# Pediatric Thyroid Cancer

**ThyCa: Thyroid Cancer Survivors' Association, Inc.**
www.thyca.org

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***This handbook*** *provides an overview of basic information about pediatric thyroid cancer— thyroid cancer in children through the age of 18 years.*

*The handbook covers the incidence, diagnosis, typical treatment options, and both short-term and long-term follow-up of pediatric patients diagnosed with thyroid cancer.*

*It also gives tips for coping with this disease, suggestions for communicating with your health care professionals, and helpful resources for support and further information.*

*While this handbook contains important information about pediatric thyroid cancer, a patient's individual testing, treatment, 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 additional thyroid cancer specialists including physicians, researchers, patients, and caregivers. We greatly appreciate everyone's contribution.*

***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 for ThyCa's goals in education, treatment, and research. Our website,* ***www.thyca.org,*** *has more 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 advice from your child's treatment team. You are advised to consult your own medical doctor(s) for all matters involving your child's health and medical care.*

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# Introduction—You Are Not Alone

A thyroid cancer diagnosis can be difficult. Please be reassured that you are not alone, whether you are a child with thyroid cancer, a parent, or other caregivers.

Our goal is to offer help, hope, and support to:

- Strengthen your knowledge through education.
- Help you and/or your child feel part of a community of survivors and caregivers as you cope with emotional and practical concerns.
- Introduce you to the many free services, information resources, and events that can help you.

This handbook is for parents and young patients trying to understand and successfully navigate the diagnosis, treatment, and long-term management of pediatric thyroid cancer.

This handbook gives you:

- Basic facts and helpful tips for coping with **pediatric thyroid cancer.**
- More details about treatment and follow-up for pediatric thyroid cancer, plus information on recent research, potential future treatments, sources of support and further information.

# 1. About Pediatric Thyroid Cancer: Basic Facts

- Thyroid cancer is a malignant tumor or growth originating within the thyroid gland. It is also called thyroid carcinoma.
- Thyroid cancer is the most common endocrine cancer in children and adults. The cause of most pediatric thyroid cancer is unknown.
- About 1.8% of thyroid cancers occur in people under age 20. The incidence appears to be increasing.
- Rates of newly diagnosed pediatric thyroid cancer have been increasing since 1973, by about 1% every year. **[Chiu 2012]**
- About 4 out of every 5 children or adolescents diagnosed with thyroid cancer are female. **[Hogan 2009]**
- For most patients, there is no identifiable explanation for why thyroid cancer developed and there are no known links between developing pediatric thyroid cancer and any dietary, behavioral or lifestyle factors. So, for the majority of patients, there is nothing that could have, or should have, been done or avoided to have prevented it from occurring.

Three identifiable risk factors include exposure to radiation (medical or environmental), inherited tumor predisposition, and possibly autoimmune thyroid disease.

- People have a greater chance of developing thyroid cancer if they were exposed to radiation during childhood and adolescence. Most commonly this is associated with radiation treatment for cancers involving the head and neck. The risk is greatest if the exposure occurred prior to 5-10 years of age. Thyroid cancer may develop as early as 3 to 5 years after radiation exposure, although it may not develop for up to 20 years or longer after the exposure.
- Other factors that may increase the chance of developing thyroid nodules and thyroid cancer in children and teens are certain inherited tumor predisposition syndromes (PTEN Hamartoma tumor syndrome, DICER1 tumor syndrome, and Familial Adenomatous Polyposis as the most common) and a prior history of autoimmune thyroid disease (either Hashimoto's/hypothyroidism or Graves' disease/hyperthyroidism).

- In most cases, treatment for pediatric thyroid cancer is very successful at controlling or eliminating the disease.
- In general, the outcomes (prognosis) for children with thyroid cancer are better than for adults with thyroid cancer. Most children and teens will not die from thyroid cancer. Their long-term survival rate, 30+ years after diagnosis, is 98% or better.
- The prognosis for any child or adolescent with thyroid cancer depends on several factors, such as:
  - Type (subtype) of thyroid cancer.
  - Whether the disease has spread (metastasized) to lymph nodes in the neck or other parts of the body, especially distant sites such as the lungs.
  - Short and long-term complications from surgical and medical treatment (that all of us are working to reduce).

# 2. Types of Pediatric Thyroid Cancer

- Like adults, most patients with pediatric thyroid cancer are diagnosed with differentiated thyroid cancer (DTC), which includes both papillary thyroid cancer (PTC) and follicular thyroid cancer (FTC). In general, differentiated thyroid cancers (vs. poorly differentiated) have a better prognosis, in part because they act more like normal thyroid cells which respond better to radioactive iodine as well as tyrosine kinase and oncogene-specific targeted therapies (these treatments will be discussed later in this handbook).
- 90% of pediatric thyroid cancer cases are PTC and 5-10% of pediatric thyroid cancer cases are either FTC or medullary thyroid cancer (MTC).
- The majority of MTC (75%) in pediatric patients is associated with an inherited syndrome called multiple endocrine neoplasia type 2 (MEN2). The remaining 25% of cases are sporadic MTC, where ‘sporadic’ means that the tumor is not inherited and not associated with an increased risk for developing other, non-thyroid tumors.
- Poorly differentiated thyroid cancer (PDTC) is very uncommon in pediatrics and there are even fewer pediatric patients that have been diagnosed with anaplastic thyroid cancer (ATC).
- Information about treatments and research advances on pediatric thyroid cancer can be found at www.thyca.org.

# 3. Pediatric Thyroid Cancer Diagnosis

Most children with thyroid cancer initially seek medical care because they or someone else (a friend, family member, or medical provider) noticed a small lump, or nodule, on their neck. Nodules may also be found during a radiological examination (ultrasound, CT scan or MRI) performed for other reasons.

- In children, thyroid cancer may also present as persistent, enlarged lymph nodes (sometimes referred to as 'swollen glands'). Enlarged lymph nodes under the jaw line are common. However, enlarged lymph nodes in the middle or lower portion of the neck, forward from the ears, are abnormal, and thyroid cancer or other malignancy should be considered as a possible cause.
- Most people with thyroid cancer are asymptomatic, they do not have any symptoms, including pain, associated with their tumors. This is often a challenging aspect of the diagnosis as most patients wonder how it is possible that they can have cancer but still feel physically normal. This is common in both pediatric and adult patients diagnosed with thyroid cancer.
- While most thyroid nodules are benign, not cancerous, about 20-30% of children with nodules are found to have cancer. This is a higher rate than is seen in adults where 5-10% of adults with thyroid nodules are diagnosed with cancer.
- Blood tests should be performed to measure how the thyroid is working (called thyroid function testing; TFT), including measuring the thyroid stimulating hormone (TSH) level.
- The most helpful radiological test is a thyroid and neck ultrasound (US). The US features of the thyroid nodule are used to determine which thyroid nodules should undergo a tissue biopsy called **fine needle aspiration biopsy (FNAB)**. In addition, if any abnormal lymph nodes in the neck are found during the thyroid ultrasound, the lymph nodes can also undergo FNAB to determine if the cancer has spread. This can help the surgeon plan the most appropriate initial procedure.
- FNAB should be performed under ultrasound guidance. For most pediatric patients, either conscious sedation or distraction methods may be used to decrease the anxiety of the procedure.
- The FNAB needle is thinner than the needle that is used to draw a blood sample. So, the procedure only allows for cells from the

nodule to be removed, it does not provide a piece of thyroid tissue.

- The cells removed during FNAB are then examined under the microscope by a doctor called a "**cytopathologist,"** to determine if they have the appearance of normal thyroid cells, of thyroid cancer or are somewhere between being normal (not cancer) and cancer. This middle level is called 'indeterminate' and about 25-30% of FNAB samples fall into this category.
- In the United States and Canada, The Bethesda System for Reporting Thyroid Cytopathology (TBSRTC) is used to characterize the cell features from the FNAB sample. TBSRTC has 6 categories with associated predicted risk of malignancy (table). There are significant differences between the estimated risk of malignancy between pediatric and adult patients, as well as between institutes where the FNAB is read. Ask your provider if they know what the predicted risk of malignancy is prior to the FNAB so that you understand the possible results, as well as the anticipated plan and options for management.
  As with all aspects of the evaluation and management, it is very important that the person performing the procedure and the person reading the FNAB are experienced in evaluation of thyroid nodules and thyroid cancer in children and adolescents.
- For a small number of patients, the FNAB does not provide enough cells to establish a diagnosis. This is called an 'unsatisfactory' or 'inadequate' sample (TBSRTC category 1).
- If the cells are determined to be benign (TBSRTC category 2), not cancerous, there is no need for further treatment or surgery. Instead, the nodule can be monitored with ultrasound to make sure nothing changes. This is referred to as "surveillance." If the nodule is very large and/or uncomfortable surgical removal is also an option, even if benign.
- If the cells are determined to be consistent with thyroid cancer (TBSRTC category 6), then surgical removal of the thyroid gland is the most common next step. This may either be complete removal of the thyroid (called a thyroidectomy) or removal of half of the thyroid (called a lobectomy). If the cancer has spread to lymph nodes, those should be surgically removed as well (referred to as a neck or lymph node dissection or lymphadenectomy).

- In approximately 25% or more of nodules, the cells are not normal, but they do not appear to be clearly cancerous. We refer to this as an 'indeterminate' result (TBSRTC categories 3, 4, or 5). This does not necessarily occur because of the lack of experience of the physician reading the slides. Rather, it is because there is only so much information that can be determined from cells compared to a larger, surgical biopsy.
  For patients with a nodule that has an *indeterminate* result, additional testing for changes in the molecular make-up of the cells may be needed to refine the risk estimate. These tests are referred to as "genomic panels" and test for changes in the DNA of the thyroid cells that drive the cells to grow and to spread (metastasize). Where available, the test may be performed on a sample obtained from an extra needle-pass during biopsy of the thyroid nodule. These tests are not always covered by insurance plans.
- Surgical removal of ½ of the thyroid, called a lobectomy, is another way to determine the underlying diagnosis. This is commonly performed for patients with indeterminate cell tissue (TBSRTC category 3, 4, or 5) and may even be warranted if a genomic panel is performed, as several driver gene alterations (genetic mutations that can potentially cause cancer) may be found in both benign and cancerous nodules. Once the nodule is removed and completely examined under the microscope by a pathologist, a final diagnosis will be made. Your treatment team will help decide if molecular testing is available and appropriate, as well as determine if your insurance will cover this additional test.
- See section 7 for more detailed information on the treatment for Pediatric Differentiated Thyroid Cancer (Papillary and Follicular).

# 4. Prognosis for Pediatric Thyroid Cancer

- The first thing to know is that the long-term outcome for children and adolescents diagnosed with thyroid cancer is favorable. This is true even for children and adolescents where the cancer has spread to lymph nodes in the neck or areas outside of the neck, such as the lungs.
- Both papillary thyroid cancer and follicular thyroid cancer grow very slowly, so a short delay in diagnosis and treatment is usually not associated with a worse outcome.
- Many patients with thyroid cancer limited to the thyroid gland can achieve 'remission'. This means the cancer can be removed with surgery alone.
- In some patients, it may be difficult to get rid of thyroid cancer even with the best of care. For patients with persistent disease, thyroid cancer may remain stable for years, even decades (meaning it may not grow or spread). At this time, we cannot predict which patients will have stable, progressive, or recurrent disease.
- It is estimated that 98% or more of children and adolescents with thyroid cancer will survive with the majority remaining in good health.
- Although survival is high, persistent disease (most commonly in the lungs) or recurrence of the cancer is more common for pediatric thyroid cancer than in adults with thyroid cancer. In children with spread to the lungs, it is often not possible to become cancer-free; however, such individuals generally remain healthy for decades after diagnosis.
- For those with extensive or progressive disease despite initial treatment, there are an increasing number of oral medications (inhibitors of the cell-pathways that are over-active in thyroid cancer) that may be used to slow the growth of thyroid cancer and even cause the cancer to shrink, although they don't cure the thyroid cancer completely. These drugs are not beneficial for all patients, and ongoing research continues to define which patients will benefit from these drugs, as well as the timing of when to start and which drug to use.
- It is important for all patients diagnosed with pediatric thyroid cancer to receive life-long follow-up care by a physician familiar

with thyroid cancer care. Follow-up should include bloodwork and radiologic imaging, typically annually.

- The bloodwork for thyroid function testing should include TSH and fT4.
- The bloodwork for tumor markers for papillary/follicular thyroid cancer markers includes thyroglobulin and anti-thyroglobulin antibodies.
- The bloodwork for medullary thyroid cancer markers includes calcitonin and CEA (carcinoembryonic antigen).
- The radiologic imaging (such as ultrasound, CT scan, etc.) should be individualized for each patient based on amount of disease.

# 5. Pediatric Medullary Thyroid Cancer

Pediatric medullary thyroid cancer (MTC) is different from pediatric differentiated thyroid cancer (DTC) in several ways.

- Medullary thyroid cancer develops from C-cells, which are different from the follicular cells that give rise to papillary or follicular thyroid cancer. Because of this difference, MTC can only be treated with surgery or, in advanced cases, with oral medications (tyrosine kinase inhibitors or oncogene- targeted therapy). MTC does not respond to radioactive iodine treatment.
- C-cells help regulate calcium metabolism in the body, and, to that end, they produce a hormone called **calcitonin**. After the thyroid gland has been removed, calcitonin levels in the blood can be measured to determine the completeness of surgery, to predict the long-term outcome, and, along with radiological imaging, to help determine if and/or when additional treatment should be considered.
- Medullary thyroid cancer is also associated with increased Carcinoembryonic antigen (CEA) levels in the blood. Monitoring CEA levels after surgery may also be useful to determine the response to treatment.
- Like patients with DTC, patients with medullary thyroid cancer who have their thyroid removed (thyroidectomy) will also need to take thyroid hormone replacement (levothyroxine, or LT4) as a once-daily pill after surgery (See section 9 for more information about thyroid hormone replacement).

This medication will need to be taken life long, to maintain adequate thyroid hormone levels. Thyroid Stimulating Hormone (TSH) levels are measured annually and may be measured more frequently if necessary. Depending on the results, an adjustment in the dose of thyroid hormone replacement therapy may be needed (see Section 9).

- There are two main types of medullary thyroid cancer: sporadic and hereditary.
- In adults, most medullary thyroid cancer is sporadic (not inherited). In children, most medullary thyroid cancer is inherited by transmission of an alteration in a gene called ***RET***.
- Individuals with an altered *RET* gene are affected by a condition called Multiple Endocrine Neoplasia (MEN) type 2. MEN2 is associated with an increased risk for developing MTC, as well as tumors of the adrenal and parathyroid glands.
  The adrenal tumors are called pheochromocytomas and overproduce adrenaline (epinephrine). Parathyroid tumors may be associated with elevated levels of calcium due to overproduction of parathyroid hormone.
  The risk of developing each of these tumor types: MTC, pheochromocytoma, and parathyroid tumors, is based on the specific variant (change) in the *RET* gene. The location of the variant is called the 'codon'.
- *RET* variants are passed between each generation of a family with a 50% risk of an individual with the variant passing it to their children. This pattern is referred to as an 'autosomal dominant' pattern of inheritance.
- Children with a first-degree family member with MTC (mom, dad, or sibling) should be offered genetic testing even if they do not have a thyroid nodule at the time of genetic screening. Testing is accomplished via a blood sample.

  If the child is found to have a *RET* variant related to medullary thyroid cancer, the physician might talk to the parents (or guardians) about the option of a thyroidectomy (removing the thyroid by surgery) ***before*** any cancer develops. For the majority of patients with MEN2, the timing for thyroid surgery is based on their calcitonin levels.

For individuals with some specific *RET* variants, where the risk of developing MTC is highest and occurs at an early age a recommendation for surgery may be made based on a child's age alone. Carriers of variants in codon 918 should undergo thyroidectomy at the time of diagnosis, ideally by 1 year of age, while carriers of variants in codons 634 and 883 should undergo thyroidectomy at or before 5 years of age. Surgery is the main treatment for medullary thyroid cancer and ideally is performed prior to tumor spread outside the thyroid gland. The adrenal and parathyroid tumors do not spread and can be surgically removed.

If MTC does spread, there are very effective oral medications that can inhibit the growth and even cause the tumors to shrink, although, to date, none of these drugs appear to permanently kill the tumor.
More information on MTC can be found in the ThyCa handbook titled, *Medullary Thyroid Cancer at www.thyca.org*.

# 6. Pediatric Poorly Differentiated Thyroid Cancer and Anaplastic Thyroid Cancer

Pediatric poorly Differentiated Thyroid Cancer (PDTC) is uncommon and pediatric Anaplastic Thyroid Cancer (ATC) is extremely rare. For information about their management, you may wish to read ThyCa's handbook *Anaplastic Thyroid Cancer* at www.thyca.org, and the American Thyroid Association's *Guidelines for the Management of Patients with Anaplastic Thyroid Cancer*.

# 7. An Overview of Management of Pediatric Differentiated (Papillary and Follicular) Thyroid Cancer

Treatment and management decisions for children and adolescents with differentiated thyroid cancer — papillary or follicular thyroid cancer and their variants —depend on a patient's individual factors.

This is a change from past years when treatment was the same for most pediatric patients.

Initial treatment can include a combination of:

- Surgery –
  - Thyroidectomy (removal of the entire thyroid) or lobectomy (removal of half);
  - Lymph node dissection (guided by pre-operative ultrasound and lymph node biopsy).

- TSH-suppression - For those that underwent total thyroidectomy, replacement of thyroid hormone (T4) with a dose large enough to suppress the thyroid stimulating hormone (TSH) below those typically seen (Section 9).
- Radioactive iodine - for some patients

The detailed recommendations for each of these treatments are found in the American Thyroid Association's *Management Guidelines for Children with Thyroid Nodules and Differentiated Thyroid Cancer*. Specialists in pediatric thyroid cancer developed these guidelines for use by physicians. An updated version of these guidelines is in progress and should be released in late 2024/2025.

**More Detailed Information:**

- Before surgery, a thyroid and neck ultrasound is performed to assess the spread of the thyroid cancer outside of the thyroid gland.
- Papillary thyroid cancer (PTC) and medullary thyroid cancer (MTC) spread (metastasize) from the thyroid to lymph nodes behind the thyroid (in the central part of the neck), then to lymph nodes in the lateral neck (in the side of the neck), and, then outside of the neck, most commonly to the lungs. Knowing if/where the cancer has spread, prior to surgery, is necessary to ensure that the proper surgery is performed. A CT scan of the neck and/or chest may also be recommended to help plan for surgery.
- Follicular thyroid cancer (FTC) spreads from the thyroid to other parts of the body through blood vessels. Because of this, spread to lymph nodes in the neck is much less common compared to PTC, and because of this a lymph node dissection is typically not required for FTC.
- In pediatric-age patients, it is less common for FTC to spread to areas outside of the neck compared to adults. The risk is best determined after the initial surgery when the tumor is inspected

under the microscope for evidence of cancer in the blood vessels of the tumor capsule.

- Following surgery, some patients undergo whole-body scan and treatment with radioactive iodine (RAI), which is also written as I-131 or $^{131}$I. The extent of the spread of the cancer outside of the thyroid, including to the lymph nodes, helps identify those individuals most likely to benefit from RAI treatment. This is discussed in greater detail in Section 11.
- RAI is not recommended for patients with MTC or anaplastic thyroid cancer because these types of thyroid cancer do not have the ability to absorb and be destroyed by I-131.
- All patients who undergo removal of the entire thyroid (total thyroidectomy) require life-long thyroid hormone replacement medication (See section 9 for more information about thyroid hormone replacement). Those patients that undergo removal of half of their thyroid (lobectomy) typically do not require life-long thyroid hormone replacement as the remaining half of the gland can produce enough thyroid hormone.
- During all phases of treatment, it is important to remember that there is no "one size fits all" treatment for thyroid cancer. Perhaps you know someone else who is a thyroid cancer survivor or discuss treatment options with someone from a support group. Keep in mind that the treatment that worked for one person may not be the best treatment for you or your child.
- Ask Questions. Open discussions with your medical team are encouraged. Ask as many questions as you feel are necessary so that you and your child understand the risks and benefits of treatment, the details of the monitoring plan, the experience of the surgeon and endocrinologist treating thyroid cancer in children and adolescents, as well as the expected outcome. Many people find that keeping a notebook of information and questions useful in understanding the large amount of information that comes with a cancer diagnosis.
- It is never wrong to seek a second opinion especially if you are not comfortable with the answers you receive or if the response to therapy is not what you expected. You and your child are an important part of the medical treatment team and taking a slow and cautious path prior to surgery and treatment will ensure your child gets the best care possible.

**Medical Team**

The medical team may include some of these different types of clinician specialists:

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|---|---|---|
| Endocrinologist | Nuclear Medicine | Genetic Counselor |
| Surgeon | Pathologist | Social Worker |
| Radiologist | Oncologist | Primary Care Clinician (pediatrician or family physician) |

**The Role of the Endocrinologist**

Endocrinology is a branch of medicine that focuses on disorders of hormone-producing organs called glands. The thyroid gland is part of the endocrine system.

Patients diagnosed with a thyroid nodule or thyroid cancer should work closely with an endocrinologist that has experience in caring for children and adolescents with thyroid nodules and thyroid cancer to ensure the best care is provided.

If your community does not have an endocrinologist, you can ask your primary care physician to consult with one. In certain hospitals and communities, an oncologist (a doctor that takes care of patients with cancer) may take on the role of the primary medical doctor helping to direct care.

- Families are encouraged to take the time to find a doctor and medical center experienced with the management of this disease. Ideally, this should occur prior to surgery.

**Thyroid Cancer Research**

Much of what we know about how best to treat thyroid cancer is the result of research that has been done in the past. This has helped identify which treatments are most effective and which treatments, for some individuals, may be unnecessary. We are constantly learning and improving the care of individuals with thyroid cancer (both children and adults).

During your child's thyroid cancer treatment, you may be invited to

participate in research. You are entitled to ask questions about the research, about what is involved, and to decide whether you wish to participate. You are under no obligation to agree to be part of a research study. Much of the time, research will not immediately benefit those that are participating, but may help those treated in the future (just as current patients benefit from knowledge gained from past research).

# 8. Surgery for Pediatric Thyroid Cancer

Surgery is generally the first and most important step in the treatment of pediatric differentiated thyroid cancer (papillary and follicular thyroid cancer) as well as pediatric medullary thyroid cancer.

There are different types of thyroid surgery and a careful evaluation of the investigations during initial visits with the Endocrinologist and Surgeon will help determine which surgery is best for an individual patient.

- **Total thyroidectomy** involves removal of the entire thyroid gland.
- **Thyroid lobectomy** involves removing only one half of the thyroid.
- **Completion thyroidectomy** is a second surgery. In some cases, after review of the tissue removed during a thyroid lobectomy by a pathologist, a recommendation is made to remove the other thyroid lobe. Often this is performed if the team feels that subsequent treatment with radioactive iodine may benefit the patient. Features that may lead to a recommendation for completion thyroidectomy include the subtype of DTC, invasive features seen under the microscope (such as tumor spread into the blood vessels or lymphatics of the thyroid gland) or spread to lymph nodes in the neck.
- **Central neck dissection** may be recommended to remove the lymph nodes that are located behind and below the thyroid gland. In some cases, removing these lymph nodes can provide important information on the invasiveness of the cancer or if any additional treatment may be beneficial. The decision to pursue a central neck dissection depends on the results of physical exam, ultrasound features of the primary nodule/tumor and lymph nodes,

as well as the fine needle aspiration biopsy of the thyroid tumor and lymph nodes.

- **Lateral neck dissection** is a surgery that removes the lymph nodes in one or both sides of the neck. This will be recommended if the ultrasound performed prior to surgery identifies abnormal lymph nodes consistent with spread of the thyroid cancer. Fine needle aspiration biopsy is usually performed prior to surgery to confirm that the lymph nodes have thyroid cancer in them.

A neck ultrasound that evaluates *all areas of the neck (the central and lateral neck) prior to the initial surgery* is **critically important** for proper and complete surgical planning. In patients with evidence of spread (metastasis) to the lateral neck, a neck CT or MRI may also be performed prior to surgery.

**Risks of Surgery:**

Although surgery is the most important step in treating thyroid cancer, there are potential risks, and it is important to be aware of these ahead of time. The most common **complications of surgery** include: (1) incomplete removal of lymph nodes due to incomplete pre-surgery imaging and evaluation, (2) damage to the parathyroid glands, the glands that control the body's ability to absorb calcium from our diet and release phosphorus from the kidneys, and (3) damage to the recurrent laryngeal nerves (RLN), the nerves that control movement of our vocal cords. These risks are described in detail below.

Thyroid cancer is less common in children and adolescents than in adults, thus it is important to seek out a medical team (**endocrinologist *and* surgeon**) that have comfort and experience treating children and adolescents with thyroid cancer.

The American Thyroid Association (ATA) guidelines for pediatric differentiated thyroid cancer recommend finding a surgeon with expertise and experience in performing thyroid surgery in children and who maintains an active, high volume of pediatric neck surgery. The more experienced a surgeon is at performing thyroid surgery, the lower the risk of complications. Nonetheless, complications can occur even for the most experienced surgeon and more extensive cancers are typically associated with higher surgical risks.

There are no published data to estimate the experience of the medical team; however, you should ask your endocrinologist about their experience in managing pediatric patients (<19 years of age) with thyroid nodules and thyroid cancer, including how many patients they evaluate per year and how many patients they actively care for. There are pediatric specialists around the US and ThyCa can help identify a specialist for you.

Remember, you are the best advocate for your child, and no one should fault you for seeking out the best treatment team available. Thyroid cancer is slow growing, so taking time to find the best care possible is recommended.

**Specific Surgical Risks Associated with Thyroid Surgery:**

1) **Hypoparathyroidism:** Low calcium levels in the blood due to damage to the parathyroid glands.

   - There are 4 parathyroid glands that are located on the back portion of the thyroid gland (two on each side). During thyroidectomy, the surgeon will carefully locate these glands and try to leave them in place without damaging them.
   - Damage to the parathyroid glands that results in low calcium and elevated phosphorus is called **hypoparathyroidism**. This condition may be temporary (transient) or permanent.
   - For patients that undergo lobectomy, the calcium and phosphorous levels in the blood do not need to be monitored as only two glands are located on each side of the thyroid gland. Because of this, at some hospitals, patients may be discharged from the hospital to go home the same day of surgery or after a one-night stay.
   - For patients that undergo total thyroidectomy, the calcium and phosphorous levels in the blood will be measured, and calcium, with the addition of the active form of vitamin D (called Calcitriol), may be prescribed if the blood calcium levels become low and/or the phosphorous elevated. In these situations, the patient may remain in the hospital for 2 to 4 days until the levels are stable. In some hospitals, intra-operative parathyroid hormone levels or post-operative intact parathyroid hormone levels may also be checked to help guide if, and when, to start calcium and calcitriol.

- Symptoms of low calcium levels include tingling and numbness, especially in the hands or feet or around the mouth, and, if the levels are low enough, muscle spasms (called tetany).
- In a small percentage of patients, surgery can result in lifelong hypoparathyroidism and the lifelong need for calcium and calcitriol replacement.

2) **Recurrent Laryngeal Nerve (RLN) Injury**: Temporary or permanent hoarseness or loss of voice, resulting from damage to the **recurrent laryngeal nerve**, a nerve that is located between the thyroid gland and the windpipe (trachea).

- If the nerve is stretched, not cut, the change in the voice quality, and the ability to eat and drink normally may be affected. This is usually temporary. In rare cases it can be permanent.
- If the nerve is cut, the changes are typically permanent. Several corrective measures are possible if this occurs. Seeing a 'voice team' with an experienced head and neck surgeon (ENT) and speech pathologist is important to optimize the outcome.
- If both nerves are injured, patients will have breathing problems and may require a tracheostomy (permanent breathing tube). Fortunately, this is very uncommon.
- When you meet with your child's surgeon you may wish to ask what percent of their patients develop transient as well as permanent hypoparathyroidism.

3) **Infection**. This is a very rare complication. It is treated with antibiotics.
4) **Bleeding**. This is rare and is controlled at the time of the operation or afterward.

**Recovery from Surgery**

- Your surgeon will give you instructions for the care of the surgical incision, as well as what activities are appropriate and when your child can resume normal physical activities. In general, you should plan on reduced physical activities for at least 2 weeks after surgery to allow for healing of the incision.

- You should be given the time and date of your post-surgery appointment before you leave the hospital, as well as the name and/or phone number of who to contact if there are any concerns after you go home.
- Rest, good nutrition, staying hydrated and mild activities like walking will also aid recovery. Sunscreen must be used to protect the incision for at least 3 to 6 months after surgery as scar tissue absorbs sunlight differently than surrounding skin and this will help the scar become less noticeable.
- For more information about surgery, visit www.thyca.org. Also, the reference book *Thyroid Cancer: A Guide for Patients,* has chapters by two thyroid surgeons on thyroid surgery and re-operative thyroid surgery (this resource is available for sale through the ThyCa website).
- ThyCa's free virtual pediatric support group and one-to-one support are helpful resources for discussing experiences and tips for coping before and after you/your child's surgery. Support is available both one-to-one and in groups —in person, by phone, and online. For more information visit www.thyca.org/pediatric.

# 9. After Surgery: Thyroid Hormone Replacement

For those that have undergone a **total thyroidectomy**, thyroid hormone replacement is needed life-long. The dose of thyroid hormone is adjusted to achieve a target TSH (measured from blood tests) and is typically slightly higher than doses required for patients taking thyroid hormone for other conditions. Dosing will depend on the type of cancer that was removed (DTC or MTC), the patient's age and body weight.

Patients who undergo a lobectomy, without completion thyroidectomy, typically do not require thyroid hormone replacement because they will likely continue to produce enough thyroid hormone.

The thyroid gland produces two hormones: long-lasting Thyroxine (T4), and a lesser amount of Triiodothyronine (T3). While T3 is the "active" hormone used to maintain the body's metabolism, it has a relatively short life, and the body gets most of the T3 it needs by converting T4 to T3 in the bloodstream and the tissues.

The most common thyroid hormone replacement medication is levothyroxine (abbreviated as LT4). This is the synthetic form of T4 and is identical to T4 made by the body. There are generic forms of this medication and brand names (Eltroxin®, Levoxyl®, Synthroid®, Tirosint®, Unithroid®, and others). There are also commercially produced, FDA-approved solution forms available for patients that have a difficult time taking pills.

Compounded suspensions of levothyroxine (those prepared by individual pharmacies) should not be used, as the amount of medicine per dose is not predictable.

Liothyronine (LT3) is the synthetic form of T3. The most common brand name is Cytomel. Ingestion of liothyronine should follow a similar pattern as levothyroxine regarding separating from food and supplements, although this has not been adequately studied. Because of the shorter half-life, liothyronine is best taken 2 to 3 times per day (vs. once daily for levothyroxine).

As noted above, the body normally converts T4 to T3 as needed. However, the American Thyroid Association notes that in some patients who do not feel completely normal on LT4 alone, a combination of LT4 with a small amount of LT3 for a trial period of 3 – 6 months "may be reasonable to determine if combination T4 and T3 therapy will help [symptoms]." (www.thyroid.org/thyroid-hormone-treatment).

There exist natural desiccated products derived from pigs that contain both T4 and T3. There is no advantage to taking 'desiccated' thyroid hormone outside of the fact that it is combined T4 and T3 therapy. The challenge of using desiccated thyroid hormone is that the ratio of T3 to T4 in desiccated thyroid hormone is higher than in humans. Based on this, it is often easier to adjust medications if separate pills of T3 and T4 are used for patients where combined therapy may be beneficial.

- **Wherever you obtain your child's prescriptions, always double check the pills when you receive them** to be sure that you are getting what your doctor prescribed. Do this for all your prescriptions, not just levothyroxine.
- Several brand-name and generic synthetic levothyroxine preparations are currently available. Although all these medications are synthetic levothyroxine, they are not identical. These differences may affect the absorption of the drug as well as the level of thyroid hormones in the blood.
- For this reason, thyroid cancer specialist physicians recommend that thyroid cancer patients consistently take levothyroxine from the same manufacturer (brand). Ask your pharmacist to make sure that he or she consistently dispenses the same brand of levothyroxine. Alternatively, your doctor may write the prescription for a specific brand name and state "no substitutions." While there isn't an inherent problem with use of generic drugs, pharmacies may change their suppliers of generics without notice. The levothyroxine pill **color** should not change, but the shape and/or markings on the tablet may change. If there is a change in shape or markings, repeat blood levels of TSH should be retested 6 to 8 weeks afterwards. If you change pharmacies, show the new pharmacist the current pill bottle and request that they dispense the same brand.

- If you need to change manufacturers for some reason, your child should have thyroid levels checked 6-8 weeks later, because the TSH may have changed and no longer be at the level recommended by your physician.
- **Store levothyroxine pills away from heat, humidity, and light.** When the weather is warm or sunny, don't leave them in a parked car, because it can become too hot. When traveling, keep pills from becoming exposed to heat and humidity.
- Levothyroxine should be taken at approximately the same time day every day under similar circumstances. Most people take their pill first thing in the morning. It is best to take it with a glass of water, at least 30 minutes to one hour before eating anything or drinking any other beverage. **Avoid taking milk, calcium, iron or multivitamins** at the same time as levothyroxine**.** This will ensure proper absorption, because food, minerals, vitamins, and other medications can interfere with absorption. Taking the tablet before bedtime may be easier for some patients. The goal is to remember to take the tablet every day and to develop a habit that is sustainable.
- Wait 3 to 4 hours after levothyroxine before taking vitamins or supplements containing calcium or iron, including certain antacids. Milk and other dairy products can be ingested 30 minutes to one hour after the pill is taken. Some non-dairy milk substitutes have more calcium than dairy. It may be best to wait a full hour to take these diary alternatives after taking levothyroxine.
- Following a thyroidectomy, it may take one or more dosage changes to find the dosage level that is correct for your child.

For more information, visit the 'Know Your Pills' page of www.thyca.org or ask us for a free handout.

**Thyroid Hormone Replacement After DTC:** Patients who had papillary or follicular cancer may be given a higher dose of levothyroxine (LT4) to cause the thyroid stimulating hormone (TSH) level to be just below the lower end of the normal range The low (also called 'suppressed') TSH is part of the treatment plan. The intention is to ensure there is no 'stimulation' of growth for any remaining thyroid cancer that may persist after surgery and RAI treatment.

- The degree of TSH suppression is based on the risk for persistent disease as defined by the American Thyroid Association pediatric guidelines (www.thyroid.org/)
    - **Low-Risk Patients:** The goal is to keep the initial TSH level between 0.5 to 2.0 mU/L, which is within the lower-end of the normal range.
    - **Intermediate-Risk Patients**: The TSH goal is between 0.1 to 0.5 mU/L, which is below or near the low end of the normal range.
    - **High-Risk Patients**: The TSH goal is less than 0.1 mU/L, which is considered fully suppressed.

- Once it is determined that the cancer is in remission (that it is gone) then the amount of levothyroxine may be reduced to allow the TSH to rise into the normal range.
- Most patients will not feel overtreated (in other words, have symptoms of hyperthyroidism) with the higher amount of levothyroxine required to achieve TSH suppression. However, if a patient develops an increased resting heart rate, jitteriness, or notices a tremor in their hands, they should let their medical treatment team know so that the thyroid hormone and TSH levels can be checked and an adjustment in medication dose can be made, if necessary.

**Thyroid Hormone Replacement After MTC:** In contrast to DTC, **medullary thyroid cancer patients** require levothyroxine dosing to maintain a *normal* blood level of thyroid stimulating hormone (TSH). Suppressive therapy is not helpful or necessary.

**Points to Remember about Thyroid Hormone Replacement**

- Some teenagers may have trouble adhering to their thyroid hormone replacement medication or other treatment, because they are often busy and distracted by school-related or social activities. **It is very important to remember that taking thyroid replacement is both important for normal body function and growth as well as keeping the cancer from growing or returning.**
    - Establishing a routine that includes taking the pill at the same time of day is important.

- Keeping the pills in a location that is consistent and part of the daily routine is a good way to help ensure compliance. Common locations include: (1) near toothbrush, (2) where phone is plugged in every night, (3) nightstand with glass of water nearby, and (4) kitchen.
- Additional reminder techniques include: (1) calendar alarms on phones, (2) pill boxes, or (3) digital caps for pill bottles that record when the bottle was last opened can help.
- Parents need to find a balance between giving their child some independence so that they gain a sense of control over their treatment and ensuring that they adhere to their treatment plan. It's up to the parents to recognize the responsibility of their child, and the child's ability to take the pill daily,

A video with a thyroid cancer expert on ThyCa's YouTube channel explains thyroid hormone replacement research, including research on T4 (levothyroxine), T3 (liothyronine), and NDT (natural desiccated thyroid).
https://www.youtube.com/watch?v=yEhPYOkvj7M

# 10. After Surgery: Staging and Risk Levels for Pediatric Differentiated Thyroid Cancer

The staging system used to predict outcomes in adults does not apply to children and teenagers. This is because outcomes for children and adolescents are generally better than in adults. Specifically, even if the thyroid cancer has spread to lymph nodes or to other areas, including the lungs, children treated for thyroid cancer have extremely high survival rates and generally remain in good health for decades after diagnosis.

In pediatrics, the degree of tumor spread helps to determine the extent of surgery and subsequently, the need for radioactive iodine treatment. The need for additional treatment (surgical, interventional radiology, and/or medical) is based on laboratory and radiological monitoring after surgery. Information on how these data are used is defined below ('risk levels') and is available in the American Thyroid Association's 'Pediatric guidelines on the evaluation and

management of thyroid nodules and differentiated thyroid cancer (www.thyroid.org).

The initial risk assessment to determine whether the patient is likely to benefit from treatment with radioactive iodine (I-131) is usually done within 6 to 12 weeks after surgery, once the results of the pathology review have been completed, although this may be delayed without negatively impacting outcome.

There are three **risk levels** in the American Thyroid Association Guidelines for Pediatric Differentiated Thyroid Cancer (Low, Intermediate and High). These categories define the likelihood of having residual disease after surgery (either in the neck or elsewhere in the body) and help identify those patients who would benefit most from additional treatments, while allowing those at low risk to avoid any unnecessary therapy.

**1. ATA Pediatric Low-Risk.** Thyroid cancer that is found to only be in the thyroid or that has spread to only a few lymph nodes in the central neck compartment.

**2. ATA Pediatric Intermediate-Risk.** Thyroid cancer that has spread to a larger number of lymph nodes in the central neck or spread to lymph nodes in the lateral neck but with no known spread to distant parts of the body (most commonly the lungs).

**3. ATA Pediatric High-Risk.** Thyroid Cancer that has spread to lymph nodes in the lateral neck, is locally invasive into neck tissue and/or muscle, or with known distant metastasis (spread) to the lungs or elsewhere.

About 20-30% of pediatric patients with thyroid cancer that has spread to lymph nodes in the lateral neck have cancer that also spread to the lungs. Unlike in adults, these lung metastases do not generally impact the long-term survival of pediatric patients.

Most often, thyroid cancer that has spread to the lungs cannot be eliminated completely. If there is a small amount of cancer in the lungs and it is not growing, then continued monitoring without additional treatment may be the best plan. Repeated treatments attempting to eliminate thyroid cancer in the lungs may cause more

harm than good.

If there is a larger amount of cancer in the lungs that is not responding to RAI, and is growing, then treatment with oral medications may be beneficial. Every year there are new and more effective drugs available. Some of these drugs target receptors on the surface of the tumor cells that are important for growth, including blood vessels, while newer drugs inhibit specific molecular changes in a patient's tumor (directed against the specific thyroid cancer genetic 'driver' alteration).

Recent evidence suggests that some of the drugs that block specific genetic molecular alterations (RET, NTRK, and BRAF/MEK) may also increase the effectiveness of RAI treatment, although it is still not clear whether this leads to better outcomes in the long run.

The use of oral medications to treat pediatric thyroid cancer is new. This type of treatment should be administered by a treatment team that has experience with the use of these drugs for the treatment of thyroid cancer in children.

# 11. Radioactive Iodine Ablation for Pediatric Patients with Differentiated Thyroid Cancer

Radioactive iodine (RAI) is a treatment that uses radiation to destroy thyroid cells (both cancer and non-cancer) that remain after surgery. The approach to RAI has evolved over the past several years.

Previously, *all* patients were given radioactive iodine following thyroid cancer surgery. More recently, however, it has been recognized that not everyone benefits from this treatment, and that it is best to offer it only to those who stand to benefit the most—individuals at highest risk for having residual or recurrent thyroid cancer after their surgery.

- The risk of having thyroid cancer remaining after surgery is primarily based on whether the tumor has spread outside the thyroid gland and, if so, to what extent and location. The ATA risk level (see Section 10 above) is determined based on the

pathology report after surgery and any radiological imaging that shows whether the cancer has spread to areas outside of the neck.

- Low-risk patients, in particular patients with no evidence that thyroid cancer has spread outside of the thyroid gland, do not generally benefit from treatment with RAI.
- Intermediate and high-risk patients, where the cancer has spread to more than 5 lymph nodes in the central neck, to any lymph nodes in the lateral neck, or to the lungs or other distant sites, *may* benefit from RAI treatment. For some patients, more than one treatment may be needed to get rid of the cancer.

Patients who might benefit from RAI treatment will typically undergo a diagnostic **whole-body scan (WBS)** about 6 to 12 weeks after surgery. The results of this scan, and blood tests performed at the same time, help clarify which patients should be offered radioactive iodine treatment.

There is some flexibility in deciding when this test and treatment are performed. Details on how to prepare for this scan and potential treatment are listed below, as well as on the ThyCa website (www.thyca.org).

**Pre-Treatment, Diagnostic Whole-Body Scan**

The Diagnostic Whole-Body Scan (DxWBS) is used to help guide if, and how much, RAI to administer.

- The goal of this pre-RAI treatment scan is to figure out how much thyroid tissue or thyroid cancer remains, where it is located and how much radioactive iodine will be needed for treatment, if necessary.
- A small dose of the radioisotope I-123 is most often used for the DxWBS, and due to the small amount and shorter half-life, there are no safety precautions that need to be followed after ingestion. If the WBS and blood tests indicate that treatment with RAI would be beneficial, the radioisotope I-131 is used subsequently. Because of the longer half-life and larger dose, safety precautions are required after I-131 (see Section 12 below).

**Radioactive Iodine Treatment**

Radioactive iodine isotope I-131 (RAI) works because thyroid cells use iodine to make thyroid hormone. The thyroid is one of the only

parts of the body that absorb iodine from our diet. Iodine is naturally found in certain foods (dairy, eggs, seafood, etc.), may be added to table salt (iodized salt), and is available as a liquid or pill supplement. Thyroid cells cannot tell the difference between normal dietary iodine and radioactive iodine.

Radioactive iodine (RAI) is given in pill form (most common) or as a liquid. When it is swallowed, the RAI is absorbed by any remaining thyroid cells. The radiation then destroys the thyroid cells, both cancerous and normal thyroid cells, with minimal effects on the rest of the body. It may take months, even years, for a radioactive iodine treatment to destroy all of the cancer cells.

The activity of I-131 is measured in millicuries (mCi) in the United States or in Gigabecquerel (GBq) in Europe. The typical dose to destroy thyroid tissue in the neck ranges from 30 to 100 mCi (= 1.75 to 3.7 GBq). Higher doses are usually administered for thyroid cancer that is in the lungs or other locations outside of the neck, typically between 100 to 175 mCi (= 3.7 to 6.5 GBq) for people with more extensive disease. In pediatrics, these doses are adjusted based on the age and weight (or body surface area) of the patient.

RAI is usually safe for patients who are allergic to seafood or X-ray contrast dyes.

# 12. Preparation for Radioactive Iodine (RAI) Therapy

### Raising the TSH Level

RAI is most effective when the TSH (thyroid-stimulating hormone, or thyrotropin) level is above the normal range. This is because TSH stimulates the thyroid, to take up iodine, including the RAI.

There are two equally effective ways to increase the TSH level. Your doctor may have reasons for recommending one option over the other, specific to your situation.

1) **Withdrawal from Thyroid Hormone Replacement:** Thyroid hormone replacement pills are stopped 2 to 3 weeks before RAI treatment. Stopping the pills will cause the TSH to rise to a level

of 30 mIU/L or higher, far above the upper end of the normal range. ***This is the most common approach to increasing the TSH in pediatric patients***. Patients may experience mild signs and symptoms of being hypothyroid, although this seems to be less common in pediatrics (see below for signs/symptoms).

OR

2) **Thyrogen® Injections:** Thyrogen® is the brand name of thyrotropin alfa (rhTSH), a form of TSH that is identical to the hormone that is produced by the pituitary gland, but it is made in the lab. Receiving injections of this drug a few days prior to RAI treatment raises the TSH level rapidly without causing the patient to experience the signs and symptoms of hypothyroidism that may result from the withdrawal method. This approach is typically used only for patients with cancer limited to the neck (not for patients with distant metastasis) and because of limited data, it may be difficult to receive insurance coverage approval for this drug for a pediatric patient.

**What It May Feel Like to Be Hypothyroid During Withdrawal from Thyroid Hormone Replacement**

Although the hypothyroid state resulting from thyroid hormone withdrawal (option #1) is temporary, it can cause one or more symptoms that last for up to 1-2 months after restarting thyroid hormone replacement. These symptoms tend to be less common and less severe in children than in adults. Symptoms can include feeling tired, decreased exercise tolerance, slower reaction time (important for patients that drive and play sports), constipation, and irregular menstrual cycles with increased cramping and blood flow, as well as other less common side effects. For unknown reasons, some people are more symptomatic than others.

Between surgery and the evaluation for RAI, to reduce the length of time and symptoms of hypothyroidism, your child's doctor may prescribe a shorter-acting thyroid hormone called Cytomel™ (LT3, liothyronine sodium) rather than levothyroxine (LT4, the form of thyroid replacement hormone that most patients take on an ongoing basis, see section 9). In contrast to levothyroxine (which usually requires 2-3 weeks of withdrawal), stopping Cytomel for 2 weeks is

typically adequate to achieve an elevated TSH. Please follow your doctor's specific instructions carefully.

**Anti-Nausea Medication:**

Some people experience nausea the first day after receiving I-131 therapy. Anti-nausea medication will decrease this if taken 30 minutes prior to receiving RAI and continued for 1-2 days after as needed. Ask your medical team about this option so that they can prescribe anti-nausea medication in advance.

**Dental Care Before RAI**

There are no requirements outside of routine, preventative dental care prior to RAI therapy. However, some doctors recommend a dental cleaning before RAI as well as the application of a dental sealant to help protect the teeth. For patients that have RAI-induced decreased salivary gland function, frequent dental care is beneficial to help reduce cavities.

**The Low-Iodine Diet**

The short-term low-iodine diet is another part of preparing to receive radioactive iodine for papillary or follicular thyroid cancer. The diet, recommended by the American Thyroid Association, increases the effectiveness of the radioactive iodine treatment.

- This diet lasts for about 2 weeks before the radioiodine therapy, and patients can go back to their regular diet 1 to 2 days after the RAI treatment.
- This diet reduces the consumption of regular iodine so that when the radioactive iodine is given for treatment, any remaining thyroid cells, including thyroid cancer cells, will be "hungry" for iodine. These cells then more readily absorb the radioactive iodine, which eventually destroys them.
- A low-iodine diet has less than 50 micrograms of iodine per day. It is a ***low*** iodine diet, not ***no*** iodine diet. Iodine is often added to table salt; however, it is not a natural component of salt, so the low-iodine diet is different from a "low-sodium" diet. The normal recommended daily allowance for iodine is 150 micrograms per day. Most people in the United States consume significantly more

than 150 micrograms daily, particularly if they eat a lot of pre-packaged, processed foods.
- There are slight variations in diet guidelines from different teams. The ThyCa diet and guidelines have received input and review by numerous thyroid cancer specialists.
- The low-iodine diet can be challenging, so patients are encouraged to plan ahead and take advantage of the many resources available through ThyCa and elsewhere online.
- See www.thyca.org and the free ThyCa *Low-Iodine Cookbook* for details, recipes, and easy snacks and meal tips.
- Another reference is the Low-Iodine Diet (LID) Life Community website that contains information about the iodine content of specific food items from grocery stores and restaurants (http://lidlifecommunity.org). However, please be careful since ingredient lists often change and similar ingredients can be substituted without requiring change (such as iodized salt replacing non-iodized salt); there is no substitute for reading the labels.

**Brief Overview of the Low Iodine Diet**

**Not Allowed—Avoid These Foods and Ingredients**

- Iodized salt, sea salt, and any foods containing iodized salt or sea salt (note: many brands of kosher salt do not have iodine, including Diamond Crystal brand).
- Seafood and sea products, including any form of seaweed (arame, dulse, furikake, hiziki, kelp, kombu, nori, wakame), as well as additives/extracts (carrageenan, agar-agar, algin, and alginate)
- Dairy products of any kind (milk, cheese, yogurt, butter, ice cream, lactose, whey, casein)
- Egg yolks or whole eggs or foods with whole eggs
- Bakery products with iodine/iodate dough conditioners or high-iodine ingredients such as dairy, eggs, and salt. Low-iodine items are fine.
- Red Dye #3, erythrosine (or E127 in Europe), including medication containing red dye #3 - check with the prescribing physician, treatment team, and/or pharmacist.
- Most chocolate (due to milk content). Cocoa powder and some dark chocolates are allowed
- Soybeans and soybean products such as soy sauce, soy milk, tofu (however, soy oil and soy lecithin are allowed)

- Iodine-containing vitamins and food supplements
- Potato skins
- Medication containing iodine such as amiodarone. If your child is prescribed this medication, check with your doctor before beginning preparation for RAI.

**Allowed Foods and Ingredients**

- Fresh or frozen fruits and vegetables
- Unsalted nuts and nut butters
- Egg whites
- Fresh meats (provided no broth injected) with some diets limiting intake to 6 ounces a day
- Most dairy substitutes (oat milk, nut milk, but NOT soy milk).
- Grains and cereal products without high-iodine ingredients (some diets limit to 4 servings a day)
- Pasta without high-iodine ingredients
- The insides of white and sweet potatoes (no skins)
- Sugar, jelly, jam, honey, maple syrup, black pepper, fresh or dried herbs and spices, all vegetable oils (including soy oil)
- Drinks - sodas (except with Red Dye #3 or E127 in Europe), non-instant coffee (espresso, drip coffee), non-instant tea (brewed tea), lemonade, fruit juices

**Read the ingredient list on all packaged foods. Check with your physician and/or pharmacist about any medications your child is taking.**

**Remember**

1) Note that sodium is not an issue. What is to be avoided is the added iodine found in iodized salt, which is widely used, especially in processed foods.
2) It is preferable to avoid processed foods while on the low-iodine diet because food manufacturers are not required to list the iodine content. Therefore, if salt is a listed ingredient, you have no way of knowing whether it is iodized or non-iodized. This does not apply to foods that naturally contain sodium without salt as an ingredient.
3) **There are many foods a person can eat while on the low-iodine diet.** It is a good idea to cook meals at home, using fresh ingredients, including fruits, vegetables, and unprocessed meats. You may wish to cook in batches ahead of the LID and freeze

portions.

# 13. After RAI — In Hospital or At Home

After receiving the RAI treatment dose, patients may be sent home immediately, or may stay in the hospital for one or more days, depending on factors such as the dose administered, local regulations, and travel distance between the hospital and home. This is a time to be careful around other family members and pets because the patient will be radioactive.

The treatment team should provide written information about guidelines for release. Each patient's home circumstances, such as whether there is an infant or a young child at home, and availability of separate bedrooms and bathrooms, may also affect the decision about going home or staying in the hospital after the treatment dose.

The RAI that is not absorbed by the remaining thyroid tissue and/or thyroid cancer is eliminated from the body through perspiration, saliva, feces, and urine. These substances will be radioactive, hence the safety precautions.

### Tips and Precautions

Below are tips and precautions to take during and after the RAI ablation treatment to help protect yourself/your child, your family members, and other people from being unnecessarily exposed to the radiation.

The precautions listed below are for the days after RAI. More guidelines and tips are on www.thyca.org, given to ThyCa by our medical advisors, in guidelines from the American Thyroid Association and in the reference book *Thyroid Cancer: A Guide for Patients*.

Please note that your child's physician and hospital may have different guidelines. Discuss any questions and concerns with your doctor, nurse and treatment team.

### The First Day

Ask your doctor about ways to protect your child's salivary glands,

which also absorb the RAI. Drinking plenty of fluids and sucking on sugar-free sour candy for the 1st 1-2 days after RAI treatment is the most important and effective approach. Your treatment team should provide instructions on when to start, how often to suck on the candy, and for how long.

- One schedule used by some programs, is to start using sour candies 2 hours after RAI and continuing to use them as continuously as possible, every 15 to 30 minutes, for 24 hours after the treatment. ***This includes overnight*** as much as possible to avoid the RAI sitting in the salivary glands for hours without being flushed out. While this will result in a long night without sleep, this plan will help decrease the potential RAI damage that can result in a permanent salivary gland dysfunction (dry mouth). Nonetheless, it is unclear whether this intensity of treatment truly offers benefit, thus it is important to discuss this with the treatment team at the time of RAI.

**In the Days After RAI**

**If your child is admitted to the hospital radiation-safety room:**

- Different jurisdictions regulate radioactive materials differently. Thus, a short hospital stay may be required depending on the dose of RAI administered as set by the jurisdiction where the hospital is located.
- If your child is admitted to a radiation-safety room in the hospital (a 'hot'
- room), your child will remain in the hospital room with the door closed until he/she is discharged from isolation by the radiation safety officer. Your child will be checked multiple times per day to determine how quickly their body clears the radiation dose. Once the radiation counts are below the threshold levels that are safe to be in public, your child will be discharged to go home. This typically takes 24 to 48 hours after RAI treatment. You should follow the 'at home' safety precautions for a full 5-7 days (see below) once discharged from the hospital.
- Bring some reading materials such as newspapers or magazines that can be left behind. The hospital room will also have a television.
- Phones, tablets, and computers with a touchscreen are best as they can be more readily cleaned. Consider placing these inside of a

disposable (e.g. Ziploc) bag during this period. Avoid using a computer with a keyboard for 5 days to decrease the chances of contaminating it. Alternatively, use a keyboard cover that can be thrown out.
- Bring eyeglasses and personal medically related equipment. If possible, avoid using contact lenses.
- Consider bringing some low-iodine snacks such as fruit and unsalted nuts in case the hospital meals include some high-iodine foods. Most hospitals only have a 'low-salt' option, which should be ordered, rather than a 'low-iodine diet option'.

**Outpatient safety precautions after RAI treatment**

Use the following guidelines regarding distance, time, and hygiene:

- Your child should stay at least 4-6 feet away (about 1 meter) from everyone except for short periods totaling less than 1 hour each day, for approximately the first 5 days. Keep the same distance from pets as well.
- Sleep alone, do not share beds with others during this week.
- Avoid kissing and physical contact with others.
- Patients do not need to be confined to their bedroom. Patients can be in the house if they can maintain distancing. You can cover a place on the couch and a chair with a towel or sheet and then wash this cover, along with any other contaminated clothing, either daily, or at a minimum, at the end of the 5-7 days.
- Do not sit next to someone in a car or public transportation or a movie theater for more than one hour. Sit in the back seat of a car, on the opposite side from the driver, if possible.

***If you need to travel by plane or other transportation after your child receives RAI,*** carry an information card or letter explaining that your child recently received radiation treatment. While the radiation amount received is low, the radiation detection devices used at locations such as airports, bus and train stations, trash collection sites, some international borders and in some buildings can detect very low radiation levels***. Your child should carry the card or letter with them for at least 3 months after receiving RAI.***

**In General**

Follow good personal hygiene practices.

- Wash hands often.
- Shower daily. Rinse the shower/bathtub and let water run for a few minutes afterwards.
- Do not share towels, washcloths, or personal items (combs, brushes, and toothbrushes).
- Flush twice after using the toilet. Use a tissue to wipe up any urine on the toilet bowl. Boys/men should sit when urinating. Wash hands and rinse the sink.
- Flush items that encounter body fluids (tissues, tampons, and toilet paper).
- Separately wash all clothing, bed linens, towels, and wash cloths. This can be done either daily or all together at the end of the one-week safety period.

Food and drink

- Drink plenty of liquids, even if you are not thirsty.
- Do not handle or prepare food that others will eat. Do not share food or drink.
- Do not share cups, glasses, plates, or eating utensils. Wash all items promptly after using. Other people may use items after they are washed.
- Do ***not*** use disposable dishes (paper/plastic) and utensils (plastic) as this will contaminate your garbage and may present a problem at the landfill if they check for the disposal of radioactive substances.

**Home Dental Care After RAI**

- Use ultra-soft or soft toothbrushes and mouthwashes without alcohol, phenol, or whitening agents.
- It is important to floss daily.

**Post-Therapy Scan**

Between 5 to 10 days after RAI treatment, a post-treatment whole body scan (RxWBS) will be performed. This scan is done in the nuclear medicine department of the hospital or community radiology center where the RAI was given.

- In some centers, a nuclear medicine doctor meets with you after the scan, or you may receive the results from your child's endocrinologist at a later meeting or on the telephone.
- This scan provides more information than the pre-treatment or diagnostic WBS (if your child received this) as the images are taken after a larger amount of radiation is administered (a *treatment* amount compared to the small, *diagnostic* amount that is used prior to RAI treatment). If a new site of thyroid cancer is found on this scan it will not require immediate additional treatment, but it will provide information about whether and where there is any remaining disease that will need to be monitored in the future.

**The Months After RAI**

Within 3 weeks, only traces of RAI remain in the body. However, it will take several months or longer for the RAI to have its full effects on any remaining thyroid tissue, both cancerous and non-cancerous. This is because the radiation destroys the cells gradually. Recent studies have shown that a single RAI treatment may still eliminate the cancer cells for more than 6 to 12 months, even up to 18 to 24 months for some patients.

# 14. Potential Side Effects of RAI Treatment

RAI is safe. Generally, patients experience few if any side effects.

Side effects of the RAI treatment may include:

- A temporary burning sensation or tenderness in the area where the thyroid was previously located.
- Nausea and upset stomach (and rarely, vomiting).
- Swelling and tenderness of the salivary glands.
- Taste changes (usually temporary) – a metallic taste and/or decreased taste.
- Dry mouth.
- Reduction in tear production or blocked tear ducts with increased tearing.

Some of these side effects may occur soon after the RAI treatment, while others may not happen for several weeks or months after the RAI treatment.

**Tips for Coping with Some Side Effects of RAI**

- **Tenderness in the neck area** can generally be treated with a warm or cold compress as well as over-the-counter pain relievers, such as ibuprofen (Motrin, Advil or other) or acetaminophen (Tylenol).
- **Swelling and pain over the salivary glands** (angle of the jaw or under the jaw). Use warm or cold compresses as well as over-the-counter pain relievers. Massage may also be used. Take the palm of the hand and with gentle pressure move it up from the jaw toward the eyes and then toward the mouth. This motion is along the path of the salivary duct and the massage will help keep the duct open, decreasing a back log of saliva that can cause pain and swelling.
- If you notice redness of the skin with the pain as well as any thick, white to yellow drainage in your child's mouth from the inside of their cheek call your doctor or go to the emergency department as these can be a sign of a salivary gland infection.
- **Dry mouth sometimes occurs.** If symptoms persist, increase fluid intake (even if not thirsty) and ask your doctor about products that help ease the problem, such as gels and sprays. In some people, especially after higher RAI doses, the impact on salivary glands, and hence the dry mouth, can be permanent. This can increase the risk of tooth decay. Therefore, it is important that child visit their dentist regularly.
- If you experience **dry eyes (reduced tear formation) or increased tearing (blocked tear duct)**, discuss this with your doctor. If your child wears contact lenses, ask how long they should stop wearing them. Artificial tears may help, either temporarily or long-term.

**Other Potential Side Effects of RAI**

- **Temporary or permanent decreases in blood cell counts** can also occur. This is not a typical side effect. Counts usually recover back to the normal range within a few weeks to months. Most physicians do not routinely monitor these levels; however, if your child has a blood test for another reason, you should be aware of this possibility.
- Any person receiving RAI treatment may have a slightly higher risk of developing bone marrow failure as well as other cancers in the future. Doctors generally agree that the risk increases after

very large doses of RAI, especially if given repeatedly over a short period of time. While the exact dose of RAI is not known, the risk seems to increase as the cumulative dose increases to 350 millicuries (mCi) or more.

- **Fertility** - most men and women that receive RAI during childhood and adolescence (and even as adults) will be able to have healthy children.
    - **Males** - Males who receive very large cumulative doses of RAI may have lower sperm counts, however they rarely become infertile. Discuss banking sperm with your child's medical team if it is likely that your son's treatment plan may include more than one dose of RAI.
    - **Females -** Some females may have irregular periods for up to a year after treatment. There does not appear to be a decrease in the ability to have children. The ATA guidelines recommend that women avoid becoming pregnant for at least 6 months to a year after treatment.

- If a woman is pregnant when diagnosed. A female who is pregnant or breastfeeding should never receive RAI in any form (I-123 or I-131). *Because of this, it is a regulatory requirement that all girls in puberty undergo a pregnancy test prior to receiving RAI treatment.* RAI should be postponed until completion of breast-feeding.

# 15. Life After Initial Therapy: Laboratory and Radiological Monitoring

**Laboratory Monitoring**

- Blood tests will be required every 3 to 6 months initially, decreasing to one to two times per year (every 6 to 12 months) once a child has finished growing and the cancer is gone (the child is in remission).
- There are two main types of thyroid blood tests: (1) Thyroid function tests (TFTs), and (2) thyroid cancer tumor markers.

1) **Thyroid function tests** (TFTs)– these tests are used to determine the correct dose of thyroid hormone replacement as well as compliance with taking the medication:

   - **Thyroid Stimulating Hormone (TSH)** – TSH is produced in the brain (pituitary gland) to drive the thyroid gland to produce thyroid hormone. There is an inverse relationship between TSH levels and thyroid hormone levels (as medication dose increases, the TSH should decrease). This is because the thyroid system is based on a feedback loop between the pituitary gland (where TSH is produced) and the thyroid hormone (T4) levels in the blood). So, if there is a slightly high amount of thyroid hormone (T4) in the bloodstream, the pituitary gland senses this and has no need to produce thyroid stimulating hormone (TSH). In other words, the higher the T4, the lower the TSH.
   - **T3** – Triiodothyronine, the active form of thyroid hormone. Its synthetic form is known as liothyronine.
   - **T4** – Thyroxine, the long-lasting thyroid hormone that is converted into T3 by the body as needed. Its synthetic form is known as levothyroxine (LT4).

2) **Thyroid cancer tumor markers** – Specific blood tests used to monitor remission or disease progression in patients with differentiated and/or medullary thyroid cancer.

   a. **Differentiated Thyroid Cancer – Thyroglobulin and anti-thyroglobulin antibodies**

- **Thyroglobulin** (Tg) is a protein that is made only in thyroid cells (normal or cancerous). It can be measured by a blood test. For patients with differentiated (papillary or follicular) thyroid cancers, measuring the level of thyroglobulin in the blood can indicate how much thyroid tissue (normal or cancerous) remains in the body after surgery.
- **Anti-thyroglobulin antibodies (TgAb)** - About one quarter of patients with differentiated thyroid cancer also have an autoimmune response that results in the formation of antibodies against thyroglobulin (called anti-thyroglobulin antibodies). For these patients, measuring thyroglobulin levels using the standard method may not give an accurate measurement of how much thyroid tissue or cancer is left. Different ways of measuring thyroglobulin may be used; however, the antibodies interfere with all of the tests to some degree. The antibodies may go away after several years after treatment and can be used as a proxy marker for thyroid cancer along with the thyroglobulin levels.

- For patients that have undergone a **total thyroidectomy and RAI** treatment, the goal is to ultimately achieve an undetectable thyroglobulin and anti-thyroglobulin antibody level. After surgery and RAI, it may take months or years for the Tg number to get down to zero or become undetectable. Measuring Tg and TgAb levels after **lobectomy** is not generally useful (see below).

- After **total thyroidectomy**, an elevated Tg level indicates that thyroid cells, either normal or cancerous, are still present in the body. Depending on the level of Tg in the blood, closer monitoring and additional radiological studies may be suggested, to help determine if further treatment would be beneficial.

- For patients that had a **lobectomy and/or did not receive RAI**, the Tg level will remain detectable.

This is because some remnant thyroid tissue nearly always remains in the neck after surgery. If a lobectomy rather than a thyroidectomy was performed, the remaining lobe will produce Tg.

- The thyroglobulin test is very sensitive. At low levels, the test may be positive, however, radiological imaging cannot always find the source (normal thyroid remnant or disease). In this situation, most physicians will continue to monitor rather than treat with additional radioiodine.

- From time to time, your child's doctor may recommend what is called a "stimulated Tg" measurement. This means that the TSH is raised, either by withdrawal (stop taking thyroid medication) from thyroid hormone or by receiving injections of the drug Thyrogen®. Once the TSH is greater than 30 mU/L, the Tg is then measured. This is done because thyroglobulin testing is more sensitive when the TSH level is elevated, leading to positive results when baseline, unstimulated measurements may have come back as "undetectable." Nonetheless, even in these circumstances, when stimulated Tg is elevated but imaging does not identify any source, further treatment is often not beneficial.

**b. Medullary Thyroid Cancer – Calcitonin and Carcinoembryonic Antigen**

- **Calcitonin** is produced by C-cells (those that give rise to MTC). Calcitonin levels normally drop after surgery (anywhere from 6 weeks to 6 months later). Tracking these values every 6 months over a period of several years is useful to determine if the cancer is gone (patient in remission) or whether there is persistent MTC. Following the rate of increase can also lend insight into the behavior of the residual tumor cells. Tumors with shorter doubling time (less than 2 years) are considered to be behaving more aggressively.

- **Carcinoembryonic antigen (CEA**) is also used for monitoring persistent MTC. It may take 4 to 5 months for elevated CEA levels to return to normal after surgery. It is a good idea to get multiple calcitonin and CEA measurements 3 and 6 months after surgery to establish a new baseline, and then to monitor these levels every 6 months on an ongoing basis.

- There should be a downward trend in the value of the tumor markers if the cancer is going away.
  - When **DTC** is gone (patient is in remission), both the Tg and TgAb should be undetectable.
  - When **MTC** is gone (patient is in remission), the calcitonin and CEA should be low or undetectable.

- With rare exception, patients will either have DTC or MTC, so only the tumors markers for DTC ***or*** MTC will be followed for each patient.

**Radiological Monitoring**

- Along with the blood tests, **radiological imaging** is used for monitoring.
- The most common way to monitor is with neck ultrasound (US).
- Additional radiological imaging can and will be used based on (1) where the cancer had spread as noted during the initial treatment and (2) what the level and trend has been for the blood tests: thyroglobulin and antithyroglobulin antibodies for patients with differentiated thyroid cancer, and calcitonin and CEA for patients with medullary thyroid cancer.
- Additional imaging tests may include:
  - CT or PET scans or MRI
  - Nuclear medicine whole body scans (WBS) using radioiodine or a different type of radioisotope for MTC called DOTATATE.

- The type and frequency of radiological imaging is based on the person's specific situation.

# 16. Long-Term Monitoring

Patients require life-long monitoring for two reasons:

- First, long-term monitoring is important to make sure that the dose of thyroid hormone replacement is appropriate— neither too low nor too high for a patient's specific situation and needs. At a minimum, patients should have their thyroid hormone levels measured once per year.
- Second, testing allows the provider to find out if there is persistent disease or possible recurrence. Some people with differentiated thyroid cancer have persistent, but stable (not growing or spreading) disease even after surgery and RAI treatment, or develop a recurrence, sometimes years or even decades after the initial treatment. The prognosis for any person with a recurrence is better if it is discovered early. This is why life-long monitoring is important.
- The exact type of monitoring, and how often it takes place, depends on the size of the original tumor and whether the cancer spread locally or distantly, as well as other factors.
- People free of disease receive less monitoring or testing than those with evidence of persistent disease.

**Monitoring will most likely include:**

- **Physical examination of the neck,** including feeling the thyroid bed area and lateral neck. Typically, this is done every 3 to 6 months for the first 2 years, and at least once a year thereafter.
- **Blood tests.** Measurement of TSH and tumor markers.
- **Neck ultrasound.** This test is a very sensitive way to find disease in the neck – lymph nodes that are cancerous generally have different physical characteristics than normal ones that can be seen on an ultrasound. Sometimes areas may be seen that are suspicious, but an ultrasound cannot determine with certainty if an area represents cancer or a less concerning finding, such as a reactive lymph node or scarring from surgery. The area may be monitored with repeated imaging to make sure it is not changing. Prior to any additional treatment, a fine-needle aspiration biopsy (FNAB) may be performed to confirm if the area is persistent or recurrent cancer prior to additional treatment, either surgery, radioiodine or other ablative techniques (thermal, chemical, high frequency ultrasound or radiofrequency).

For people in intermediate-risk or high-risk categories, i.e.: patients with spread of the cancer to the lungs or other areas away from the neck, long-term monitoring may also include:

- RAI Whole Body Scan
- CT Scan
- MRI
- **PET/CT Scan**. A PET scan or combined PET/CT scan is sometimes done when blood testing in someone with differentiated thyroid cancer reveals thyroglobulin levels above a certain measure, but the disease does not show up on an ultrasound, CT, MRI, or an RAI-whole body scan.

**After Testing.** If testing shows persistent or recurrent disease, treatment may include some or all of the treatments discussed earlier, including additional surgery and RAI treatment. Alternatively, it may make more sense to continue to monitor the disease since treatments have risks, and many patients have persistent disease that does not cause any symptoms and remains stable (not changing) for many years. The decision about further treatment needs to be a discussion with your doctor, your child and you, reviewing the benefits and risks of treatment.

# 17. Residual or Recurrent Disease

"Persistent" or "residual" disease is a term used to describe patients whose cancer has never fully become undetectable.

"Recurrent" disease is a term used to describe patients whose initial treatment successfully eliminated all detectable cancer for a period of at least 6 months to 1 year, but who then has evidence that their cancer returned either by laboratory, radiological imaging, or both.

- All patients who have had thyroid cancer require life-long surveillance, and those with persistent or recurrent cancer may need to see their doctor more often for blood tests and imaging tests.
- Individuals that have persistent or recurrent disease require ongoing monitoring to determine whether the disease is stable (staying the same), progressive (getting larger or spreading) or regressing (going down in size or amount).

**New medications for patients with advanced and progressing thyroid cancer**

Some patients have progressive disease after standard treatments. This includes:

1) Patients with differentiated thyroid cancer (DTC) treated with radioactive iodine that did not respond and continues to grow and/or becomes symptomatic; or
2) Patients with medullary thyroid cancer that is growing and cannot be removed with surgery.

For such individuals, there are new medications that are being developed that *may* be of benefit. The medications include the tyrosine kinase inhibitors (TKIs) and oncogene-specific inhibitors that target the abnormal gene (DNA variant) in the cancer cells. Several of the oncogene-specific inhibitors have been shown to increase the ability of DTC to absorb radioiodine. *These should be considered only by doctors with particular expertise in treating children with "advanced" thyroid cancer.* Often these medications are available as part of a clinical trial. If the thyroid cancer fits either of these descriptions, your child's doctor will discuss whether it is appropriate to consider these drugs and whether this treatment can be started at the hospital where your child is receiving care or if referral to a center with greater experience in treating advanced thyroid cancer is worthwhile.

# 18. Finding the Right Care Team for Your Child

Thyroid cancer is less common in pediatric patients compared to adults. Because of this, many endocrinologists, surgeons, radiologists, pathologists and other members of the medical team, may not be familiar with evaluating and treating pediatric patients with thyroid cancer or with current medical literature defining approaches to care in children.

As with all cancers, treating pediatric patients with thyroid cancer benefits from a team of experienced physicians, with one physician as the team leader. Patients should also continue seeing their family doctor for routine well-child exams, sports physicals and other illnesses (colds, vomiting, diarrhea, etc.).

For patients who are not near a high-volume pediatric thyroid cancer treatment center, the local medical team may communicate with specialists at one, through phone calls, emails, or other means to provide the best care possible for your child. Treatment may also be split between centers, where surgery and medical care (RAI and/or other medical therapy) is provided at the high-volume center with surveillance visits at the local facility in an effort to optimize care and outcome and reduce the costs and burden of travel except when necessary.

**Here are some points to consider:**

- Thyroid cancer is less common in children and adolescents than in adults. Therefore, more specialized expertise is important, and we encourage you to find the team with the greatest amount of experience in evaluating and treating pediatric thyroid cancer.
- You deserve physicians who are willing to listen to all of your questions and are willing to seek advice from specialists if it is needed.
- A doctor treating thyroid cancer should be open to reviewing the latest treatment guidelines and research literature, as well as discussing treatment options with researchers and experienced clinicians, including (if needed) those involved in clinical trials of new treatments.

- ThyCa's website has links to professional associations with lists of their member physicians involved in thyroid cancer care. Participants in online support groups also share names of specialists involved in their own care.

# 19. Tips for Preparing for Appointments

- Ensure that you have received authorization from your insurance company to visit the care center prior to traveling, including authorization to see the endocrinologist, surgeon and for procedures (laboratory, radiological imaging, fine needle aspiration, and surgery).
- Bring a summary of your child's health history to his/her first visit, including reports from all thyroid cancer doctors. Examples: pathology report from FNA (if a biopsy was previously performed), scan/imaging results as well as a copy of the actual images (CD/DVD or Cloud link), surgical report (if previous surgery was performed), with related pathology report. Most of these items will be requested at the time of the intake phone call with the pediatric thyroid center/clinic. In addition, most thyroid centers will request that any FNA and/or surgical pathology slides (in addition to the written report) are sent for review prior to the initial appointment.
- Bring a list of medications your child is taking, **including traditional or alternative medications,** or even the bottles of medications. This includes prescription medications, over-the-counter medications, and nutritional supplements, including dose (strength) and frequency (number of times taken each day).
- Cancer treatment may be a very stressful process. It is helpful to write down any and all questions in a notebook or create a document on your phone and/or laptop 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 doctor's and nurse's answers/instructions.
- Keep notes and records in a loose-leaf 3-ring binder or in file folders to help organize them.
- Most thyroid cancer teams have access to psycho-social support (social workers and/or psychologists). Do not hesitate to ask your team if this is available. You are not alone in this journey and having a helping hand to guide you can ease the experience.

- Plan to arrive 15 minutes before appointments.
- Bring something to keep you and your child busy and calm while you wait.
- Young patients specifically report fear of blood tests, blood draw, and needles. If this is a problem for your child, talk to your doctor and/or nurse.
    - Skin numbing cream may be prescribed and applied to the skin approximately 20-30 minutes before the blood draws.

# 20. Tips for Communicating and Remembering What Your Doctor and Nurse Say

- Having good communication with your treatment team is one of the keys to getting good medical care.
- You want the best care for your child. Be the best advocate to ensure this happens. Ask questions and make sure you and your child understand the plan and expected results. Let the treatment team know what is most helpful.
- A parent or guardian will need to accompany all patients younger than 18 years of age. It is also nice to be present even after your child turns 18 years of age if they agree. Remember, two (or more) sets of ears are better than one.
- Feel free to take notes.
- Ask for an explanation of unfamiliar terms and definitions.
- Ask for a visual aid when appropriate. Seeing what the provider is talking about on a chart or other visual aid will help a patient understand and remember.
- Ask if the doctor or nurse has any printed information to give you and/or can provide links to websites where additional information can be found (including www.thyca.org, www.thyroid.org and others).

(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.)

# 21. Questions You May Want to Ask

For more questions to ask during appointments, go to www.thyca.org

and type "questions to ask" in the search box.

Remember, every patient is different. The evaluation and treatment plan will depend on your individual situation.

**About the Cancer**

- What type of thyroid cancer does your child have?
- Is there a risk that anyone else in the family may also have the same cancer (is it heritable)?

**About Any Treatment Being Discussed**

- What are the treatment options? What are the advantages and disadvantages of the treatment recommended?
- How will we know if the treatment is working?
- What is the duration of treatment? What is the duration of recovery from treatment?
- What are possible short-term side effects? What can help prevent side effects? What will help patients cope with them if they occur?
- Are there any long-term side effects?
- What happens when my treatment is over? What is the plan for long-term surveillance care and follow-up?
- Will the treatment change our day-to-day activities? How?

**More Topics to Discuss with Medical and Surgical Providers:**

- Ask the endocrinologist how many new thyroid cancer patients they see every year and how many are they currently treating and monitoring?
- How many thyroid surgeries does the surgeon perform every year?
- How often is a second surgery needed and why?
- How frequent are complications, including (1) damage to the recurrent laryngeal nerve and other nerves in the neck and (2) hypoparathyroidism (loss of the ability to make the hormone that controls calcium and phosphorous).
- If radioactive iodine (I-131) treatment after surgery will be needed and what will be used to decide if and how much I-131 is given?
- What is the target range of thyroid hormone replacement after surgery and what labs will be followed?

- What other treatments may be considered if the patient presents with very advanced disease or develops progressive disease that is not responding to surgery and/or RAI?
- What is the prognosis?

**Points to keep in mind:**

- Ask questions. The medical visits are for the patient and family.
- Some answers may change over time, based on changes in the response to therapy as well as advances in research and medical care.

# 22. Living with Pediatric Thyroid Cancer

- Consider requesting accommodation for children while they are in school and going through this journey. Students have legal options such as 504 plans in public schools (Section 504 of the U.S. Rehabilitation Act of 1973) and Individual Health Plans that can assess, document, and plan the need for additional accommodations and/or program modifications which may be needed at school. Unfortunately, many parents must fight for these rights and are not aware that there are laws in place mandating that these accommodations occur for a child with a medical disability that may affect their learning for a small period of time (such as when they undergo thyroid hormone withdrawal for RAI).

# 23. For more information

- **The illustrated 470-page reference book *Thyroid Cancer: A Guide for Patients (3rd* edition, 2019)** is available on www.thyca.org**.** An in-depth reference recommended for patients and caregivers, and helpful resource for medical professionals. The first edition is also available in Spanish. This reference book was written by more than 30 medical professionals, plus patients and caregivers, and reviewed by many more. Editors are Douglas Van Nostrand, M.D., Leonard Wartofsky, M.D., Gary Bloom, and Di Wu, M.B.B.S., M.Med.
- The American Thyroid Association's Management Guidelines for Children with Thyroid Nodules and Differentiated Thyroid Cancer. ***https://www.liebertpub.com/doi/pdfplus/10.1089/thy.2014.0460***.

Revised ATA pediatric guidelines should be published in 2024/2025.

- **Visit our website www.thyca.org.** It receives review and input from more than 50 medical experts. It has information, support, plus links to events, support services, and numerous helpful organizations and additional resources. ThyCa has support groups for:
  - - Teens with thyroid cancer. Young people between 13and 21 who have been diagnosed with thyroid cancer can connect with each other (note: all attendees have to have a working camera to participate).
  - - Parents and caregivers of pediatric thyroid cancer survivors.

# 24. How 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, other handbooks, patient brochures and wallet cards, free downloadable Low-Iodine Diet Guidelines and Cookbook, Sportpacks with thyroid cancer information for pediatric patients, and other materials to give to patients. We also provide research funding to grant recipients selected by an expert panel of the American Thyroid Association.

**Free Services & Resources:** Comprehensive website • Person-to-person support • Local support groups • Online support groups • Awareness brochures • Seminars, workshops • Annual International Conference • Over 100 Videos with Experts; YouTube channel • Online newsletter • Free Handbooks on all types of thyroid cancer • Downloadable Low-Iodine Cookbook • Social Media • more

Please contact us for more information and free materials:

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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.

## Pediatric Thyroid Cancer

Visit www.thyca.org to download this handbook, which is available in English.

Visit iTunes or GooglePlay to download this handbook in ePub format.

Our materials are provided free of charge to anyone who needs them. E-mail us at thyca@thyca.org and we will be happy to mail you individual copies or bulk quantities.

*Courtesy of*

**ThyCa: Thyroid Cancer Survivors' Association, Inc.**

*ThyCa is a 501(c)3 nonprofit organization. We welcome your tax-deductible donations to help us continue providing support and educational materials to anyone dealing with thyroid cancer.*

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