TRUTHS ABOUT THE LONG-TERM MANAGEMENT OF THYROID CANCER

Presented by

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Myths and Truths About Thyroid Cancer

Light of Life Foundation
checkyourneck.com

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

Eisai

Foreword

From diagnosis to long-term care, everyone's thyroid cancer journey is different. There are different types of the disease, various therapeutic options and numerous treatment plans. But one thing we know to be universal: thyroid cancer has an impact that lasts well beyond diagnosis and initial treatment. As survivors ourselves, we have come to understand the need for vigilance in the lifelong monitoring of our health and the importance of developing new skills to help us cope, both physically and emotionally. As you move beyond the initial stages of your treatment, our goal is to shed light on some common experiences when it comes to the lifelong care of people who have had thyroid cancer. This will help you understand what to expect and what questions to ask as you move forward with managing your care.

With this guide, created by the Light of Life Foundation, Inc., ThyCa: Thyroid Cancer Survivors' Association, Inc., and Eisai Inc., we hope to help make the "new normal" a little less challenging. We support and encourage everyone affected by thyroid cancer to work with their doctor to determine their best course of action, and to become their own advocate while navigating their individual thyroid cancer journey.

— **Gary Bloom,** Thyroid cancer survivor, Co-Founder and Executive Director of ThyCa: Thyroid Cancer Survivors' Association, Inc.
www.ThyCa.org

— **Joan Shey,** Thyroid cancer survivor, President and Founder of the Light of Life Foundation, Inc.
www.LightofLifeFoundation.org

Initial Treatment for Thyroid Cancer

Treatment of thyroid cancer depends on the type and stage of the disease and the patient's age and overall health.[1] Surgery is often the first step.[1] In fact, you may have already had one of the different types of surgery used to treat thyroid cancer, and may be wondering about what happens next. One treatment that is often used for papillary and follicular thyroid cancers following surgery is **radioactive iodine**.[1] This oral form of radiation is intended to target and destroy any remaining microscopic thyroid cancer cells that were not accessible to the surgeon at the time of the operation.[1,2]

The surgery to remove all or part of your thyroid means your body may not be able to produce thyroid hormones naturally.[1] This can lead to numerous long-term effects, including changes in weight, energy level and body temperature.[3] To address this, most people will require a lifelong course of **thyroid hormone replacement therapy**.[3] The goal of this therapy is to normalize levels of **thyroid-stimulating hormone (TSH)**, a hormone that is involved in controlling your body's metabolism.[1] For most patients, this treatment is in the form of a daily pill.[1] Your doctor will tailor your dose based on the risk that the disease will **persist or recur (come back)**.[4] You will need periodic blood tests to ensure that your dose of hormone therapy is appropriate—neither too low nor too high for your body's needs.[4,5] Dose adjustments may be necessary throughout your life.[5]

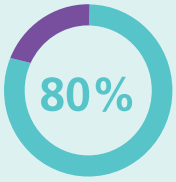
"It's normal to have questions about what the rest of your life looks like now that you've been treated for thyroid cancer. There will be challenges, but for many patients, thyroid cancer is manageable with lifelong care. As long as you continue to care for yourself physically and emotionally, you can continue to lead your life."

— Joan Shey, Thyroid cancer survivor, President and Founder of the Light of Life Foundation, Inc.

Since it's important that you understand all aspects of your care, you should feel comfortable asking your **health care team** any questions you may have. This team of professionals, which may include an **endocrinologist, surgeon, oncologist, nuclear medicine specialist, primary care physician, and nurse,** is there to support you.

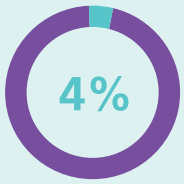
A Closer Look: How Initial Treatment Differs According to Type of Thyroid Cancer

There are several types of thyroid cancer.[1] Initial treatment depends on the type and stage of the cancer and on your overall health.[1]



The most common type of thyroid cancer is **papillary thyroid cancer**, which accounts for about 80% of thyroid cancers.[1] Most papillary thyroid cancers generally grow slowly.[1] However, some variants of papillary thyroid cancer are known to be more aggressive.[1] Most patients undergo surgery to remove part or all of the thyroid.[1] Some patients, including those with cancer that has spread beyond the thyroid, may receive radioactive iodine (RAI) therapy following surgery.[6] For patients with small or "micro" papillary thyroid tumors that are deemed "low-risk," doctors may recommend closely watching the condition before initiating further treatment.[6]

About 10% of all thyroid cancer cases are **follicular thyroid cancer**.[1] Follicular thyroid cancer is usually considered more aggressive than papillary thyroid cancer.[1] The treatment of follicular thyroid cancer is similar to the treatment of papillary thyroid cancer.[6]



Medullary thyroid cancer accounts for approximately 4% of thyroid cancers.[1] It is different from other types of thyroid cancers because it is a neuroendocrine tumor.[7] Neuroendocrine tumors form from cells that release hormones into the blood in response to a signal from the nervous system.[8] Surgery to remove the thyroid gland is nearly always recommended for patients with medullary thyroid cancer; patients also may undergo removal of lymph nodes in the neck.[7] RAI cannot be used in the treatment of medullary thyroid cancer.[9] Because medullary thyroid cancer can be hereditary (familial), it is important for patients to undergo genetic testing.[1] More information can be found at www.thyca.org/mtc.

Anaplastic thyroid cancer is an aggressive form of cancer that spreads quickly to other organs, and therefore immediate treatment is crucial.[1] Only about 2% of thyroid cancers are of the anaplastic type.[1] Anaplastic thyroid cancer does not respond to RAI; however, some patients benefit from external-beam radiation or chemotherapy, and in the rare cases in which the disease is confined to the local area, surgery to remove the thyroid may help reduce symptoms caused by the tumor.[1,9,10]

Lifelong Observation

Because thyroid cancers can recur in up to 30% of patients—even 10 to 20 years after initial treatment—your doctor will work with you to determine an appropriate schedule for **ongoing monitoring**.[1,11] This may include a number of tests to look for persistent disease or possible recurrence.[12] The type of testing and how frequently it needs to occur will depend on the specific type of thyroid cancer, the tumor size, whether the cancer has spread, and other factors.[12]

Some tests your doctor may recommend include:[1]

- Physical neck examination
- Radioactive iodine whole body scan
- Neck ultrasound
- PET scan, CT scan or combined PET/CT scan
- Blood tests
- MRI
- Chest X-ray

"Connecting with a thyroid cancer patient organization is a great way to understand your options and advocate for yourself, and also learn about additional resources that can help you with your ongoing care."

— Gary Bloom, Thyroid cancer survivor, Co-Founder and Executive Director of ThyCa: Thyroid Cancer Survivors' Association, Inc.

You and your doctor should discuss a plan to fit your situation. Each time testing occurs, you should discuss the results and any future testing or treatment needs with your doctor. It is important to maintain your plan for long-term monitoring and testing because the prognosis is better if recurrence is discovered early.[13]

Persistent or Recurrent Thyroid Cancer Can Be Treated

If testing shows persistent or recurrent disease, the course of treatment will depend on many factors, such as cancer type and prior treatment, as well as site of recurrence within the body.[1] As with all points in care, you should ask your doctor questions and discuss any concerns about your care.

"Learning that your cancer has come back can be very difficult. It's important to speak candidly with your doctors about their experience with patients like you, and to thoroughly investigate your options in both care providers and treatment."

— Gary Bloom, Thyroid cancer survivor, Co-Founder and Executive Director of ThyCa: Thyroid Cancer Survivors' Association, Inc.

Treatments for recurrent thyroid cancer may include:

Surgery

May be useful in controlling local recurrences or cancer that has spread to lymph nodes or other localized sites[9]

Radioactive Iodine

Can be used for papillary and follicular thyroid cancers to destroy any thyroid tissue not removed by surgery or to treat the cancer if it has spread to lymph nodes and other parts of the body[1,2]

Chemotherapy

Designed to attack rapidly growing cells, including cancer cells; May be used for anaplastic and medullary thyroid cancers; Also may be used in patients with advanced differentiated thyroid cancer who do not respond to other treatments or for whom other treatments are not appropriate[1,6,12]

Targeted Therapies

Designed to block the action of certain enzymes, proteins, or other molecules involved in the growth and spread of thyroid cancer cells; Unlike standard chemotherapy, targeted therapies more precisely identify and attack specific types of cells that support tumor growth[17]

External Beam Radiation

Most often used for cancer that returns after initial treatments, especially if there is evidence that the cancer cells do not take up radioactive iodine, or to treat distant metastases from cancer that has spread[1,18]

Additional treatment options, such as radiofrequency ablation and percutaneous ethanol (alcohol) injections, may be used for select circumstances.[1] Immunotherapy is also being tested as a further treatment option in thyroid cancer. If conventional treatments are not successful or suitable to your situation, you might discuss participating in a clinical trial with your doctor.[1]

You May Be Wondering...

What's new in thyroid cancer research?
Thyroid cancer research is ongoing. In the past few years, new treatments have been approved for advanced cases of thyroid cancer, and physicians continue to explore the diagnosis and management of the disease. As new approaches to care emerge, you may have more questions about what they mean for you. It's strongly recommended that you continue to work with your doctor and discuss the implications that new research has on your ongoing care.

Why are cases of thyroid cancer on the rise?
It's true that thyroid cancer diagnoses have been increasing over the past decade.[1] Some of this may be due to an increase in the use of thyroid ultrasounds, which can detect small nodules that would not have been found otherwise.[1]

Why am I hearing about "watchful waiting"?
In some cases, when small nodules are detected, doctors are taking a **"watch and wait"** approach, and instead of surgery, they're recommending follow-up ultrasounds to monitor nodule growth.[1,11] This is often referred to as **active surveillance**.[15]

Could it be true that my cancer may not have been cancer after all?
Researchers and physicians have been discussing the potential reclassification of a specific subset of thyroid nodules, which would mean they would no longer be referred to as "cancer." (These tumors are currently known as **encapsulated follicular variant of papillary thyroid cancer**).[16] This is because this type of tumor, with a proposed new name of **"noninvasive follicular thyroid neoplasm with papillary-like nuclear features,"** or NIFTP, is considered **indolent (slow-growing)** and carries a very low risk of adverse outcomes.[16] If you were originally diagnosed and treated for a follicular variant of papillary thyroid cancer, you may want to ask your doctor about his or her thoughts on the reclassification and what it may mean for you.

Learning to Cope with the "New Normal"

Most patients living with cancer would agree that support is critical during treatment and recovery; this is certainly true for patients living with thyroid cancer. You need people you can turn to for strength and comfort. Support can come in many forms: family, friends, cancer support groups, faith community or spiritual groups, online support communities, or one-on-one counselors. What's best for you depends on your situation and personality.

"The support of my family and friends was very important to me. I also came to lean on the patient community. Talking to people with similar experiences helped me feel less alone. I would encourage anyone with thyroid cancer, regardless of where they are in their journey, to reach out to loved ones and to seek advice and support from other patients. I believe sharing information and experiences helps people continue to educate themselves and benefits them as their care evolves."

— Joan Shey, Thyroid cancer survivor, President and Founder of the Light of Life Foundation, Inc.

The Light of Life Foundation, Inc., ThyCa: Thyroid Cancer Survivors' Association, Inc., and Eisai Inc. have joined together to raise awareness of thyroid cancer and support those living with the disease. The *Myths and Truths About Thyroid Cancer* campaign aims to dispel the myth that thyroid cancer is a "good cancer" and illustrate the life-changing realities of the disease.

Patients can visit LightofLifeFoundation.org and ThyCa.org for more information on the different types of thyroid cancer, support and resources.

References

1. American Cancer Society. Thyroid Cancer. http://www.cancer.org/acs/groups/cid/documents/webcontent/003144-pdf.pdf. Accessed November 4, 2016.

2. National Cancer Institute. NCI Dictionary of Cancer Terms: Radioactive Iodine. http://www.cancer.gov/publications/dictionaries/cancer-terms?cdrid=45855. Accessed November 4, 2016.

3. Easley J, Miedema B, Robinson L. It's the "Good" Cancer, so Who Cares? Perceived Lack of Support Among Young Thyroid Cancer Survivors. *Oncol Nurs Forum*. 2013;40(6):596-600.

4. American Thyroid Association. Thyroid Hormone Treatment. http://www.thyroid.org/wp-content/uploads/patients/brochures/HormoneTreatment_brochure.pdf. Accessed November 4, 2016.

5. Northwestern Medicine. Thyroid Hormone Replacement Therapy. http://thyroidclinic.nm.org/thyroid-hormone-replacement-therapy.html. Accessed November 4, 2016.

6. Haugen BR, Alexander EK, Bible KC, et al. 2015 American Thyroid Association Management Guidelines for Adult Patients with Thyroid Nodules and Differentiated Thyroid Cancer. *Thyroid.* 2016;26(1):1-133. doi: 10.1089/thy.2015.0020.

7. Wells SA, Asa SL., Dralle H, et al. Revised American Thyroid Association Guidelines for the Management of Medullary Thyroid Carcinoma: The American Thyroid Association Guidelines Task Force on Medullary Thyroid Carcinoma. *Thyroid.* 2015;25(6):567-610. doi:10.1089/thy.2014.0335.

8. National Cancer Institute. NCI Dictionary of Cancer Terms: Neuroendocrine Tumor. https://www.cancer.gov/publications/dictionaries/cancer-terms?CdrID=44904. Accessed November 4, 2016.

9. National Cancer Institute. Thyroid Cancer Treatment (PDQ®)–Health Professional Version. https://www.cancer.gov/types/thyroid/hp/thyroid-treatment-pdq#section/all. Accessed November 4, 2016.

10. Smallridge RC, Ain KB, Asa SL, et al. American Thyroid Association Guidelines for Management of Patients with Anaplastic Thyroid Cancer. *Thyroid.* 2012;22(11):1104-1139. doi:10.1089/thy.2012.0302.

11. National Comprehensive Cancer Network. NCCN Clinical Practice Guidelines in Oncology: Thyroid Carcinoma. V1.2016.

12. National Cancer Institute. Thyroid Cancer Treatment (PDQ®)–Patient Version. https://www.cancer.gov/types/thyroid/patient/thyroid-treatment-pdq#section/all. Accessed November 4, 2016.

13. Nguyen QT, Lee EJ, Huang MG, et al. Diagnosis and Treatment of Patients with Thyroid Cancer. *Am Health Drug Benefits.* 2015;8(1):30-40.

14. Monchik JM, Donatini G, Iannuccilli J, Dupuy DE. Radiofrequency Ablation and Percutaneous Ethanol Injection Treatment for Recurrent Local and Distant Well-Differentiated Thyroid Carcinoma. *Ann Surg.* 2006;244(2):296-304.

15. National Cancer Institute. NCI Dictionary of Cancer Terms: Active Surveillance. https://www.cancer.gov/publications/dictionaries/cancer-terms?CdrID=616060. Accessed November 4, 2016.

16. Nikiforov YE, Seethala RR, Tallini G, et al. Nomenclature Revision for Encapsulated Follicular Variant of Papillary Thyroid Carcinoma: A Paradigm Shift to Reduce Overtreatment of Indolent Tumors. *JAMA Oncol.* 2016;2(8): 1023-1029.

17. National Cancer Institute. NCI Dictionary of Cancer Terms: Targeted Therapy. http://www.cancer.gov/publications/dictionaries/cancer-terms?cdrid=270742. Accessed November 4, 2016.

18. Brierley JD, Tsang RW. External Beam Radiation Therapy in the Treatment of Differentiated Thyroid Cancer. *Semin Surg Oncol.* 1999;16(1):42-49.