

****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.
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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**
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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.