

# Living With Thyroid Eye Disease

In June of 2024 we asked people affected by thyroid eye disease (TED) three questions through an online survey to better understand their experience and perspectives.

**35** people living with TED responded.

This is what they shared:

**Q1**

What are the first words that come to mind when you think about TED?

When describing TED in 5 words or less, people chose terms that described their symptoms and terms that illustrated the emotional impact TED has on them as a person.



Most common words in larger text size.

## Q2

### What do you wish you had known about TED when you were first diagnosed?

Two themes arose from people's responses, which centered around the need for more information on TED, medical care, and treatment options.

#### 1

#### TED is a lifelong condition that affects all aspects of life

- *"That this disease will never go away and could come back. This disease can be lonely and have emotional struggles."*
- *"More understanding of the disease and what to expect."*
- *"That it would be an entire lifestyle change."*
- *"Knowing the mental health issues that I may experience. Living with TED can lead to feelings of frustration, anxiety, depression, and social isolation."*

#### 2

#### Need to see a doctor who specializes in TED and understand all available treatment options

- *"To see a TED specialist to address it right away, so I can learn about my options."*
- *"How limited the treatments are and how long it takes to actually find and see a doctor that knows about TED."*
- *"Where to go for help. I saw 3 different eye doctors who didn't know what was happening."*
- *"I wish I knew about radioactive iodine triggering TED."*

# Q3

## What do you wish others understood about living with TED?

Many responses centered around the need for understanding, which can go a long way in helping someone as they navigate the challenges they have living with TED.

### 1 It is important to be kind and compassionate to people with TED

- *“It takes a village, and we need a strong support network and to keep the communication open.”*
- *“Kindness, support, compassion and accurate information is vital.”*
- *“I wish other TED patients would know how much agency we have when dealing with TED. Those without TED - there is tremendous power in ‘kindness’ and it is so appreciated when navigating TED. Compassion from others helps to melt away the feelings of isolation and hopelessness.”*

### 2 TED does not define the person who is living with the condition

- *“That is a new style of life we need to learn to live with and as much as it sucks, it doesn’t define who we are!”*
- *“I know my eyes were hard to look at. Please continue to include me in activities.”*
- *“I’m still the same person.”*

**Thank you to all who shared their personal, lived experiences with us. This understanding helps to build awareness around TED, forge connectivity and community, and facilitate patient-driven solutions to improve care and treatment.**



**Thank you to the TED Community Organization and Prevent Blindness for sharing this survey opportunity with their community members.**



This infographic was developed by Viridian Therapeutics with input provided by patient advocates.

Material is intended for educational purposes and does not constitute diagnosis or treatment recommendations. Please speak with a healthcare professional for all medical questions.

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