

# Understanding the challenges faced by the thyroid cancer community

Results from a 2021 #TruthAboutTC Thyroid Cancer (TC) Survey

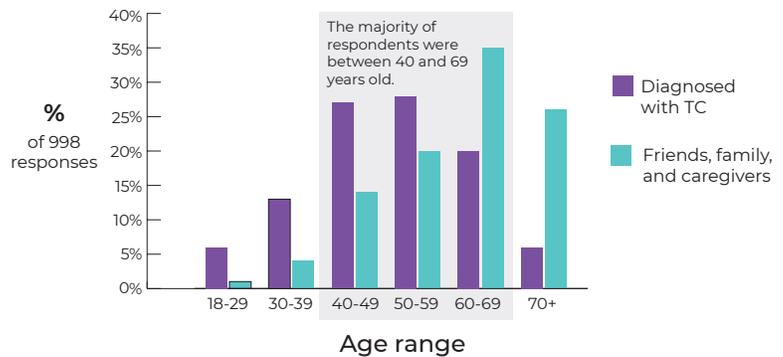
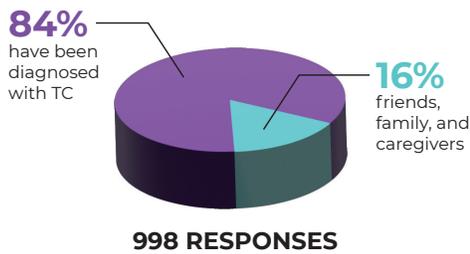


## THE TC COMMUNITY DESERVES TO BE HEARD

Living with cancer isn't easy. There are challenges that are unique to those living with thyroid cancer, particularly as it relates to long-term care and emotional well-being. To better understand how these concerns impact the TC community, **ThyCa: Thyroid Cancer Survivors' Association, Inc., the Light of Life Foundation, the Thyroid, Head and Neck Cancer (THANC) Foundation, and Eisai Inc.** teamed up to conduct a survey of people living with thyroid cancer and the people close to them. Nearly 1,000 people responded. The findings from this survey will help inform awareness and advocacy initiatives for patients and their families.

## A COMMUNITY OF MANY VOICES

998 members of the TC community took the survey. Of those who responded:



## AWARENESS MATTERS

Early detection is a key factor in the treatment of TC.<sup>1</sup> However, for a significant percentage of survey respondents, their diagnosis was delayed. Greater awareness is needed to help people reach their diagnosis earlier.



**34%**

of respondents living with TC said they did not notice symptoms before being diagnosed.



**67%**

of respondents living with TC didn't see a doctor within the first year of noticing symptoms.



**35%**

of respondents who noticed symptoms said it took more than a year for them to be diagnosed.



**17%**

of respondents living with TC went undiagnosed for more than 3 years!

## What the community is saying



DIAGNOSED WITH TC



FRIENDS, FAMILY, AND CAREGIVERS

These insights will guide the #TruthAboutTC campaign in developing resources and programming to address the TC community's needs.

## KEY TAKEAWAY FROM SURVEY

Lack of emotional support rose to the top as the most commonly reported challenge among member of the TC community.

### Do you feel heard?

One of the most revealing takeaways from the survey is the revelation that many within the TC community experience difficulty communicating the challenges of their disease. The survey results identified a clear unmet need to help people with TC discuss their concerns with their health care team as well as with their friends and family.

### Are emotional needs being met?

Fear and worry are major aspects of life with cancer. But is the emotional toll of the disease being adequately addressed? Responses from the community indicate this is an area that needs significant improvement.

#### Among those diagnosed with TC,

**76%** said coping with the emotional stress of living with cancer was a real challenge

**64%** expressed a strong fear of recurrence or relapse.

**42%** reported a strong feeling that they lacked emotional or social support.

### Is the community getting the care it needs?

Many within the community have questions about the care they receive.

**45% of respondents diagnosed with TC** expressed concerns about feeling that their specific needs are not being addressed.

**71% of friends, family, and caregivers** who responded said they were worried whether their loved ones were getting the health care they needed.

**41% of respondents diagnosed with TC** said understanding how nutrition plays a role in their diet was a challenge for them.

**61% of friends, family, and caregivers** who responded were worried about their loved ones' nutritional well-being.



#### Among those diagnosed with TC,

**77%**

said communicating the emotional impact of the disease to others was a serious challenge.

**67%**

expressed concern about feeling that their specific needs were not being addressed when communicating with their health care provider.

**30%**

reported a strong feeling that their diagnosis wasn't being taken seriously enough.

#### Among friends, family, and caregivers,

**68%** were particularly concerned about whether their loved ones were receiving the emotional support they need.

**71%** said they worry about the long-term outcome of the disease.

## YOU ARE NOT ALONE!

If you encounter communication challenges or feelings of anxiety, be sure to advocate for yourself. For questions about your care, proactively work with your care team to get the answers you need. Educate yourself on the disease and the resources available on [www.TruthAboutTC.com](http://www.TruthAboutTC.com). And when you're ready to talk, support groups are ready to listen.

Thank you for being part of the TC community. Add your voice to TC advocacy by sharing your story on social media with the hashtag #TruthAboutTC.

### Find support groups

[www.thyca.org/sg](http://www.thyca.org/sg)

[www.thancguide.org/resources/support-groups-hotlines](http://www.thancguide.org/resources/support-groups-hotlines)

Reference:

1. Lin JS, Bowles EJA, Williams SB, Morrison CC. Screening for thyroid cancer: updated evidence report and systematic review for the US Preventive Services Task Force. *JAMA*. 2017;317(18):1888-1903. doi: 10.1001/jama.2017.0562