

**EXECUTIVE SUMMARY

What Patients Want Their Doctors to Understand About Living With TED**

The TED patient write-in responses reveal a powerful and consistent message: **patients with Thyroid Eye Disease want to feel seen, believed, and fully understood as whole people—not just as clinical cases.** Their comments underscore gaps in emotional support, communication, and the day-to-day realities of navigating TED. Across all responses, five core themes emerged.

1. The Profound Whole-Life Impact of TED

Most frequent theme

Patients wish their clinicians understood that TED affects **every dimension of life**—physical comfort, daily functioning, appearance, emotional well-being, relationships, and identity. Many emphasized that the effects extend far beyond the eyes.

Patients want doctors to understand:

- TED is **life-changing**, not cosmetic.
- It affects confidence, social engagement, and the ability to work or drive.
- It alters one's sense of self and safety navigating the world.

2. The Emotional and Psychological Toll

Respondents described intense emotional strain—anxiety, fear, uncertainty, grief over appearance changes, and isolation.

Key insights:

- Patients want acknowledgment that TED can be traumatic.
- Emotional distress is often minimized or overlooked in clinical visits.
- Validating the psychological experience is as important as treating symptoms.

One patient described it as “*a burden that touches every part of life.*”

3. The Need for Clear, Compassionate Communication

A major recurring theme is **communication gaps**—patients don't always feel heard, informed, or guided with the clarity they need.

Patients express that they want:

- More transparent explanations of disease progression.
- Realistic expectations about treatment timelines and outcomes.
- More time to ask questions without feeling rushed.
- Doctors who listen deeply and take their concerns seriously.

Several noted how hard it is to navigate a fragmented or siloed medical system.

4. The Experience of Physical Discomfort, Pain, and Functional Impairment

Patients mentioned:

- Persistent pain, pressure, or aching.
- Light sensitivity.
- Difficulty with reading, driving, or working.
- Fatigue from constantly managing symptoms.

These symptoms often feel under-recognized or dismissed as “mild” despite being debilitating.

5. The Significance of Appearance Changes

Patients want clinicians to understand the psychological and social impact of:

- Eye bulging
- Eyelid changes
- Facial asymmetry
- Visible inflammation

These changes can drastically affect self-esteem, interpersonal interactions, and willingness to appear in public. Patients ask for empathy, not minimization.

Synthesis: What Patients Most Want Providers to Know

Across all responses, one unifying insight stands out:

Patients want their doctors to understand that TED is not just a medical condition—it's an emotional, social, and identity-shaping experience.

To feel fully supported, patients are asking for:

- Deep listening
- Acknowledgment of emotional reality
- Clear, proactive communication
- A whole-person lens on care
- Empathy around the invisible and visible burdens

Conclusion

This dataset provides a clear call to action for the TED medical community: **patients want partnership, compassion, and understanding—not only clinical expertise.** Their voices illustrate a strong desire for a more holistic, human-centered approach that recognizes the lived experience of TED.