Thyroid Eye Disease (TED) LIFE MANAGEMENT GUIDEBOOK

for Patients, Caregivers, and Families

This guidebook was developed by Horizon Therapeutics with input from people living with TED and their caregivers to help others impacted by TED manage the disease, update their lifestyles, and guide them through their journeys.
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Dear Friend,

You probably found this guidebook because either you or your loved one has been impacted by Thyroid Eye Disease (TED).

TED has many symptoms that can affect all aspects of your life. While living with TED can pose challenges, there are ways to make your daily activities easier and assist you in maintaining a healthier, more productive lifestyle.

This guidebook includes life management tips from real patients and caregivers who have been living with TED. In fact, some of us have been living with it for more than a decade.

TED affects everyone differently and its impact varies from time to time, but we have focused this guide on some of the more common symptoms.

Along our journeys with TED, we’ve collected some valuable tips that have made our lives easier; we hope they will also help you with yours.

Best wishes,

TED Patient and Caregiver Advocates
**AT HOME**

Making your home environment safe and convenient is important. Here are some suggestions:

<table>
<thead>
<tr>
<th>TED SYMPTOMS</th>
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<tbody>
<tr>
<td>DRY EYES</td>
<td>LIGHT SENSITIVITY</td>
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1. Be mindful of potential symptoms such as dizziness, changes in depth perception and balance, and eye fatigue in your daily activities.
   - Be aware of dust getting in your eyes while cleaning.
   - Keep your eyes moist at night by using a sleeping mask or coverlet. (Ask your doctor about adhesive patches or eye ointments.)
   - Avoid areas with direct airflow from vents and fans.
2. Wear tinted glasses or sunglasses to soothe light sensitive eyes.
3. Replace light bulbs to soften light color and brightness or install dimmer switches and dimmable light bulbs to control brightness.
4. Adjust TV and furniture placement so you can see the screen clearly without any glares or double vision.
5. Use screen covers for monitors, laptops, and other screens to reduce brightness.
6. Use window films or shades to soften outside light.

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**TED SYMPTOMS**

- Light Sensitivity
- Double Vision
- Dry Eyes
- Bulging Eyes
AT HOME (Continued)

Make your home environment safe from slipping or tripping
- Wear footwear that will help avoid slipping
- Eliminate throw rugs, cords, and other objects on the floor
- Use contrasting, colored tape to mark first and last steps on stairs
- Avoid confusing patterns on steps

Allan, who lives with TED

“TED caused double vision, and my window of normal vision became smaller. Judging distances became difficult. I moved the TV and sofa around so I can see it well when I sit down. I also made sure that where I sit does not have a vent blowing air directly to avoid my eyes from drying.”

Bea, who lives with TED

“With TED, the level of light sensitivity for my eyes changes daily. Using a light dimmer switch to adjust the brightness has made my eyes feel so much better.”
GOING OUT

Living with TED does not mean that you have to stay home. Here are a few tips:

TED SYMPTOMS

DRY EYES

LIGHT SENSITIVITY

BULGING EYES

DOUBLE VISION

Be mindful of potential symptoms such as dizziness, changes in depth perception and balance, and eye fatigue in your daily activities.

Avoid busy times and run errands during off-peak hours. Inquire about senior and at-risk shopper hours at grocery stores.

Carry your eye drops and other frequently used medications with you.

Take breaks and sit in places where your line of sight is best, away from windows, glare, and fans.

Carry sunglasses with large lenses or wraparound sunglasses to:

• Reduce light exposure when going outside or entering buildings with bright lights

• Prevent dust from getting in your eyes

• Cover your eyes if you are concerned about appearance

If you are traveling, keep items you may need handy. Consider checking your extra luggage.

Wear a wide brim hat to block the wind and dust from getting in your eyes.

Travel with a companion if possible, especially if you experience occasional dizziness.

Avoid going alone to bus, train or airport terminals if the constant motion causes lightheadedness.

GOING OUT

Living with TED does not mean that you have to stay home. Here are a few tips:
STAYING POSITIVE

Here are some suggestions that may help you maintain healthy lifestyle and stay positive.

1. Practice meditation and breathing exercises to reduce stress and anxiety.

2. Take a selfie on your good days as a helpful reminder and self-esteem booster.

3. Talk to your family and friends to seek emotional support. Tell them how you are feeling and what you are going through so they can understand you and your situational needs better.

LaQuilla, who lives with TED

“You don’t have to suffer alone. There are people who are willing to help you, but you have to reach out.”
4. Consider speaking with a professional counselor to cope with the social and emotional effects of TED.

5. Take the time to enjoy relaxing hobbies. Consider listening to audiobooks and enjoying your favorite playlist of songs.

6. Connect with other TED patients and read their stories online. Consider connecting with patient advocacy groups, local support groups, and online patient communities.

Christine, who lives with TED

“The most important thing I have learned in my 11 years of experience with Thyroid Eye Disease is that I am not alone. There is a wealth of resources available for improving one’s quality of life. These resources offer you a doorway to a beautiful life.”
There are many existing technology platforms and features that may assist with your daily life.

Here are a few:

- Increase font size and adjust screen brightness level
- Utilize vision accessibility features on smartphones. Android and iPhone both have built-in functions to help low-vision users such as screen reader, color inversion/correction, etc.
- Use text-to-speech apps that can read documents aloud when you take a picture of a document
- Use voice-activated virtual assistants (e.g., Amazon Alexa, Google Assistant, Siri)
FOR CAREGIVERS

Being a caregiver to your loved one with TED can be rewarding but stressful.

Giving care and support for your loved one with TED can be a challenge.

Here are a few helpful reminders and suggestions:

Realize that your life will be impacted by your loved one’s diagnosis.

Be patient as your loved one goes through a difficult time.

Ask how you can help, but don’t treat your loved ones as if they are helpless.

Become informed about TED and its management and treatment options.

Remember to take time for yourself. You will be better able to help your loved one if you are rested and healthy.

Ask for help from your friends and family.

Talk to others about what you are going through.
ADDITIONAL RESOURCES

If you have TED, know that you are not alone.

There are many organizations and communities dedicated to helping those with TED and vision problems. These resources can help you:

- Learn more about TED and related topics
- Connect with peer-to-peer support resources
- Find information on workplace accommodations and other employment-related issues
- Locate various types of assistance services and accommodations

For more information and resources on TED, visit ThyroidEyes.com or Facebook.com/ThyroidEyes
FINDING YOUR CARE TEAM

Thyroid Eye Disease (TED) is unique and rare, and not all doctors are used to treating it. That is why it is important to see an eye specialist, such as an ophthalmologist or oculoplastic surgeon, who specializes in treating TED.

Ophthalmologists & Oculoplastic Surgeons Who Specialize in TED

These TED Specialists have the experience to diagnose TED and provide you with the care you need. When it comes to your care, they do a number of things, such as:

- Conduct a comprehensive baseline exam
- Conduct additional exams to see how your TED is changing over time
- Develop a TED treatment plan
- Decide how often your TED should be checked

Endocrinologists

Endocrinologists specialize in glands and their hormones, like the thyroid and the important hormones it makes. While these specialists do not treat TED, they can help manage separate thyroid conditions like Graves’ disease, that people with TED often develop. Your endocrinologist may:

- Help manage a thyroid condition, like Graves’ or Hashimoto’s
- Discuss the risk of developing TED
- Work with your TED Specialist to ensure the medicines for your thyroid condition do not interact with or affect medicine you need for your TED

To find a TED Specialist near you, visit TEDdoctors.com
PREPARING FOR
A DOCTOR’S APPOINTMENT

- Call the doctor’s office to confirm your appointment and add a reminder to your calendar.
- Ask a family member or friend well in advance to accompany you to your scheduled appointments.
- Prepare a list of the medicines and any vitamins or supplements that you take.
- Take close-up selfies to monitor progression and keep a running list of symptoms.
- Keep a calendar or treatment diary to track doctor visits, treatment appointments, test results, symptoms, questions, and more.
<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
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</thead>
<tbody>
<tr>
<td>What specific changes should I look out for with TED?</td>
<td>Should I take pain relief medications?</td>
</tr>
<tr>
<td></td>
<td>Which ones?</td>
</tr>
<tr>
<td>How often should I schedule appointments for my TED?</td>
<td>Can a warm or cold compress on my eyes help with swelling and irritation?</td>
</tr>
<tr>
<td>How is TED treated and managed?</td>
<td>What are prism lenses, and can they help my double vision?</td>
</tr>
<tr>
<td>What eye drops should I be using?</td>
<td>How will I know when what I am experiencing is an emergency?</td>
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</tbody>
</table>
If you are visiting a new doctor, ask how many TED patients the doctor treats each year (if possible, ask before making the first appointment).

Don’t downplay your symptoms; what you may see as complaining, your doctor may see as valuable information to help better manage your TED.

Be specific. The more detail you give the doctor, the better it can help them to understand the true impact of TED on your life.

Ask questions that you prepared, in the order of importance to you.

Keep a notebook to take notes. If possible, have a family member or friend attend and take notes for you or record the visit on your phone (make sure you obtain the doctor’s permission to record).
AFTER A DOCTOR’S APPOINTMENT

- Review notes and record updates in a notebook.
- Discuss the visit with your loved ones.
- Update and organize medical information such as changes in medications, test results, and more.
- Update your calendar with follow-up appointment dates.
- Contact your doctor if you observe worsening symptoms or have concerns.
- Consider obtaining a second opinion from another doctor if you are interested in hearing another perspective.