Understanding thyroid cancer

why?
you or someone you know has just been diagnosed with thyroid cancer, you are not alone. The American Cancer Society estimates that over 35,000 new cases of thyroid cancer are diagnosed each year.
Although receiving a diagnosis of thyroid cancer can be frightening, the good news is that most forms of thyroid cancer have a very high treatment success rate, especially when found and treated early. The five year survival rate for thyroid cancer is over 97%.

Educating yourself about thyroid cancer is important and may help you feel empowered. This booklet has been designed to give you basic information about thyroid cancer and its treatment, and to provide you with additional resources and support.

While this booklet contains important information about thyroid cancer, it should not be a substitute for discussions with your doctor.
**About Thyroid Cancer**

Thyroid cancer is a disease affecting your thyroid gland, an important gland in your neck that controls your metabolism (the way your body breaks down food to produce energy and how efficiently it uses that energy). The good news about thyroid cancer is that treatment for most people is successful. However, despite high treatment success, thyroid cancer recurs in a large number of people, sometimes many years after the initial diagnosis. Thus, long-term monitoring for recurrence of the tumor is very important.

**Your Thyroid Gland**

Your thyroid gland is located at the base of your neck, just below your Adam’s apple. It is shaped like a butterfly. One wing, or lobe, of your thyroid gland lies on each side of your windpipe.
What does the thyroid gland do?

The purpose of your thyroid gland is to produce, store, and release thyroid hormones into your bloodstream. These hormones, called T3 and T4, affect almost every cell in your body and help control your metabolism. Thyroid cells take up circulating iodine from the blood to create T3 and T4, which are then released into the bloodstream and carried to organs in the body, including the liver, kidneys, muscles, heart, and brain.

If you have too little thyroid hormone in your blood, your metabolism slows down. This condition is called hypothyroidism. If you have too much thyroid hormone in your blood, your metabolism speeds up. This condition is called hyperthyroidism.
How does the thyroid gland work?

The amount of thyroid hormone produced by your thyroid gland is controlled by a gland in your brain called the pituitary gland. Another part of your brain, the hypothalamus, helps the pituitary do its job. The hypothalamus sends information to the pituitary gland, which, in turn, controls the thyroid gland. The thyroid gland, pituitary gland, and hypothalamus all work together to control the amount of thyroid hormone in your body.
These organs work similarly to the way a thermostat controls the temperature in a room. Just as the thermometer in a thermostat senses the temperature of a room, your hypothalamus and pituitary gland sense the amount of thyroid hormone in your bloodstream. If your thyroid hormone level is low, the pituitary gland “turns on the heat” by releasing thyroid-stimulating hormone (TSH). TSH sends a signal to your thyroid gland to make more thyroid hormone. The thyroid hormone is then released directly into your bloodstream.

**WHEN YOUR THYROID HORMONE LEVELS HAVE BEEN RESTORED** to a normal level, your pituitary gland senses this and "turns off the heat," slowing its production of TSH back to normal.
What is Thyroid Cancer?

Thyroid cancer is a malignant growth or tumor in the thyroid gland. Although thyroid cancer represents only 2% of all cancers, it is the most common cancer of the endocrine system (the endocrine system consists of glands throughout the body that produce hormones).

Thyroid cancer occurs in both men and women and can occur at any age. However, thyroid cancer occurs almost three times more often in women than in men. Among both men and women, the number of new cases of thyroid cancer is increasing at a faster rate than any other type of cancer.

There is a very high treatment success rate for most types of thyroid cancer when diagnosed and treated early. Despite high treatment success, it is important to know that up to one-third of thyroid cancers can recur, sometimes even decades after the initial treatment. For this reason, thyroid cancer requires long-term monitoring to make sure that the cancer has not come back, or if it has, to begin treatment right away.
Different Types of Thyroid Cancer

Not all thyroid cancers are the same. There are four main types of thyroid cancer:

- Papillary
- Follicular
- Medullary
- Anaplastic

Papillary and follicular cancers, often referred to as “well-differentiated” thyroid cancers (WDTC), are the most common. Together, they account for about 90% of thyroid cancers. Generally, the prognosis, or long-term outlook, for patients diagnosed with WDTC is very good. With regular checkups and long-term monitoring, the 20-year survival rate is nearly 93%.
Medullary and anaplastic thyroid cancers are much less common, and are usually more difficult to treat, although great strides have been made in the treatment of all thyroid cancers.

The prognosis for any given thyroid cancer patient depends on several factors, including the type of thyroid cancer, whether the disease has spread to other parts of the body, and the patient’s age at diagnosis. Early and aggressive treatment as well as commitment to long-term monitoring is essential to achieve the best outcome.

**MOST doctors recommend that people who have had thyroid cancer be monitored for recurrence for the rest of their lives.**
What Causes Thyroid Cancer?

It is not clear what causes thyroid cancer. However, there are certain factors that may increase the risk of getting thyroid cancer such as exposure to high levels of radiation and family history.
Getting Diagnosed

Thyroid cancer can be discovered by a doctor or other health care provider (HCP) who feels a lump, or nodule, on the front of the patient’s neck. Thyroid nodules are common, but only 5%–10% turn out to be cancerous.

To confirm whether a thyroid nodule is cancerous, your doctor will probably refer you to an endocrinologist, a doctor who specializes in diseases of the endocrine system including the thyroid gland. The endocrinologist will usually perform a fine needle aspiration (FNA) biopsy to learn whether a thyroid nodule is benign or cancerous. During this procedure, a small needle is inserted through the skin into the thyroid nodule. The needle draws out a sample of the material, or tissue, inside the nodule. This sample is then examined under a microscope. These biopsies are generally quick and usually do not cause much discomfort. In addition to a biopsy, the endocrinologist may recommend a blood test to measure the level of thyroid hormone in your body, and thyroid imaging tests or scans to take a picture of your entire thyroid gland.
What if the nodule is thyroid cancer?

Thyroid cancer treatment usually consists of surgical removal of the thyroid gland (thyroidectomy), radioiodine remnant ablation, and long-term monitoring.

TREATMENT PATHWAY

1. Surgical Removal
2. Radioiodine Remnant Ablation
3. Long-Term Monitoring
Surgical Removal of the Thyroid Gland

Once diagnosed, the first step in the treatment process for well-differentiated thyroid cancer (WDTC) is surgery to remove the thyroid gland. This is called a thyroidectomy. Thyroidectomy is a delicate procedure because the thyroid gland is surrounded by many blood vessels and nerves.

Thyroidectomies are done in a hospital operating room under a general anesthetic. The surgeon may remove all or part of the thyroid gland depending on the size of the tumor and whether it is suspected that the cancer has spread to other parts of the thyroid gland.

Following surgery, your surgeon or endocrinologist will usually prescribe thyroid hormone replacement therapy. This will replace the hormone your thyroid gland was producing prior to its removal. Without thyroid hormone replacement therapy, you will become hypothyroid. Many people who become hypothyroid cannot function normally in their day-to-day routine.
Remnant Ablation

In addition to a thyroidectomy, some patients may benefit from an additional treatment called radioiodine remnant ablation. Radioiodine may be used to destroy any remaining thyroid tissue that the surgeon was not able to remove during the thyroidectomy. Thyroid remnant ablation is not recommended for all patients; whether it is will depend upon risk factors such as tumor size and tumor staging.

Thyroid remnant ablation is performed by giving you a dose of radiation in the form of a capsule or liquid. This radiation, called radioactive iodine, targets and destroys any remaining thyroid cells that may be present in the body. These cells may be normal thyroid cells, cancerous thyroid cells, or both. This procedure is usually done several weeks after the thyroidectomy.
After your treatment has been completed, you will be placed on thyroid hormone replacement therapy. Thyroid hormone replacement therapy consists of taking thyroxine which replaces one of the hormones that your thyroid gland would have produced naturally. This is important because thyroid hormone has a role to play in regulating your metabolism.

**Remnant ablation makes future testing more accurate in identifying a recurrence. It may also reduce the risk of the cancer from returning and spreading.**
Long-Term Monitoring

There are three main tests that doctors may use after treatment to determine whether any thyroid cancer cells remain in the body: thyroglobulin (Tg) testing, ultrasound, and whole body scans.

Up to 30% of well-differentiated thyroid cancer patients experience a recurrence. Two-thirds of those recurrences occur within 10 years of initial treatment; many take place decades later.

The prognosis of a recurrence is improved when it is discovered early. This is why routine checkups are important for the rest of your life, particularly in the first 5 to 10 years after surgery when the risk of your cancer returning is the highest.

**THYROID** cancer can come back or spread to other parts of the body even many years after thyroidectomy. Regular follow-up visits with your doctor are very important.
Thyroglobulin (Tg) Testing

Tg is a protein made only by thyroid cells. Tg testing measures the amount of Tg in your blood. If you’ve had your thyroid removed, you should have little or no Tg in your body. A positive Tg test, however, may indicate that thyroid cells, which may or may not be cancerous, are still present in your body. Depending on the level of Tg in your blood, your doctor may want to monitor you more closely with other tests or prescribe additional treatment.

A negative Tg test is usually a good sign that your treatment was successful. However, it does not exclude the possibility that cancerous thyroid cells might still be present since the amount of Tg in the blood may be too low for the blood test to identify.
**Ultrasound**

Ultrasound is a valuable imaging tool that is utilized by health care providers (HCP) in the management of thyroid cancer. Ultrasound is very useful to evaluate the neck area without radiation. It can be used to evaluate suspicious nodules within your neck and to evaluate for possible cancer recurrences.

**Whole Body Scan**

Another test that checks for the return or spread of thyroid cancer is called a whole body scan (WBS). To prepare for a WBS, you will be asked to swallow a capsule or liquid that contains a very small amount of radioactive iodine (RAI). This will be absorbed by any remaining thyroid cells in your body. You will then be asked to return for the scan in about 48 hours. This involves lying down under a large camera that scans for x-rays being emitted by any remaining radioactive iodine that may have been captured in your body. If any thyroid or thyroid cancer cells are present, they may show up as spots on the x-ray film. However, if only microscopic thyroid cancer cells are present in the body, they are not always visible on the scan.
Will there be any special preparation for these tests?

**Low-Iodine Diet**

Iodine, contained in many foods, is absorbed by thyroid cells in your body. Your doctor may ask you to avoid certain foods and medicines that contain iodine for a few weeks before your ablation procedure or whole body scan (WBS). Doing so will deplete your body of its natural storage of iodine, allowing any remaining thyroid cells to better absorb the radioactive iodine given to you before these procedures. Be sure to let your doctor know if you've had any other x-ray procedures in the month before your test since some x-ray exams use iodine-containing chemicals that could interfere with your scan.
Being on a low iodine diet can be challenging. However, there are several cookbooks now available to help you select and prepare healthy, low iodine meals before your testing if your doctor thinks this is important for your care.

Foods to avoid that contain iodine:

- Iodized salt and sea salt
- All dairy products (milk, sour cream, cheese, cream, yogurt, butter, ice cream)
- Margarine
- Egg yolks
- Seafood (fish, shellfish, seaweed, kelp)
- Foods that contain carrageen, agar-agar, algin, or alginate — all of these are made from seaweed
- Cured and corned foods (ham, bacon, sausage, corned beef, tuna, etc.)
- Marinated chicken or turkey
- Dried fruit
- Canned vegetables
- Bread products that contain iodate dough conditioners
- Chocolate
- Molasses
- Soy products (soy sauce, soy milk, tofu)
- Foods that contain FD&C Red Dye #3

Consult your doctor before discontinuing or substituting medications and dietary supplements that may contain FD&C Red Dye #3.

There are other resources available to help you learn more about thyroid cancer. Following is a list of some organizations that might be of help to you.
Where can I find more information?

GENZYME CORPORATION
500 Kendall Street
Cambridge, MA 02142
Phone: 1-800-745-4447
Web site: www.genzyme.com

AMERICAN CANCER SOCIETY
Phone: 1-800-ACS-2345 (800-227-2345)
Web site: www.cancer.org

NATIONAL CANCER INSTITUTE
6116 Executive Boulevard
Room 3036A
Bethesda, MD 20892-8322
Phone: 1-800-4-CANCER
Web site: www.cancer.gov

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THYCA: THE THYROID CANCER SURVIVORS’ ASSOCIATION
P.O. Box 1545
New York, NY 10159-1545
Phone: 1-877-588-7904
E-mail: thyca@thyca.org
Web site: www.thyca.org

LIGHT OF LIFE FOUNDATION
P.O. Box 163
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