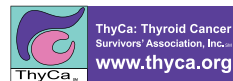


# PATIENT PERSPECTIVES ON NAVIGATING THYROID CANCER

*Presented by*



## Foreword

*For most people, receiving the news that you or a loved one has been diagnosed with thyroid cancer is a very emotional time, leaving you feeling anxious, possibly confused and maybe even fearful. These feelings are completely normal, which is why this informational guide has been created by The Light of Life Foundation, ThyCa: Thyroid Cancer Survivors' Association, Inc. and Eisai Inc. It is our hope that this guide will give patients and their caregivers, friends and family valuable information to begin to navigate their own personal thyroid cancer journey, as well as offer additional places to find resources and support.*

*It isn't uncommon for thyroid cancer patients to be told if they have to get a cancer, thyroid cancer is the one to have, or that it is a "good cancer," because patients are often successfully treated. This idea can leave patients feeling confused or unsupported, because their disease and treatment still have a significant impact on their lives.*

*Together, we want to shine a light of truth on the life-changing realities of living with thyroid cancer - the most rapidly increasing cancer in the United States.<sup>1</sup>*

- **Joan Shey**, Thyroid cancer survivor, Founder of the Light of Life Foundation
- **Gary Bloom**, Thyroid cancer survivor, Co-Founder and Executive Director of ThyCa: Thyroid Cancer Survivors' Association, Inc.

## Diagnosis: The First Step

It's possible that you may have heard thyroid cancer referred to as the "good cancer."<sup>2,3</sup> This may be because the majority of patients with differentiated thyroid cancer, which accounts for 94% of all cases, are successfully treated — which, without a doubt, is good news if you or a loved one is among the 62,450 new cases of thyroid cancer that will be diagnosed this year.<sup>1,4</sup> However, whether successfully treated or not, all cancers can have a significant impact on a person's life – beginning with the shock and distress of hearing the word "cancer" at diagnosis – and thyroid cancer is no exception.<sup>5</sup>



*"I awoke from the surgery alone in my hospital room. The surgeon came in and informed me that I had undergone a total thyroidectomy due to the discovery of multiple malignant nodules with cancer in my lymph nodes. I was shocked and unprepared to find myself at 38 years old with metastatic papillary thyroid cancer – just like my father, who was diagnosed more than 20 years before. Prior to walking out of the room, the surgeon patted me on the leg and told me not to worry – that I had gotten 'the best cancer you can get.' As he left, I felt utterly devastated and afraid."*

- **Victoria R. Ballesteros**, Thyroid cancer survivor

## Thyroid 101: Start with the Facts

The thyroid is a butterfly-shaped endocrine gland in the neck, which makes hormones that help regulate the body's metabolism and affect numerous other functions in the body, including brain development and the heart and nervous systems.<sup>1,6</sup>

One of the early symptoms of thyroid cancer can be the feeling of a lump on the neck.<sup>1</sup> While most of these growths or tumors are benign (non-cancerous), in some cases, they are cancerous and can spread into nearby tissues and to other parts of the body.<sup>1</sup>

Thyroid cancer can cause any of the following signs or symptoms, but these symptoms do not necessarily indicate a thyroid cancer diagnosis:<sup>1</sup>

- A lump in the neck, sometimes growing quickly
- Swelling in the neck
- Pain in the front of the neck, sometimes going up to the ears
- Hoarseness or other voice changes that do not go away
- Trouble swallowing
- Trouble breathing
- A constant cough that is not due to a cold

It's important to remember many other things can cause these symptoms and that many thyroid lumps (nodules) do not indicate cancer.<sup>1</sup> Even so, if you believe you have a suspicious lump in your neck, you should talk to a doctor about having it checked.

Thyroid cancer is a heterogeneous disease, which means there are many different types with different outcomes.<sup>1,7</sup> Each instance of the disease can be as unique as the individual patient affected. Therefore, the stage of your disease when you were first diagnosed is an important factor in choosing treatment options and can indicate a lot about the likelihood of successful treatment.<sup>1</sup>

### Types of Thyroid Cancer

There are several types of thyroid cancer, which include:

#### Differentiated Thyroid Cancer

Consisting of papillary and follicular types, differentiated thyroid cancer is the most common and accounts for 94% of thyroid cancer.<sup>1,4</sup> The majority of differentiated thyroid cancers are successfully treated with surgery to remove part of or the whole thyroid gland and radioactive iodine (RAI), an oral form of radiation that targets and kills thyroid cancer cells.<sup>1,4</sup>

- **Papillary Thyroid Cancer** Most common type, commonly diagnosed between the ages of 30 and 50 years<sup>8</sup>

- **Follicular Thyroid Cancer** Often diagnosed between the ages of 40 and 60 years<sup>8</sup>

#### Medullary Thyroid Cancer

Medullary thyroid cancer makes up about 4% of all thyroid cancers.<sup>1</sup> It is more likely to run in families and is associated with other endocrine disorders.<sup>8</sup> Because of this, anyone with this type should have additional genetic testing. Depending on the type, medullary thyroid cancer can occur in childhood or early adulthood or in older adults.<sup>1</sup>

#### Anaplastic Thyroid Cancer

Anaplastic is the rarest form of thyroid cancer, affecting up to 2% of thyroid cancer patients.<sup>1</sup> Though it can occur in younger people, it usually occurs in patients older than 65 years.<sup>8</sup> Anaplastic thyroid cancer often spreads quickly and is very difficult to treat.<sup>1</sup>

## After Diagnosis: Assemble Your Cancer Care Team

After your initial diagnosis, you will want to begin to find the right healthcare team to fit your needs. This may include, but isn't limited to, an endocrinologist, medical oncologist, radiation oncologist and surgeon.<sup>1</sup>



*“When I think of what I would tell a person starting a thyroid cancer journey, I’d say, make sure that you are at peace with your diagnosis. Then I’d work to find a good surgeon and endocrinologist who will give you individual care that’s current to the guidelines.”*

- **Gary Bloom**, Thyroid cancer survivor and Co-Founder and Executive Director of Thyca: Thyroid Cancer Survivors’ Association

It is important to have honest, open discussions with your healthcare team. When considering the right team for you, your first concern should be your comfort and ability to ask any question, no matter how minor it might seem. Some of the questions you might want to ask are:<sup>1</sup>

- What kind of thyroid cancer do I have?
- Has my cancer spread beyond the thyroid gland?
- What is the stage of my thyroid cancer? What does this mean in my case?
- Are there other doctors I need to see?
- How much surgery do I need?
- What other treatment choices do I have?
- What should I do to be ready for treatment?
- What are the risks and possible side effects of treatment?
- Will I need to take thyroid hormone for the rest of my life?
- What are the chances that my cancer will come back after treatment?
- What would we do if the treatment doesn’t work or if the cancer recurs?
- What type of follow-up will I need after treatment?

## Beginning Treatment: What to Expect

While there are many different types of thyroid cancer, the initial treatment for almost all patients, except for some with anaplastic thyroid cancer, is usually surgery to remove either part of or the whole thyroid.<sup>1</sup>

Depending on the type of thyroid cancer and the tumor size, surgery may be followed by RAI treatment.<sup>1</sup> Because the thyroid gland absorbs nearly all of the iodine in your body, when RAI is taken into the body (either as a liquid or a pill), it collects in the thyroid cells and kills them.<sup>1</sup> This is a way to kill remaining cancer cells with little effect on the rest of the body.<sup>1</sup> However, during RAI treatment, and for some time after, your body will give off radiation, which will require you to stay in the hospital and/or away from others to keep them from being exposed to this radiation.<sup>1</sup>

Other treatment options include:<sup>1</sup>

- External beam radiation, which uses high-energy rays to kill cancer cells and shrink tumors.
- Thyroid hormone therapy, which replaces missing thyroid hormone after surgery and helps to maintain the body's normal metabolism; it can also be used to try and stop remaining cancer cells from growing. This treatment is given in pill form.
- Chemotherapy, which uses medication to kill cancer cells. It may be taken by pill or administered through an IV.
- Targeted therapy, which are drugs that attack one or more specific targets on cancer cells.

The good news is most patients are successfully treated.<sup>1</sup> However, follow-up care continues for life and can be emotionally and physically draining.<sup>1</sup>



*"As a thyroid cancer survivor myself, I urge people to stop referring to thyroid cancer as the 'good cancer,' as I believe it downplays a patient's experience. I hear time and time again from patients how difficult their diagnosis and treatment were and that their scars are more than skin deep. My hope is to educate about the many types of thyroid cancer and change the thyroid cancer conversation."*

- **Joan Shey**, Thyroid cancer survivor and Founder of the Light of Life Foundation

## Beyond Initial Treatment: How Will Life Change?

After completing treatment, patients will likely feel relieved to be through with that part of their journey. But, thyroid cancer is a life-long journey. Every person's experience will be different and they will have to find their "new normal." Patients may experience some or all of the following:

- Without a functioning thyroid gland, patients must take daily hormone replacement medication for the rest of their lives.<sup>1</sup>
- There are long-term physical and emotional challenges associated with thyroid cancer and its treatment, including: lack of energy, difficulties concentrating, fatigue, weight gain, memory loss, migraines and depression.<sup>2,9</sup>
- Since most thyroid cancers grow slowly and can recur in up to 30% of patients even 10 to 20 years after initial treatment, you need follow-up care to check for cancer recurrence or spread, as well as for monitoring and management of possible side effects of certain treatments.<sup>1,10</sup> Because thyroid cancer can recur decades later, this care can continue for a lifetime and can be a source of anxiety.<sup>1,9</sup>
- Some patients experience a post-surgery complication called hypoparathyroidism, a lack of parathyroid hormone, which helps regulate calcium, phosphorus and vitamin D levels in the blood and bones.<sup>11</sup> This can lead to muscle cramps and spasms, brittle nails, dry hair and skin, seizures, and cataracts, among other issues.<sup>11</sup>
- Patients treated with radioactive iodine can experience blocked salivary ducts, which leads to dry mouth and dental issues, including tooth loss.<sup>12</sup> Others may experience excessive tearing from blocked tear ducts.<sup>12</sup>



*"When I was diagnosed with thyroid cancer, I went through radioactive iodine treatment and as a result of the treatment, my tear duct was completely blocked. I had to have eye surgery five years later to have a completely new tear duct made. And people call thyroid cancer a 'good cancer'?"*

- Ellen Fishman, Thyroid cancer survivor

It's normal for many patients living with thyroid cancer to feel drained and depressed after treatment.<sup>1,3,5</sup> This may be due to recovery from surgery and the cancer treatment itself.

At this stage of the journey, it's important to make self-care a priority. This includes getting enough rest, practicing healthy eating habits, and even taking some "time away from cancer." For at least a short time each week, try to return to favored activities—like going to the movies, taking short walks, or returning to a hobby.

### What Happens if the Disease Advances?

Less than 10% of patients diagnosed with differentiated thyroid cancer will progress to metastatic disease.<sup>13</sup> Of those patients, 15-30% will become refractory, or fail to respond to RAI; these cancers exhibit a more aggressive behavior and are more difficult to treat.<sup>4,13,14,15</sup> Medullary and anaplastic thyroid cancers, which are diagnosed in about 6% of all patients (4% and 2%, respectively), often require different treatment options and can spread quickly to other parts of the body.<sup>1</sup> Anaplastic thyroid cancer is the most aggressive form of thyroid cancer, with the most severe effects on patient health and overall survival.<sup>16</sup>

It is important to ensure that patients are aware of the resources and support available in the thyroid cancer community.

If a patient's cancer recurs, progresses or does not respond to treatment, it may be the right time to include a medical oncologist in his or her healthcare team. Patients should talk to their doctors about recommended oncologists.

### Ongoing Care: Facts about Persistent or Metastatic Thyroid Cancer

As discussed, follow-up care is necessary to check for cancer recurrence or spread, as well as for monitoring and management of possible side effects of certain treatments.<sup>1</sup>

If follow-up tests show that the cancer is still present following treatment, the cancer can be referred to as "persistent."<sup>17</sup> If the cancer returns following a clean scan, it is said to have "recurred."<sup>1</sup> Patients who have been successfully treated can still potentially experience recurrence up to 10 to 20 years after initial treatment, which is why it is important to continue follow-up care.<sup>1</sup>

In some people, the cancer metastasizes or spreads to other places in the body beyond where it was first detected.<sup>1</sup> Metastases may occur in neck tissue, lymph nodes, and in other places in the body, particularly the lungs, bones, or liver.<sup>1</sup>



*"Once a patient's disease progresses or is recurrent, they face new challenges and have different needs than patients with other forms of thyroid cancer. It is essential for patients with metastatic or recurrent thyroid cancer to find a medical oncologist who has experience in treating patients with advanced thyroid cancer."*

- **Marcia Brose**, MD, PhD, Associate Professor and Director of Rare Cancers and Personalized Therapy at the University of Pennsylvania's Abramson Cancer Center

## Getting Back On Track: Care and Support

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 as well. You need people you can turn to for strength and comfort. Support can come in many forms: family, friends, cancer support groups, church or spiritual groups, online support communities, or one-on-one counselors. What's best for you depends on your situation and personality.

The Light of Life Foundation, ThyCa: Thyroid Cancer Survivors' Association and Eisai 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](http://LightofLifeFoundation.org) and [ThyCa.org](http://ThyCa.org) for more information on the different types of thyroid cancer, support and resources.

## Additional Patient Resources

General Thyroid Cancer Information

[American Thyroid Association](#)

[CancerCare](#)

[The Light of Life Foundation](#)

[ThyCa: Thyroid Cancer Survivors' Association, Inc.](#)

Different Types of Thyroid Cancer

[ThyCa - Thyroid Cancer Types, Stages and Treatment Overview](#)

Thyroid Cancer Support

[Light of Life - Facebook Page](#)

[ThyCa - Support Groups](#)

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