

EXECUTIVE SUMMARY

What TED to NED Means to Patients Living with Thyroid Eye Disease

TED Community Organization — CONNECTED 2025 Conference

Overview

During CONNECTED 2025, participants reflected on what ****NED—No Evidence of Disease—**** means for them personally. Responses revealed a deeply human portrait of hope, longing, resilience, and the very real physical and emotional burdens carried by people with TED.

Most respondents described NED not as a single medical milestone, but as a **return to freedom**—freedom from double vision, pain, disfigurement, fear, uncertainty, and barriers to daily life. For many, NED is also a reclamation of identity, confidence, and independence.

Six major themes emerged.

1. Clear, Comfortable Vision and Ending Double Vision

The most dominant theme was the desire to **see normally again**.

Patients expressed longing for:

- Resolution of **double vision**
- Ability to **drive safely**
- Ability to **work, read, and perform daily tasks**
- Relief from light sensitivity and eye strain

Representative comments:

- “Being able to maintain eye contact without looking cross-eyed.”
- “No more double vision—being able to drive and go back to work.”
- “Single vision is a dream.”
- “Not bashing into things or breaking objects. Not falling.”

For many, **ending double vision** is synonymous with regaining independence.

2. Reduction of Swelling, Bulging, and Facial Changes

A second major theme was the desire for a return to a more normal appearance—both for comfort and for emotional well-being.

Patients described NED as:

- Less or no bulging
- Reduced eyelid swelling or retraction
- A face they recognize in the mirror
- No longer feeling “disfigured”

Examples:

- “Normal appearance. No swelling. No pain.”
- “Feeling comfortable with my appearance again.”
- “No disfigurement of my face.”
- “Looking like I did pre-TED.”

For many, NED is not perfection—it is **recognizability**, and the ability to move through the world without self-consciousness.

3. Freedom From Pain, Pressure, and Daily Symptoms

Many described NED as relief from the constant physical discomfort that TED imposes.

Patients wished for:

- No more eye pain
- No pressure behind the eyes
- No migraines
- No tearing or extreme dryness
- Eyelids that close fully

Examples:

- “No symptoms.”
- “Walking through life without focusing on TED symptoms every day.”
- “Less bulging, less tearing/dry eye, improved vision.”

NED is described as a **quiet body**—eyes that do not constantly demand attention.

4. Stability, Predictability, and an End to Fear of Flare-Ups

NED is not only the absence of symptoms—it is the absence of **fear**.

Many patients want:

- A stable, non-progressing disease
- No unpredictable flare-ups
- Confidence that improvements will last
- The ability to stop living in a “cloud of uncertainty”

Examples:

- “Excellent management of flare-ups.”
- “Permanent, stable eye disease without unpredictable flares.”
- “No longer living with concern that TED will return.”

For some, NED means **safety**—the end of waiting for the next setback.

5. Restoring Identity, Confidence, and Emotional Well-Being

TED deeply affects personal identity. Many patients expressed emotional dimensions of NED:

- Feeling like themselves again
- Regaining social confidence
- Recovery from the isolation TED often causes

Examples:

- “Regaining life as before—being social and comfortable again.”
- “Independence and decreased sense of isolation.”
- “Feeling like myself again... no more fear of flare-ups.”
- “TED is a heartbreaking mental toll—it can make a wallflower out of an extrovert.”

Here, NED is framed as *wholeness*—a return to freedom of movement, self-expression, and joy.

6. Medical Markers and Functional Milestones

Some respondents described NED in clinical or measurable terms:

- Normalized eye measurements
- CAS score of 0
- Stable antibody levels (TSI/TRAb)
- Post-surgical alignment
- Ability to resume exercise without triggering symptoms

Representative comments:

- “CAS of 0 for several consecutive months.”
- “Normal antibody levels.”
- “Back to normal intraocular pressure.”

For these individuals, NED means meeting **both medical and functional benchmarks**.

Conclusion

Across all responses, NED is described as a **whole-person experience**—physical, emotional, visual, and social.

NED is:

- A **return to clear vision**
- A **comfortable, recognizable appearance**
- A **body free from constant discomfort**
- A **mind free from fear and uncertainty**
- A **life reclaimed—independent, social, confident**
- A **hopeful marker that healing is possible**, even if not identical to pre-TED life

Patients understand that NED may not mean “perfect” or “cured,” but they overwhelmingly believe it means **better, stable, and livable**.

Their words paint a shared vision for the TED Community Organization’s mission: to help every patient move toward a life where TED no longer defines their days, their identity, or their future.