is a blood test (called **thyroglobulin** or **Tg test**) and the other is an x-ray scan, called a **Whole Body Scan (WBS)**. Your doctor may decide to test you with both tests or sometimes just with the blood test. These check-ups are referred to as your follow-up period and are seen as an important part of thyroid cancer treatment and prevention.

Thyroglobulin (Tg) blood test

A Tg test is a blood test that measures the amount of thyroglobulin, a protein that stores thyroid hormone, in your blood. Thyroid cells are the only cells in your body that make thyroglobulin. If thyroglobulin shows up in your blood test, then you know that thyroid cells are present somewhere in your body.

Whole body scan (WBS)

The WBS test requires that you take a capsule or drink containing a small, safe amount of radioactivity, called **¹³¹I (radioiodine one-three-one)**. After you have taken the capsule or drink, you will lie down under a large camera that takes an x-ray picture scan of your body. If any thyroid cells are present in your body, they will show up as spots on the film.

Will this testing have an impact on my life?

In the past, performing the Tg and WBS tests, required that you discontinue your hormone medication for 2 to 6 week before the test, which causes you to become hypothyroid. This is called the "withdrawal method". This method allows the body to produce enough TSH to make the tests as accurate as possible. TSH creates the optimal condition for the remaining thyroid cancer cells to absorb the radioactive iodine (¹³¹I). With the withdrawal method, patients can feel the symptoms of hypothyroidism up to 10 or 12 weeks. This can have detrimental effects on your quality of life.

* Mazzaferri EL, Jhiang SM. Long-term impact of initial surgical and medical therapy on papillary and follicular thyroid cancer. *Am J Med.* 1994 Nov;97(5):418-28.

WHAT YOU NEED TO KNOW ABOUT HYPOTHYROIDISM

Hypothyroidism – the disease state caused by insufficient production of thyroid hormone by the thyroid gland.

Many people suffer from hypothyroidism (a thyroid gland that has a lower activity than a normal functioning gland) but are not aware that something can be done about it, or have not been able to talk to their doctor about how they feel. Moderate symptoms of hypothyroidism can be mistaken for other diseases and states.

What causes hypothyroidism?

The reasons for becoming hypothyroid can be put into two categories; natural causes, meaning caused by the body itself, or as a result of an external factor. In this booklet we'll be discussing hypothyroidism as a result of the removal of the thyroid gland, related to the treatment of thyroid cancer.

Most people who develop thyroid cancer will have either part or their entire thyroid gland removed, this is called a **(partial) thyroidectomy**. After a thyroidectomy the thyroid produces insufficient hormone levels and the person becomes hypothyroid. In this situation hormone medication will be prescribed to replace the T₃ and T₄ restoring the hormones to a functional level. It does take a bit of time for the body to adjust to this medication, because there is a different level suitable for each person.



SYMPTOMS OF HYPOTHYROIDISM

- Slowed speech and a hoarse, breaking voice. Deepening of the voice can also be noticed.
- Impaired memory – forgetfulness
- Decreased concentration
- Increased sensitivity to heat and cold
- Increased desire to sleep
- Physical fatigue
- Slow heart rate diminished cardiac output and decreased contractility.
- Shortness of breath
- Sluggish reflexes
- Muscle cramps and joint pains
- Dry puffy skin, especially on the face
- Dry hair, often hair loss
- Brittle fingernails
- Depression (especially in the elderly)
- Irritability
- Decreased sex drive
- Weight gain and obesity
- Abnormal menstrual cycles (women)
- Anemia caused by impaired hemoglobin synthesis
- Slowed metabolism
- Constipation

Every human body is different, which is why each person may experience different levels of severity of these symptoms. Because hormones can additionally be affected by external factors, it's useful to avoid any abnormal stress, maintain a balanced diet, and keep to a regular schedule. It is important to think of these aspects before discussing your hypothyroid condition with your doctor, because it will enable you to provide him/her with a better insight to assess your medical situation.

PSYCHOLOGICAL EFFECTS OF HYPOTHYROIDISM

Your hormones and your mental disposition are closely related. Your blood-hormone level is important for regulating your psychological function. When there is a hormonal imbalance, psychological effects are a primary concern to the person involved, and recognizing them is an important step in seeking medical advice.

Examples of these effects are:

D O U B T

Doubt concerning yourself. Doubt why you feel so tired all the time without any physical explanation and why physical abilities are progressively decreasing.

F E A R

Fear of becoming absent-minded due to continually worsening spells of temporary forgetfulness caused by hypothyroidism.

L A C K O F U N D E R S T A N D I N G

Not being able to understand why you have mood swings: sudden onset of crying without cause or becoming aggressive. Feeling misunderstood by your doctor or family and friends. Not being able to come to terms with the changes in your own behavior.

A L I E N A T I O N

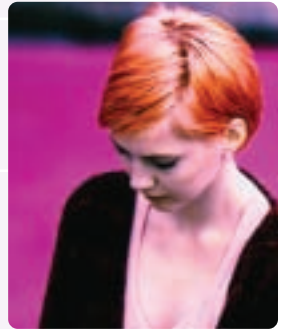
The sense of not knowing whom you are. A sense of losing yourself or the aspects of your character. A distancing between yourself and family/friends to the extent that loss of contact occurs.

A P A T H Y

A feeling of not being able to enjoy things in life, not caring. Not being able to go out and do things because you feel numb on the inside.

G U I L T

Feelings of guilt about having emotional outbursts without cause.



Because every person is different, you may experience these effects to a differing extent compared to others. Do not be afraid to continue to express your emotional discomfort. It can be hard for your family and friends to understand what you are going through. There are various patient organizations that can also offer support.

HOW TO ADDRESS YOUR SYMPTOMS OF HYPOTHYROIDISM TO YOUR MEDICAL PROFESSIONAL

The psychological effects can have a severe impact on your self-confidence. That's why it is important to try to talk to your doctor about these effects in a 'matter of fact' way. Try to write down how you are feeling. This will help you to take a step back from your emotions and allow you to look at these feelings from a different perspective. The more clearly and precisely you address these feelings the better your doctor will be able to understand you. Remember that a doctor may find it difficult to find a solution to your psychological complaints and may tend to focus on a physical explanation. Remember that your doctor can only assess your medical situation based on the information you provide.

The symptoms related to hypothyroidism can be related to other illnesses as well. That is why it is important to be clear and specific. It can be easy to get caught up in details (too much in some cases) that will divert your doctor from being able to best interpret your situation. For clear communication it's best to have a diary that lists where, when and how often your symptoms were experienced.

How can I get on with my life, knowing that my cancer might come back?

It's most important to get regular checkups to make sure that you remain cancer free. If you find it difficult to have regular checkups for any reason, talk with your doctor or nurse about your concerns. It's also important to take good care of yourself by eating well, exercising regularly, and managing stress. Learning relaxation methods, learning to set priorities, and remembering to laugh all help to reduce stress. Take pleasure in doing things that you did before your diagnosis.

Remember, you do not have to go through this alone. Talk to family and friends about whatever fears and questions you may have, and consider joining a thyroid cancer support group or patient organization. At a support group, you'll find other people who are willing to share their firsthand experience with thyroid cancer.



"After the initial scare of cancer, I knew that it was something I certainly wanted to avoid in the future. Regular check-ups are an important step in that process. When I heard about an alternative method, which is accurate, more prompt and would allow me to continue my normal life, I was intrigued. I collected some information and asked my doctor about the possibilities. At the next check-up we'll be using this method."

Q&A

QUESTIONS AND ANSWERS

What is a biopsy and why is it done?

Your doctor can use a **fine needle aspiration biopsy (FNAB)** to learn whether a thyroid nodule is benign or cancerous. With this test, the skin may be numbed and a small needle is inserted into the thyroid nodule in order to remove samples of tissue or fluid, which are then analyzed in a lab. The test is fast, safe, and usually causes little discomfort.

What if my nodule is cancerous?

Even if it turns out to be cancerous, the thyroid nodule in most cases will grow very slowly. Once a patient has treatment, the outlook is very good – most thyroid cancers can be totally removed with surgery and follow-up therapy. This surgery, called **thyroidectomy**, removes part or all of the thyroid gland. Thyroid surgery is commonly followed by treatment with radioactive iodine to destroy “leftover” normal thyroid cells, as well as thyroid cancer cells. This procedure is called **ablation**.

Is thyroid cancer curable once ablation has been completed?

Due to the standards of surgery and radiation therapy, thyroid cancer has a high cure rate. More than 80% of all cases are cured. However maintaining follow-up testing is an essential aspect in the early detection of any recurrence.

After a thyroidectomy can you lead a normal life?

It is very possible to lead a normal life after a thyroidectomy, however you will need to take thyroid hormone treatment (T_3 & T_4) as your body can no longer produce its own. In addition, regular check-ups will allow for the early detection of cancer recurrence.

How often should a patient have follow-up medical visits?

Your doctor can recommend the best option for your medical situation. In general Tg tests will be carried out every 6 to 12 months as well as a whole body scan once every year. Depending on the results over a period of time your doctor may decide to re-assess the frequency.

Why might my doctor tell me to avoid certain foods before my whole body scan?

Thyroid cells in your body take up iodine whether the iodine is radioactive or not. You will take a very small amount of radioactive iodine before your whole body scan. This is necessary so that the scan shows the radioactive areas in the body. Your doctor may ask you to avoid medicines and foods that contain iodine for two weeks before your test. This ensures that the cells will take up plenty of the radioactive iodine and show up clearly on the scan.

Be sure to let your doctor know if you've had any other x-ray and/or scanning procedures in the month before your whole body scan. Some of these procedures use iodine-containing chemicals that might interfere with your test.

Can I continue working and are there any activities I should stop doing when I'm off my hormone medication?

Every person may experience the symptoms of hypothyroidism differently. For some people continuing to work, is possible, for others it becomes too difficult. It's important to be open and clear about your situation to yourself and those around you. If your doctor is using the thyroid hormone withdrawal method, and because the follow-up period can be a yearly occurrence, it may be wise to discuss this with your superior or boss. If you have the energy to keep following your usual lifestyle then you should. Listen carefully to your body and do not force yourself to continue the same routine if you are experiencing symptoms of hypothyroidism. In some cases it can be wise to be cautious, particularly when driving, because not only could your concentration level be influenced but also your reflexes in general, making you more prone to accidents.

Is being hypothyroid permanent?

In case of hypothyroidism caused by thyroid cancer, the symptoms are not permanent. The symptoms of hypothyroidism may occur due to the fact that you may be asked to discontinue your hormone medication during the follow-up period. Once you start taking your hormone medication again your body will need a little time to adjust, but soon after you'll stop experiencing symptoms of hypothyroidism.

I am losing contact with my family. I feel like a stranger in my own home. Can this be related to the hypothyroid follow-up period?

Yes, the emotional and psychological effects you experience during your follow-up period may be related to the discontinuation of your thyroid hormone medication.

These effects can be unpleasant for the person involved as well as for family and friends. That is why it's important to have an open dialogue with your family and friends as well as with your doctor. Only by discussing your experiences will you find the best way to resolve your hypothyroidism.

GLOSSARY

Ablation

Treatment with radioactive iodine after surgery to destroy remaining normal thyroid cells as well as thyroid cancer cells in the thyroid bed/neck.

Benign

Non-cancerous, not life threatening.

Clinical Oncologist

A physician who cares for patients with cancer.

Endocrine glands

Glands that release hormones directly into the bloodstream.

Endocrinologist

A physician who cares for patients with disorders of endocrine glands i.e. hormone-related disorders.

Euthyroid

Having a thyroid gland that functions normally and consequently there is a proper amount of thyroid hormone in the bloodstream.

Fine Needle Aspiration Biopsy (FNAB)

A method where a thin needle is inserted into thyroid tissue and the sample is withdrawn for testing.

Goiter

An enlarged thyroid gland.

Hormones

Chemicals produced by an endocrine gland and released into the blood. Hormones travel to other organs of the body where they produce their effect.

Hyperthyroidism

Symptoms of increased activity of organs due to excess thyroid hormones in the bloodstream.

Hypothyroidism

Symptoms of decreased activity of organs due to a deficiency of thyroid hormones in the bloodstream.

¹³¹I radioiodine

A form of radioactive iodine used in the diagnosis and treatment of some thyroid disorders.

Metabolism

The use of calories and oxygen to produce energy.

Nuclear medical physician

A physician who cares for patients with many medical disorders, and is responsible for administering radioactive substance and the scanning procedure.

Radioactive iodine (RAI)

Radioactive isotopes of iodine (^{131}I) used in the diagnosis and treatment of some thyroid disorders. RAI is also used for treatment of thyroid cancer, in which cases the patient takes a large dose of radioactive iodine to kill any recurrent or metastasized thyroid cells.

Recombinant human thyroid-stimulating hormone (rhTSH)

PrThyrogen[®], a hormone similar to the body's own thyroid stimulating hormone but produced in a laboratory.

T₃ (triiodothyronine)

One of the hormones produced and secreted by the thyroid gland.

T₄ (thyroxine)

The primary hormone produced and secreted by the thyroid gland.

Tg test

A method that measures the level of thyroglobulin (Tg) in the blood.

THT (thyroid hormone therapy)

Therapy consisting of thyroid hormone medications.

Thyroglobulin (Tg)

Large protein that is produced by the thyroid tissue. The level of Tg in the bloodstream can be monitored to detect thyroid cancer recurrence.

Thyroid gland

A two-lobed, butterfly shaped gland lying at the base of the throat that produces hormones essential for a variety of metabolic processes in the body. When iodine is ingested, much of it goes to the thyroid gland.

Thyroid hormones

T₄ and T₃, two hormones that tell the body how fast to work and how to use energy. T₄ (thyroxine) is the primary hormone produced by the thyroid gland and T₃ (triiodothyronine) is the secondary hormone produced by the thyroid gland.

Thyroid nodule

A lump/growth in or on the thyroid gland.

rhTSH (recombinant human Thyroid Stimulating Hormone)

PrThyrogen[®], a hormone similar to the body's own thyroid stimulating hormone only produced in a laboratory.

Thyroid-stimulating hormone (TSH)

A hormone secreted by the pituitary gland in the brain that stimulates the thyroid gland to produce the thyroid hormones T₄ and T₃.

Thyroidectomy

Surgical removal of the thyroid gland.

Whole body scan (WBS)

Images of the entire body after ingestion of radioactive iodine.

MORE INFORMATION

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