

The thyroid gland can become overactive (hyperthyroidism) or underactive (hypothyroidism). This is most often due to an autoimmune disease in your body. For more information, visit PreventBlindness.org/thyroid-eye-disease

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Thyroid Eye Disease

(Also known as Graves' Ophthalmopathy or Graves' Eye Disease)

What is Thyroid Eye Disease?

Thyroid eye disease (TED), also known as Graves' ophthalmopathy or Graves' Eye Disease, is an autoimmune disease in which the immune system causes inflammation and swelling which leads to abnormalities within muscle tissue and fat behind the eye. An overactive thyroid gland (hyperthyroidism) is usually caused by Graves' disease. Up to one-half of people with Graves' disease develop TED. In some people, TED can occur with normal levels of thyroid hormones (euthyroid) or low levels of thyroid hormones (hypothyroidism). TED may occur in patients who already know they have thyroid disease, or it may be the first sign of Graves' disease. While TED often occurs in people living with hyperthyroidism or Graves' disease, it is a distinct disease and treating hyperthyroidism may not resolve the TED symptoms and signs.

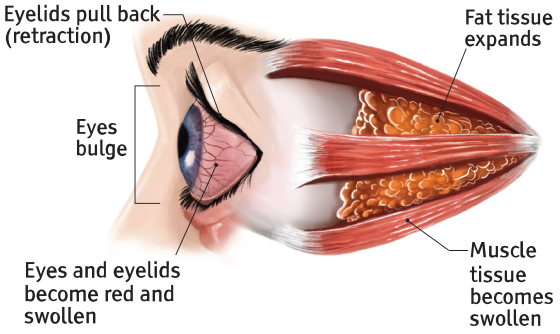


Photo credit: ThyroidEyes.com

Who is at Risk for TED?

TED is most commonly associated with Graves' disease, however it can also occur **without** a diagnosis of Graves' disease.

Other risk factors for TED include:

- **Age:** Usually affects middle-aged adults but can occur at any age
- **Gender:** Females are affected more than males
- **Family history** of TED
- **Smoking:** Smoking increases the risk of TED by 7–8 times, causes TED to have a longer "active phase", and it reduces the effectiveness of treatments
- **Radioactive iodine therapy:** Radioactive iodine has been used to treat hyperthyroidism and Graves' disease. This treatment should be used with caution in people with TED as it may worsen the condition unless steroids are given at the same time
- Low blood levels of **selenium**, a dietary mineral
- Low blood levels of **vitamin D**

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What are the Symptoms of TED?

Symptoms of TED are caused by the tissues, fat, and muscles of the eye socket swelling and pushing the eyeball forward. Tissues around the eye also may swell and become thickened. It is not unusual for symptoms to be worse in one eye more than the other. TED changes over time, with symptoms that can appear anytime and range from mild to severe. The appearance of TED can be different for each person.

The symptoms of thyroid eye disease include:



In more severe TED, there may also be:

- Trouble moving eyes
- Inability to completely close your eye causing corneal exposure or even an ulcer*
- Blurred or loss of vision due to optic nerve compression (colors may appear dull or dim), or corneal damage from an ulcer leading to scarring

If you have Graves' disease, eye symptoms most often begin within six months of disease diagnosis. Very rarely, eye problems may develop long after the Graves' disease has been treated. In some patients with eye symptoms, hyperthyroidism never develops and, rarely, patients may have hypothyroidism. The severity of the eye symptoms is not related to the severity of the hyperthyroidism.

***Note:** The cornea is a clear layer that covers the front of the eye. A corneal ulcer is an open sore on your cornea and it can cause scarring and permanent loss of the vision. A corneal ulcer causes redness of the eye, pain and usually a decrease in vision. You should seek immediate attention from your eye doctor if you experience these problems.



How is TED Diagnosed?

If you have thyroid disease or suspect that you may have TED, your doctor may recommend that you see an eye doctor (ophthalmologist). TED is usually managed by an ophthalmologist. Management of more severe forms of the disease may require a team of ophthalmologists, including specialists in eye plastic surgery, eye muscle surgery, neuro-ophthalmology, and endocrinology (the hormone systems of the body). They will be able to evaluate your symptoms, recommend a course of treatment, discuss surgical options to improve eye function and appearance, and help you watch for any problems with decreased vision.

To assess your vision and the changes in the tissues around your eyes, there are several tests you can expect your ophthalmologist to perform. The following tests are often conducted:

- **Visual acuity** – to determine how well you can see far away and up close
- **Stereopsis testing** – to measure your depth perception and binocular vision (how your two eyes work together)
- **Color vision** – to determine how well you see colors
- **Visual fields** – to assess your central and side vision
- **Eye movements** – to see how much your eye muscles have been affected
- **Eyelid measurements** – to measure the eyelid position on the eye
- **Eye measurements** – to measure the amount of eye bulging (protrusion)
- **Eye pressure readings** – to determine the pressure inside the eye
- **Optic nerve visualization** – to look into the back of your eye to see if the optic nerve is affected
- **Magnetic resonance imaging (MRI) scan or computed tomography (CT) scan** – to see how much enlargement there is in the tissue and muscles behind the eye

How is TED Treated/Managed?

In its severe form, TED can last for several years and the disease can progress at multiple points long after the early stages of the disease. The exact length of time varies by each individual. If it is left untreated, the inflammation may gradually decrease by itself but may cause damage to vision through the course of the disease. Inflammation also can flare up later. Sometimes, the changes caused by the enlargement of the tissues (such as bulging eyes or double vision) may not go away. This can impact your quality of life and how you complete everyday tasks. The goal of treatment is to limit severe inflammation and swelling, protect the front of the eye and prevent vision loss.

TED is usually managed by an ophthalmologist. Any underlying thyroid problems will be managed by your primary care doctor (PCP) or by a specialist in the hormone systems of the body (an endocrinologist).

If a thyroid issue is suspected, evaluation and treatment are critical. The first priority is to restore your normal thyroid function. In addition, eye conditions should be examined and treated at the same time as your thyroid gland treatment. Eye problems may continue to progress even after your thyroid function returns to normal.

What Can I Do to Help My Vision?

If you have TED, your ophthalmologist may recommend one or more of the following treatments to help soothe your eyes and improve your vision:

- **Cool compresses:** Apply cool compresses to your eyes. The extra moisture and cooling effect may provide relief.
- **Sunglasses:** When you have TED, your eyes are more sensitive to sunlight and UV rays. Wearing sunglasses helps protect your eyes from both sun and wind.
- **Lubricating eye drops:** Use lubricating eye drops, like artificial tears. It may help relieve dryness and scratchiness. Make sure to use eye drops that do not contain redness removers. Lubricating gels can be used before bed to prevent the cornea (the front of the eye) from drying out because your eyelids may not close completely when sleeping.
- **Taping:** Talk with your doctor about taping your top and bottom eyelids together to help protect the front of your eye (cornea) from drying when your eyelids do not close completely during sleep.
- **Elevate your head when lying down:** Keeping your head higher than the rest of your body may reduce swelling and may help relieve pressure on your eyes.

- **Quit smoking:** Smoking (and secondhand exposure to smoke) is an important risk factor for TED. If you smoke, quit, and avoid secondhand smoke.
- **Stress management:** Try to reduce or avoid stress whenever possible. Ways to reduce stress can include connecting with others, exercising, and getting enough sleep.
- **Steroids:** Swelling in your eyes may be improved by treatment with steroids (such as hydrocortisone or prednisone). Your ophthalmologist may recommend either intravenous or oral medication. **Note**, make sure you discuss the risks of using steroids with your doctor before use.
- **IV (intravenous) infusion:** There are intravenous infusion treatments (putting drugs into a vein) that are FDA-approved medications for the treatment of TED.
- **Clinical trials:** Researchers are studying new ways to treat TED through clinical trials. If you're interested in learning more or seeing if a trial might be right for you, talk to your doctor or visit clinicaltrials.gov. Learn more about clinical trials at: PreventBlindness.org/clinical-trials-for-eye-diseases-and-vision
- **Nutrition:** Talk to your health care provider to see what foods and supplements may be helpful to eat more of or to avoid.
- **Prisms:** TED can cause scar tissue to develop in your eye muscles. This can lead them to become tight and pull your eyes out of alignment, causing double vision. If double vision occurs, glasses containing prisms may be prescribed by your doctor. However, prisms do not work for all people with double vision and your doctor may recommend patching one eye for temporary relief or eye muscle surgery as a more effective option when changes have stabilized.
- **Eyelid surgery:** When you have TED, the eyelids are usually more widely open with a "startled" look because the muscles in the eyelids may tighten and pull the upper lid up and the lower lid down. You may have difficulty closing your eyelids, leaving the front of the eye (cornea) more exposed, which causes tearing, irritation and susceptibility to developing a corneal ulcer. Eyelid surgery may help reduce exposure of the cornea.
- **Strabismus (eye muscle) surgery:** Eye muscle surgery may help correct your double vision by moving the affected muscle(s) farther back from its original position on the eyeball. This surgery will help to correct your double vision when reading and looking straight ahead. Sometimes, you may need more than one surgery to get effective results.



- **Orbital decompression surgery:** TED can cause swollen tissues around the eye that compresses the optic nerve. The optic nerve provides the connection between your eye and the brain. When the nerve is compressed, color vision becomes abnormal, lights may seem dimmer than usual, and the sharpness of the vision decreases. Orbital decompression surgery can be done to improve your vision. The surgery makes the eye socket bigger or removes some of the excess tissue. When the nerve is compressed, the goal of surgery is to get the eye and the inflamed tissue more space and decrease pressure on the optic nerve. Even when the optic nerve function is not compromised, orbital decompression may be used to restore comfort and appearance by reducing the bulging of the eyes. If orbital decompression surgery is recommended, it is usually performed prior to eye muscle surgery and/or eyelid surgery, if needed.

Your ophthalmologist will require some time for your TED to stabilize before recommending surgery. The active or inflammatory stage of TED can last for several years and the disease can progress at multiple points long after the early stages of the disease. During this time, your ophthalmologist will avoid surgically treating your symptoms unless your vision is threatened. In cases such as a corneal ulcer or optic nerve compression, urgent surgery may be recommended.

How to support your coverage options with TED?

Reach out to your insurance company directly: This is the most important step. Describe your circumstances, including your TED diagnosis, and ask if they offer coverage for health services.

Understand your insurance processes/requirements: Every insurance carrier is different. Request information directly from them about the process for securing coverage, including any requirements for a Letter of Medical Necessity (LMN) from a physician.

Talk to your human resources department: Look into benefits your employer provides. Some employers provide wellness initiatives or perks that could encompass coverage or reimbursement for health needs like emergency funds to cover expensive treatments.

Living with TED

Take Care of Your Mental Wellness

Loss of vision can lead to feelings of depression, anxiety, and loss of independence. Some individuals may notice a change in their desire to socialize with others, or increased frustration with the additional time it may take to accomplish daily tasks. If you experience any of these symptoms, know there is help available.

Learn about resources to help support your mental wellness after experiencing vision loss at LowVision.PreventBlindness.org/vision-loss-and-mental-wellness

Maximize the Vision You Have

Low vision specialists are trained to help patients with vision loss learn how to use their remaining vision to its fullest potential, to manage daily activities such as:

- Improving lighting conditions
- Using accessible technology, such as smart phones, tablets, virtual reality, computers, and smart home devices
- Using low-tech solutions, such as magnifiers or simple home modifications

Find a low vison rehabilitation center near you at LowVision.PreventBlindness.org/finding-low-vision-rehabilitation-services

For more information, visit PreventBlindness.org/thyroid-eye-disease

Additional Resources:

TED Community Organization TedCommunity.org

Focus On Eye Health Expert Series: Thyroid Eye Disease (TED) youtu.be/-g2UPKrQWCU?feature=shared

Graves' Community GravesCommunity.org

The Graves' Disease and Thyroid Foundation – Support Groups GDATF.org/community/support-groups

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