

Thyroid Nodules

Testing and Follow-Up:
A Handbook for Patients and Caregivers



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Thyroid Nodules

This handbook provides an overview of thyroid nodules, their testing, and typical follow-up options. As this handbook notes, most thyroid nodules are benign, not cancerous.

For people whose nodules are thyroid cancer, the handbook also discusses free support services and other resources to help both patients and caregivers cope with the emotional and practical impacts of a thyroid cancer diagnosis.

While this handbook contains important information about thyroid nodules, your individual course of testing and follow-up may vary for many reasons.

Writers, Editors, and Reviewers. This handbook combines the significant efforts of Members of ThyCa's Medical Advisory Council as well as numerous additional thyroid cancer specialist physicians, researchers, patients, and caregivers. We greatly appreciate everyone's expertise and support.

Medical Advisory Council. ThyCa is fortunate to have a distinguished Medical Advisory Council of more than 50 professionals, who are world recognized experts in thyroid cancer. They provide valuable counsel and support of ThyCa's goals in education, treatment and research. Our website www.thyca.org has details.

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Please note: The information in this handbook is intended for educational purposes and is for general orientation. It is not intended, nor should it be interpreted, as medical advice or medical instructions or to replace your doctor's advice. You are advised to consult your own medical doctor(s) for all matters involving your health and medical care.

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Introduction - You Are Not Alone

Discovering that you or someone you know has one or more thyroid nodules can be difficult, even when you know that most thyroid nodules are benign and not cancerous.

Please be reassured that you are not alone.

Our goal is to offer help and support to strengthen your knowledge through education.

This handbook is for anyone with a thyroid nodule.

This handbook provides:

- Basic facts and helpful tips for coping with **thyroid nodules**
- Information about testing and follow-up, and what to expect following diagnosis

In addition, if your testing results in a diagnosis of thyroid cancer, we aim to:

- Provide you with further information
- Introduce you to the many free services, resources, and events that can help you
- Help you feel part of a community of thyroid cancer survivors and caregivers as you cope with emotional and practical concerns

1. Thyroid Nodules: Basic Facts

- A thyroid nodule is a growth or lump in the thyroid gland that may be malignant (cancerous) or benign (not cancerous).
- More than 90% of nodules are benign, which means that they are not cancerous.
- Many or most nodules are very small and are unlikely to be detected by physical exam or symptoms.
- Thyroid nodules are very common. They become more common as people get older.
- Overall, about 5% of women and 1% of men have a thyroid nodule that can be felt on physical exam. With imaging or autopsy studies that detect very small nodules, it is estimated that up to 50% of people over the age of 65 have at least one thyroid nodule.
- Most nodules are too small to make a noticeable lump or bulge in the neck. Instead, most nodules are found by chance through a routine physical examination and neck check during a doctor visit, or during imaging done for an unrelated reason.
- In children and teenagers, between 20% and 30% of thyroid nodules are likely to be cancerous.
- Early stage thyroid cancer is usually painless, and usually without symptoms.

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- Some symptoms that may appear in some patients include:
 - An abnormally large lymph node (a “swollen gland”) in the neck that does not go away over a few months.
 - Hoarseness that has no known cause and does not go away.
 - Difficulty breathing or shortness of breath.
 - Difficulty swallowing hard or firm foods or an unusual sensation (a “lump”) when swallowing.
 - Unexplained chronic cough or throat clearing.

Points to keep in mind:

- Tell your doctor or primary health care professional if you experience any of the symptoms listed above. These might indicate the need for more medical follow-up.
- Ask for a neck check during routine medical and dental appointments.
- Don’t hesitate to ask questions about your symptoms and neck checks.
- A Neck Check card with further information about thyroid health awareness is available from ThyCa as well as on our website (www.thyca.org). It was developed by the American Association of Clinical Endocrinologists.

More About Thyroid Nodules

Evaluating a Nodule: Overview

Steps in evaluating a thyroid nodule may include:

Patient's history, including:

(1) any past head or neck irradiation;
(2) radiation exposure; and
(3) family history (including history of thyroid cancer or other thyroid disease), or a syndrome such as Cowden's Syndrome (PTEN hamartoma), multiple endocrine neoplasia (MEN) 2, familial polyposis, Carney complex, or Werner syndrome in a close relative.

- Physical examination of the thyroid and neck for thyroid enlargement, enlarged lymph nodes, or signs of local obstruction caused by an enlarged thyroid gland.
- Thyroid function lab tests – blood tests, including TSH (thyroid-stimulating hormone) test.
- Neck ultrasound, including cervical lymph nodes.
- Fine needle aspiration (FNA) biopsy, likely under ultrasound guidance, if the nodule is more than 1 centimeter in size and meets ultrasound criteria for FNA.
- Thyroid scan with low-dose radioactive iodine or else technetium, a short-living isotope used in nuclear medicine scans, if the blood testing shows that the TSH (thyroid stimulating hormone) is below normal.

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- Other testing may involve molecular markers if the FNA cytology of the thyroid nodule shows atypical cells or a solid growth pattern (“indeterminate”). Indeterminate means that the FNA cannot determine whether or not the nodule is cancerous.
- Additional sections of this handbook give further details about evaluating thyroid nodules.

Points to keep in mind:

- Your doctor will discuss with you which diagnostic tools are most appropriate for you. Don’t hesitate to ask questions about the role and use of each tool.
- The fine needle aspiration (FNA) is the most reliable way to determine whether a nodule is benign, definitely cancerous, or possibly cancerous.
- The FNA cannot always determine whether cancer is definitely present. In this case your doctor may recommend:
 - Molecular marker testing of tissue from the FNA.
 - Re-biopsy of the nodules after 3-6 months.
 - Watching the nodule(s) and re-evaluating after some agreed-upon time interval or growth of the nodule.
 - Thyroid surgery and a tissue analysis after surgery to determine the diagnosis.

2. If You Have a Nodule...

Finding a nodule, or lump, on your thyroid may be alarming. It is important to keep in mind that most of these nodules are not cancer although they may require some medical care.

Your ongoing care may consist of periodic monitoring by your doctor. However, there is a chance that more medical care may be necessary.

In either case, discuss with your doctor your options for further monitoring or for treatment.

You may be wondering, ‘Why did this happen to me?’ The cause of most thyroid nodules is unknown. However, nodules are more common in some people, including:

- Older adults
- People who have been exposed to radiation to the head or neck, especially during childhood
- People with iodine deficiency
- People with other thyroid disorders, such as Hashimoto’s thyroiditis
- People whose parents have thyroid nodules

Some thyroid nodules are very small. Others may be large enough to interfere with breathing or swallowing. Some people may have only one nodule, and some may have several.

- Nodule size is not necessarily directly related to the risk of thyroid cancer. Very small nodules (less than 1 centimeter in size) usually do not require any kind of treatment or evaluation, but may be monitored by ultrasound for growth.

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- The number of nodules is also not related to whether or not the nodule is cancerous.

As mentioned, once a thyroid nodule is diagnosed, the next step is to evaluate the nodule to determine the likely course and outcome. Usually, this is done only if the nodule is more than 1 centimeter in size.

There is a wide range of possible findings of thyroid nodule testing, all discussed in this handbook.

3. Types of Thyroid Nodules

Thyroid nodules can develop in several ways. Most nodules are benign, not cancerous.

You may have heard the term “goiter” to describe an enlarged thyroid gland. A goiter is an enlarged thyroid gland from any non-cancerous cause. A goiter may have multiple nodules (multinodular goiter) or just be an enlarged thyroid without nodules.

The type of treatment you need for your nodule depends on what type of nodule you have. This includes the size and location of the nodule, as well as what kind of cells are in the nodule.

Thyroid nodules can be:

- Solid
- Fluid-filled (cystic)
- Partially cystic (filled with both fluid and solid)

Nodules that are mostly cystic are less likely to be cancerous than are solid nodules. Your doctor will be able to make this evaluation by testing the nodule for cancer, but the ultrasound can also often help determine if the nodule is solid or cystic.

4. Outcomes After Finding a Thyroid Nodule

If Your Nodule is Benign

Although knowing that you have any kind of thyroid nodule can be scary, most nodules are benign and only require observation, not treatment. This means that your doctor will check your nodule on your subsequent routine medical check-ups.

Many of these benign nodules never get bigger or cause other health problems.

However, it is still important to follow-up with your doctor on observational visits, to make sure that the nodule is not changing or growing.

If your thyroid nodule is related to the over-functioning or under-functioning of your thyroid gland (hyperthyroidism or hypothyroidism), you may receive medications, including radioactive iodine, or other treatments to regulate the amount of thyroid hormone your body produces.

If You Have Thyroid Cancer

The most common types of thyroid cancer are differentiated thyroid cancer—papillary thyroid cancer or follicular thyroid cancer or their variants such as tall cell and Hurthle cell.

The most common forms of differentiated thyroid cancer have very high long-term survival rates (over 90-95%), especially when diagnosed early and at a young age.

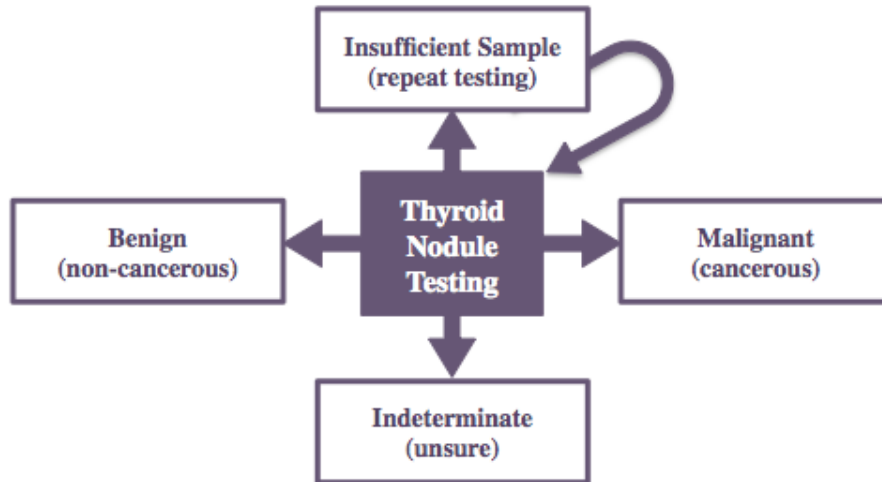
While the prognosis for most people with differentiated thyroid cancer is very good, the rate of recurrence or persistence can be up to 30%, and recurrences can occur even decades after the initial treatment.

Medullary and anaplastic thyroid cancer are rare and more difficult to treat. Together, they account for about 5% of all thyroid cancer. It is important for everyone with thyroid cancer to have an accurate diagnosis of the type of thyroid cancer, as well as appropriate treatment based on expert Medical Treatment Guidelines, and lifetime medical follow-up.

All thyroid cancer is life-disrupting and worrisome, and some types and variants can be complex and difficult to treat. Therefore, it is important that you have regular follow-up. Health monitoring should continue throughout your lifetime.

ThyCa's website www.thyca.org has detailed information about the management of each type of thyroid cancer, as well as free handbooks, videos with experts, and support groups

5. Thyroid Nodule Evaluation and Possible Results



The testing and follow-up steps that you will receive for your thyroid nodule will depend on whether the nodule is benign (non-cancerous) or malignant (cancerous), or whether testing needs to be repeated or added testing done.

- When you are diagnosed with a thyroid nodule that is more than 1 centimeter in size that meets ultrasound criteria for biopsy, your doctor will likely test your thyroid function and perform a fine needle aspiration (FNA) biopsy to extract cells from the nodule, to see whether the nodule is cancerous or not.
- For information about what to expect when you have a Fine Needle Aspiration, see Section 6 of this handbook (page 17).

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- The American Thyroid Association recommends using the Bethesda System for reporting FNA findings. It has six categories: I. Nondiagnostic/unsatisfactory — insufficient sample; II. Benign; III, IV, & V. Atypia or Suspicious — indeterminate, needing further analysis; VI. Malignant — cancer.
- If the nodule is NOT cancerous, which happens more than 90% of the time, the most common follow-up is to see the doctor regularly for monitoring/observation. This is sometimes called “watchful waiting” or “active surveillance.” This means that your doctor is not immediately concerned and wants to monitor the nodule to see whether the nodule changes over time. If it does not change, no treatment is necessary.
- If the nodule IS cancerous, which happens less than 10% of the time, your doctor will discuss treatment options with you. Your doctor will also talk to you about the types and stages of thyroid cancer, because these affect the course of treatment.
- For more information about thyroid cancer types and treatments, visit our website www.thyca.org. Our free handbooks: *Thyroid Cancer Basics*, *Medullary Thyroid Cancer*, and *Anaplastic Thyroid Cancer* are available by download as PDFs from www.thyca.org, as ePubs on iTunes and GooglePlay, and by mail by sending an e-mail request to thyca@thyca.org.
- Numerous videos with experts regarding all types of thyroid cancer are available on our YouTube Channel for further explanations.

- When certain types of thyroid cancer are suspected, further testing may also be recommended.
 - For example, patients who are suspected of having anaplastic thyroid cancer may be recommended to receive a core or open (surgical) biopsy, to confirm the diagnosis.
 - Patients who are suspected of having medullary thyroid cancer may be recommended to receive a chest x-ray, a CT (computerized tomography) scan of the neck and chest, or other imaging techniques as well as blood testing of calcitonin and carcinoembryonic antigen (CEA).
 - The American Thyroid Association (ATA) doesn't recommend for or against routine measurement of serum calcitonin as a screening test to detect medullary thyroid cancer in patients with thyroid nodules. ATA recommends that physicians decide whether this technique is useful for patients in their clinic.

- There are times when the FNA biopsy results are indeterminate, which is also called an “indeterminate,” “suspicious,” “unsure,” or “inconclusive” outcome of the FNA biopsy. The different words are possible because different pathologists may use slightly different wording. If you receive this test result, your doctor may request that you have another FNA test fairly soon (usually within 3-6 months). When an FNA is repeated, ultrasound should be used.

- If you receive indeterminate results, your doctor may recommend molecular (genetic) testing to look for genetic evidence of thyroid cancer. Section 7 of this handbook (page 20) has more information about molecular testing.

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- If the FNA results are suspicious for thyroid cancer, your doctor may recommend surgery. Discuss all recommendations to be sure that you understand the reasons for them.
- If you receive indeterminate FNA results, but ultrasound features of your nodule are very suspicious, your doctor may recommend surgery to remove the nodule.
- It may be helpful to have indeterminate results reviewed by a second pathologist, to get a second opinion. A specialist in cytopathology may be able to interpret your FNA sample to find a more definitive answer. Your doctor should be supportive of you getting a second opinion, and may be able to refer you to a specialist if you are not already seeing one. You can also visit the websites of the following medical professional organizations, which have lists of thyroid specialist physicians. These organizations are a resource for help in finding a cytopathologist or other specialist for a second opinion:
 - American Thyroid Association
 - American Association of Clinical Endocrinologists
 - The Hormone Foundation, affiliated with The Endocrine Society
- Sometimes, the FNA reports “insufficient sample,” “non-diagnostic sample,” “unsatisfactory sample,” or similar wording. This means that the FNA did not provide enough of a sample for testing. Therefore, the FNA test will have to be repeated. This usually happens within 3 to 6 months after the original FNA, although sometimes it may happen sooner.

6. Fine Needle Aspiration (FNA): What to Expect

The main way to find out if your nodule is cancerous or benign is with an FNA. If the FNA cannot determine what type of nodule is present, you may be referred for molecular/genetic testing.

Key Points:

- Tell your doctor all the medications and supplements that you take, including aspirin, nonsteroidal anti-inflammatory drugs (NSAIDs), and prescription blood thinners such as argatroban, pradaxa, warfarin, or xarelto. Your doctor may advise you to stop taking certain medications several days before the FNA test. If this happens, don't forget to ask your doctor about when you can resume taking your medication.
- You should not need to stop eating or drinking, or change most medications, before an FNA.
- When you arrive for the FNA, wear clothes that allow the doctor to easily access your neck. If you wear a turtleneck or shirt with a collar, it should have buttons or a zipper to allow the doctor to easily reach your neck for the FNA. Avoid wearing jewelry around the neck, or large earrings.
- Your neck will be wiped with an alcohol swab. Then it is dried with a piece of gauze.
- Physicians who perform FNAs may include endocrinologists, internists, surgeons, pathologists, radiologists, and other physicians who have learned how to perform the procedure and who have the physical facilities needed.

- The FNA uses a very small needle, thinner than what is used to draw blood, to draw cells from the nodule in your thyroid. The risk from a fine needle aspiration thyroid biopsy is the same as when you have blood drawn, including minimal swelling, aching, and a bruise.
- The cells will be applied to glass slides and then examined under a microscope.
- Because the needle is so small, injecting anesthesia may not be necessary. However, you may be asked to hold an ice pack on the area to be evaluated, to provide mild anesthesia. For some patients, your skin may be sprayed with ethyl chloride, another way of providing a mild anesthesia. You should discuss with your doctor whether you want anesthesia for the biopsy.
- You will probably lie down on your back for the FNA itself. A pillow or towel will be placed under your shoulder blades to fully expose your neck.
- The needle will be inserted only for a very short time (less than 10 seconds). You can breathe during the procedure but should NOT talk or swallow. Most patients have 3 needle sticks to get a proper sample, although some require more.
- The complete FNA procedure usually takes about 30 minutes, plus time for registration and other paperwork. Each “needle stick” takes only a few seconds.
- Most patients do not require a bandage or prescription pain medication following an FNA. If you do not have contraindications (meaning that it’s inadvisable for you to use), you can take Tylenol or use a cold compress (ice cubes in a plastic bag) if you experience pain.

- The procedure should not disrupt your daily life. Most patients can drive, exercise, or work immediately after an FNA, although heavy lifting is not recommended. Ask your doctor about any restrictions needed in your situation, and for how long.
- Your FNA samples will be sent to a pathology lab, where experts will examine the cells to determine your diagnosis. They will communicate with your doctor, who will let you know the results, often within 48-72 hours. The molecular studies need to be sent to a specialized lab and usually will take another 3-4 weeks for the results.
- Some doctors will give results over the phone, while others prefer to have patients come in to the office, to give results in person. Some doctors ask the patient to come for a follow-up visit one week after the FNA, to give results and follow-up information. You should discuss with your doctor how you want to receive the results of the test.

Editor's Note: The information in this section was adapted from *Fine Needle Aspiration of the Thyroid: The Patient's Guide*, by Yolanda C. Oertel, M.D., Cytopathologist. This handbook is available free of charge from ThyCa: Thyroid Cancer Survivors' Association, Inc. [www.thyca.org]. Also available is the physician's manual by Dr. Oertel: *Fine Needle Aspiration of the Thyroid: A Procedural Guide for the Physician*.

7. Molecular Testing for Thyroid Cancer

Using newly available technology, doctors can now test indeterminate FNA samples that were taken at the time of the FNA for genetic evidence of thyroid cancer.

This is sometimes called testing for “molecular markers,” because the tests look for molecular genetic evidence of malignancy (cancer) in the sample from the thyroid nodule.

Different types of tests are available to detect molecular genetic markers in a thyroid nodule:

- **Afirma®** is a gene-expression classifier.
- RosettaGX Reveal®, a miRNA classifier; **ThyraMIR**, an miRNA classifier, is combined with a test called **ThyGenX**, an 8 gene mutation panel.
- **ThyroSeq®** is a gene mutation, gene fusion and gene overexpression analysis

These tests look for different types of molecular evidence. They all are used for the same purpose: to indicate whether or not malignancy, or cancer, is present in an FNA sample.

The Afirma and ThyroSeq gene classifiers are best at predicting whether a nodule with indeterminate cytology is likely benign (“rule out” cancer). The mutational panel and miRNA classifiers are best at predicting whether an indeterminate nodule is malignant (“rule in” cancer). ThyroSeq has a unique ability to be both a “rule in” and “rule out” test for cancer.

The results of this testing help to determine whether or not surgery is needed. Therefore, the molecular testing may help reduce the number of unnecessary surgeries.

Before this testing became available, most patients with “indeterminate” results had thyroid surgery, and the final tissue analysis often showed that the nodule was benign. These molecular tests are still being evaluated in routine clinical practice but all experts agree that the tests will reduce the number of unnecessary thyroid surgeries of indeterminate nodules. Your doctor will talk with you about whether this additional testing is needed and which test is the best for your nodule and your biopsy results.

Points to remember about Molecular Testing:

- These tests are not used as a primary diagnostic test, but instead are used only after an indeterminate FNA result, in order to provide more clarification that will determine whether or not surgery is needed.
- The tests can help your doctors decide whether surgery is necessary, the extent of thyroid surgery (lobectomy versus total thyroidectomy), or, if not, what type of treatment or monitoring is best for you. If you receive an “indeterminate” result, you may want to talk to your doctor about getting tested for these molecular markers.

8. If the Nodule Is Benign

If your nodule is benign, the follow-up consists of periodic observation, or “watchful waiting.”

If the nodule changes in size over a period of time, you should arrange to have additional testing.

Discuss your situation with your physician so that you understand what is recommended and why.

9. If the Nodule Is Thyroid Cancer: Brief Overview of Next Steps

Your treatment will be tailored to your own circumstances, including your type of thyroid nodule.

There are four types of thyroid cancer: papillary, follicular, medullary, and anaplastic. Papillary and follicular are also called “differentiated thyroid cancer” and have an excellent long-term prognosis if diagnosed and treated at an early stage. Medullary thyroid cancer (MTC) and anaplastic thyroid cancer (ATC) are more complex and can be difficult to treat.

If your nodule is cancerous, your treatment will depend on what type of thyroid cancer is in the nodule, whether it has spread to local lymph nodes or distant sites (lung or bone most likely), your age at diagnosis, and other factors.

Occasionally, a nodule with medullary or anaplastic thyroid cancer also has differentiated thyroid cancer (DTC). The American Thyroid Association Guidelines for medullary and anaplastic thyroid cancer discuss treatment decision-making for these situations.

Thyroid cancer treatment and follow-up may include:

- Surgery—usually the first step for treating large nodules that are cancerous. Surgery for some patients may consist of a lobectomy—removal of one lobe of the thyroid. For other patients, a total thyroidectomy may be recommended. The recommendation about the extent of surgery is based on the test findings for the individual patient. An evolving practice of “active surveillance” is increasingly being employed especially in Japan for single small nodules (under 1

centimeter) in the middle of the thyroid gland in patients over age 65.

- Radioactive iodine ablation for some people with papillary or follicular thyroid cancer, or their variants). You should discuss with your doctor whether radioactive iodine may be a helpful treatment for you.
- Thyroid hormone replacement therapy for anyone who has had either most or all of their thyroid gland removed or supplemental thyroid hormone for some patients who have had partial removal of the thyroid. A blood test measurement of thyroid stimulating hormone (TSH) will help determine this decision.
- External beam radiation including gamma knife radiation – for some patients with extensive and invasive cancer. It is fairly uncommon to use this treatment.
- Chemotherapy, including new targeted therapies, sometimes in a clinical trial – for some patients. Fortunately, this is rarely needed.
- There are additional treatment modalities, such as radiofrequency ablation, percutaneous ethanol (alcohol) injections, and thermal ablation, for selected circumstances. Different types of immunotherapies are also in clinical trials.
- Thyroid cancer patients receive periodic follow-up testing such as blood testing for thyroid hormone levels and tumor markers (thyroglobulin and thyroglobulin antibodies for DTC and calcitonin and carcinoembryonic antigen (CEA) for MTC), ultrasound, and other imaging. The type and frequency of testing is based on the patient's type of thyroid cancer as well as the individual circumstances of their thyroid cancer.

Points to keep in mind:

- Discuss your situation and your treatment with your physician so that you understand what is recommended and

why.

- Thyroid cancer treatment may include removing all or most of the cancer to help prevent the disease from coming back (recurrence) or spreading (metastasis).
- Treating thyroid cancer often uses two or more of the above treatment approaches.
- Expect to have follow-up testing and monitoring over your lifetime.

10. Pregnancy and Thyroid Nodules

The evaluation is generally the same as for nonpregnant women.

- If the pregnant woman has normal TSH or is hypothyroid, a fine needle aspiration should be done if the nodule is clinically relevant.
- If the TSH is below the normal range, the FNA can be deferred until after pregnancy and the cessation of lactation. Then an I-123 scan can be done to evaluate the nodule's function if the TSH remains suppressed.
- If a nodule is papillary thyroid cancer and grows substantially or if there is suspicion of spread to lymph nodes, surgery should be considered. If it hasn't grown or spread to lymph nodes, or if it is discovered in the second half of pregnancy, surgery can usually be deferred.
- If the FNA result shows suspicion for papillary thyroid cancer, keep the TSH at 0.1 to 1.0 during pregnancy.

11. Children and Teens: Thyroid Nodules and Thyroid Cancer

The steps and care of children and teens with thyroid nodules or thyroid cancer are largely similar to that of adults, with modifications based on differences such as the prognosis for thyroid cancer in young people being very good, even though

spread to lymph nodes or beyond is more common than in adults.

Nodules and care in young people are explained in videos with experts, available on ThyCa's YouTube Channel, and in the detailed guidelines on Pediatric Thyroid Cancer Management, published by the American Thyroid Association.

12. Background About the Thyroid Gland

Why is the thyroid gland important? The thyroid gland is an endocrine gland that affects how you feel and how your body functions. It produces hormones that circulate in your blood to the rest of your body.

Where is the thyroid gland and how big is it?

The thyroid gland is located in the front of your neck, just below the voice box or Adam's apple. You usually cannot feel your healthy thyroid gland through your skin.

This gland is small. In an adult, it usually weighs one half to three fourths of an ounce (14 to 20 grams). It is about an inch wide (2.5 centimeters). It is shaped like a butterfly, with one "wing" (lobe) on each side of the windpipe (trachea). The two lobes are connected by a thin piece of tissue called the isthmus.

The thyroid gland contains 2 important types of cells. These are thyroid follicular cells and C cells (also referred to as parafollicular cells). C cells produce calcitonin, a specific hormone that helps to regulate the body's use of calcium. Differentiated thyroid cancer and anaplastic cancer are cancers of the follicular cells. Medullary thyroid cancer is cancer of C cells.

What are parathyroid glands?

The parathyroid glands are four small glands behind the thyroid

gland. They produce parathyroid hormone, important in regulating your body's calcium levels.

What does the thyroid gland do?

The thyroid gland produces thyroid hormones, which affect each body tissue, depending on the nature of the tissue. Your bloodstream carries thyroid hormones to all parts of your body.

A main effect of thyroid hormones is to regulate your body's metabolism. Thyroid hormone regulates the rates of metabolism of carbohydrate, protein, and fat; growth and development; and physical and mental development and function. In the heart, thyroid hormone affects the heart rate.

People with thyroid nodules that are possibly cancerous usually have normal levels of thyroid hormone. Also, most people with low or high levels of thyroid hormone do not have cancer.

Thyroid disorders involving low or high thyroid hormone levels are much more common than thyroid cancer. Too little thyroid hormone in the bloodstream can result in a condition known as *hypothyroidism*, which causes metabolism to slow down, and may cause people to feel tired. Too much thyroid hormone in the bloodstream can result in a condition known as *hyperthyroidism*, which causes metabolism to speed up, and can result in an increased heart rate, among other symptoms.

Hypothyroidism and hyperthyroidism are not usually related to thyroid cancer. However, anyone who has either condition should discuss treatment with their doctor, because each can have a serious negative impact on a person's overall health and quality of life.

What is thyroid cancer?

Cancer is a term used for diseases in which abnormal cells divide without control and are able to invade other tissues. Cancer cells

can spread to other parts of the body through the blood and lymph systems.

Thyroid cancer begins in thyroid cells. Growths within the thyroid gland are called nodules. Thyroid nodules are common. Most thyroid nodules are benign. Less than 1 in 10 is cancerous.

What causes thyroid cancer?

It's not known why some people develop thyroid cancer and others do not. However, no one can catch thyroid cancer from another person.

People with certain risk factors are more likely than others to develop thyroid cancer. However, most people with the most common risk factors do not develop thyroid cancer.

Some risk factors include:

- Exposure to certain radiation (such as ionizing radiation, the type of radiation used in xrays), particularly during childhood. However, radiowaves, microwaves, and other common waves are not a risk factor for thyroid cancer.
- Personal or family history of goiter.
- Some inherited genetic syndromes.

13. Finding the Right Doctor for You

Specialized expertise is important. Patients with thyroid nodules need testing and follow-up based on the most currently available information.

This section gives general comments about physician selection, together with some specific points to consider, plus lists of sources for finding physicians for consultation with you or your doctor, or for your treatment.

Testing and follow-up for thyroid nodules may involve a team of physicians, with one physician as the team leader. You will likely see one or more other doctors in addition to your family doctor.

The professionals involved in thyroid nodule evaluation may include:

- Endocrinologist
- Endocrine Surgeon or Other Surgeons.
- Pathologist or Cytopathologist

Here are some points to consider:

- If you are not located near a medical center with extensive expertise in this health area, then it is important to find a doctor who is willing to consult with an expert specialist. Your physicians should be willing to consult with specialists familiar with thyroid nodule evaluation and follow-up.
- ThyCa's website has links to professional associations with lists of their member physicians involved in thyroid issues.
- Many specialists have spoken at ThyCa conferences and

workshops. Their names can be found at <http://thyca.org/conferences.htm>.

- ThyCa's [Medical Advisory Council](#) Members include specialists. Their names and brief biographies can be found at www.thyca.org/about-us/medical-advisors/.
- Participants in ThyCa's free online support groups and local support groups also share names of specialists involved in their own care. To learn more and to take part in a group, visit the Support Groups section of our website, at www.thyca.org/sg/

14. Tips for Preparing for Appointments

(Adapted from material from Washington Hospital Center in DC)

1. Bring a picture ID, your health insurance card if you have one, and your referral, if required by your insurance.
2. Bring a summary of your health history. Examples: pathology report from a previous FNA, scan/imaging results, and past laboratory test results related to your thyroid.
3. Bring a list of medications you are taking. This includes prescription medications, over-the-counter medications, and nutritional supplements, including dose (strength) and frequency (number of times you take it each day).
4. Testing and treatment may be stressful processes. It is helpful to write down your questions so that you don't forget to ask about anything that is important to you. You may also find it helpful to make notes of the doctors' answers/instructions.
5. Keep your notes and records in a binder or in file folders to help organize them.

6. Plan to arrive 15 minutes before your appointment.
7. Bring something to keep you busy and calm while you wait.

15. Tips for Communicating With Your Doctor and Remembering What Your Doctor Says

Having good communication with your doctors is one of the keys to getting good medical care.

- Take a family member or friend to the appointment. Two sets of ears are better than one.
- Have someone take notes.
- Ask for an explanation of unfamiliar terms and definitions.
- Ask for a visual aid. Seeing what your doctor is talking about on a chart or visual aid will help you remember.
- Ask if the doctor has any printed information to give you.
- Ask questions. Be your own advocate. Let your doctor know what is most helpful.
- *(Adapted from tips at ThyCa support group meetings and from *Teamwork: The Cancer Patient's Guide to Talking With Your Doctor* by L.R. Brusky and others.)*

16. Questions You May Want To Ask About Nodules

For more questions to ask during your appointments, go to www.thyca.org and put “questions to ask” in the Search box.

Remember, every patient’s treatment is different. The answers will depend on your individual situation.

About the Nodule

- What kind of thyroid nodule do I have?
- Is my nodule benign or malignant?
- If my nodule is malignant, what is the stage of my thyroid cancer?

About Any Follow-Up Testing or Treatment Being Discussed

- What are my testing or treatment options?
- What are the advantages and disadvantages of the testing or treatment recommended?
- What are possible short-term side effects? What are the possible long-term side effects? What can help prevent side effects? What will help me cope with them if they occur?
- What happens when my treatment is over?
- How will the treatment change my day-to-day life?

More Possible Topics to Discuss:

- Surgery
- Other Testing
- Other Treatments
- Long-Term Follow-Up Care
- Thyroid Hormone Replacement
- About my prognosis

Points to keep in mind:

- Ask questions. The medical visits are for you. Also remember, you do not have to find all answers immediately.

- Some answers may change over time, based on changes in your personal medical situation and research advances.

17. Living with Thyroid Cancer

If you find out that your nodule is cancerous, please remember that each person's journey with thyroid cancer is unique. Please remember, you are not alone.

ThyCa is here to help you cope with the challenges of all the aspects of this disease. We have published free handbooks filled with information and helpful tips for coping with each type of thyroid cancer. You may download them from our home page www.thyca.org as a PDF or get them as an ePub (on iTunes and GooglePlay), or ask us to mail you a copy.

- *Thyroid Cancer Basics* (about all types of thyroid cancer)
- *Anaplastic Thyroid Cancer*
- *Medullary Thyroid Cancer*
- more handbooks are in development

Many patients and caregivers have found it helpful to consider these questions, suggested by oncologist A. B. Weir, M.D., in "*When Your Doctor Has Bad News.*"

- How will I learn to live with my illness?
- Who am I now? How can I matter?
- Do I have a new mission?
- What gifts can I give?
- How do I best prepare my loved ones to live with my illness?
- Can this type of life be my finest hour?

We invite you to find support and education from ThyCa's free local support groups, free online groups, and special events.

18. For More Information – ThyCa Website, Handbooks, Videos, Events, More

ThyCa: Thyroid Cancer Survivors' Association, is here for you. We provide information and support to thyroid cancer patients, as well as patients with thyroid nodules that are being investigated to determine the diagnosis.

1. Website. Visit www.thyca.org.

The website was developed by patients, caregivers, and physicians. The medical information receives review and input from more than 50 experts.

The website is very comprehensive. It provides information, support, events calendar, support groups, added free support services, awareness tools, research fundraising, and more. You will find details about detection, diagnosis, treatment, and follow-up, from leading experts in the field. Materials are available in 10 languages: English, Chinese, French, Greek, Hebrew, Italian, Japanese, Portuguese, Russian, and Spanish.

2. Videos with Experts on ThyCa's YouTube Channel.

3. Events Calendar. It lists dozens of free events sponsored by ThyCa plus cooperating organizations. Come to support group meetings, seminars, workshops, and the annual International Thyroid Cancer Survivors' Conference.

4. Support Groups. Local support groups and online support communities are wonderful ways to share experiences, resources, and coping tips with other patients and caregivers.

5. Social Media.

Facebook—

<https://www.facebook.com/pages/THYCA/231492537404?ref=mf>

Twitter— <https://twitter.com/ThyCaInc>

Instagram— ThyCaInc

6. Free Publications.

Numerous free publications are available on our website for downloading, and as ePubs, including:

- *Thyroid Cancer Basics Handbook*. In English, Chinese, Hebrew, Italian, Russian, and Spanish
- *Anaplastic Thyroid Cancer Handbook*. In English, Chinese, and Spanish
- *Medullary Thyroid Cancer Handbook*. In English, Chinese, and Spanish
- *Low Iodine Cookbook*. In English, French, Portuguese, and Spanish
- One-Page Low-Iodine Diet Guide. In English, Japanese, and Spanish

Thyroid cancer awareness materials are available on our website, plus more publications, newsletters, & free information packets.

6. Physician Guidelines. The American Thyroid Association has published physician guidelines for thyroid nodules and the management of each type of thyroid cancer. They're linked from ThyCa's website. The National Comprehensive Cancer Network Guidelines are also available.

7. Reference Book. We recommend, for further information for patients and caregivers, **the illustrated 439-page reference *Thyroid Cancer: A Guide for Patients (2nd edition, 2010)***. The 1st edition is also available in Spanish and the 2nd edition in Chinese. It is also a helpful resource for medical professionals. Its authors are over 30 medical professionals, plus patients and caregivers. Editors: Douglas Van Nostrand, M.D., Leonard Wartofsky, M.D., Gary Bloom, Kanchan P. Kulkarni, M.D.

8. Helpful for coping with any type of thyroid cancer or other cancer, is ***Medullary Thyroid Cancer Memoirs (2015)***. Nearly 400 pages of stories, reflections, understanding, and inspiration from 66 people. Editors: William Kenly, Galina McClain, and Elizabeth Simons.

19. Thyroid Cancer? ThyCa can help.

We are an internationally recognized, medically advised organization providing **free** support services to people with thyroid cancer.

- **For patients and caregivers** — We offer information and understanding to patients and their families when they need it most.
- **For the public** — We promote awareness for early detection, and provide outreach and education year-round. We sponsor Thyroid Cancer Awareness Month each September.
- **For professionals** — We provide this free handbook, patient brochures and wallet cards, free downloadable Low-Iodine Cookbook for patients with differentiated thyroid cancer, and other materials to give to patients. Plus research funding, with grant recipients selected by an expert panel of the American Thyroid Association.

Free Services & Resources: Award-winning website • Person-to-person support • Local support groups • Online support groups • Awareness brochures • Seminars, workshops • Annual International Conference • Over 50 Videos with Experts; YouTube Channel • Online newsletter • Downloadable Low-Iodine Cookbook • Free Handbooks on all types of thyroid cancer • Materials in 10 languages • Facebook, Twitter • More

Please contact us for more information and free materials:

ThyCa: Thyroid Cancer Survivors' Association, Inc.

www.thyca.org • thyca@thyca.org

Toll-free 877-588-7904 • Fax 630-604-6078

P.O. Box 1102, Olney, MD 20830-1102

ThyCa: Thyroid Cancer Survivors' Association, Inc., is a nonprofit 501(c)(3) organization of thyroid cancer survivors, family members, and health care professionals, advised by distinguished thyroid cancer specialists and dedicated to support, education, communication, awareness for early detection, and thyroid cancer research fundraising and research grants.

Thyroid Nodules: Testing and Follow-Up A Handbook for Patients and Caregivers

This handbook is available free of charge in different formats.

- You may download it from our website www.thyca.org in 8 ½ x 11 inch format, for a loose-leaf binder or other binding.
- It will also soon be available as an ePub on iTunes and GooglePlay, also from www.thyca.org
- In its compact handbook form (5 ½ x 8 ½ inches), we mail individual copies to patients, caregivers, and anyone interested in thyroid cancer.
- We also mail the handbook in bulk, free of charge, to physicians and other health care professionals, and to thyroid cancer support groups and related organizations.

Thank You Very Much to our Donors
Your generous contributions make possible this handbook, our other publications, support services and resources, and events.

Courtesy of

ThyCa: Thyroid Cancer Survivors' Association, Inc.
Support • Education • Communication • Hope Through Research

Serving people with thyroid cancer, and their families, friends, health care professionals, and the public worldwide since 1995

www.thyca.org