Your Guide to Thyroid Eye Disease

What is Thyroid Eye Disease (TED)?

Thyroid eye disease is a condition in which the eye muscles, eyelids, tear glands and fatty tissues behind the eye become inflamed. This can cause the eyes and eyelids to become red, swollen and uncomfortable and the eyes can be pushed forward (‘staring’ or ‘bulging’ eyes).

In some cases there is swelling and stiffness of the muscles that move the eyes so that they no longer move in line with each other; this can cause double vision. Rarely TED can cause reduced vision from pressure on the nerve at the back of the eye or ulcers forming on the front of the eyes if the eyelids cannot close completely.

TED – also known as Graves’ Orbitopathy– is an autoimmune condition. It occurs when the body’s immune system attacks the tissue around and behind the eye, causing inflammation in the tissues. In most patients, the same autoimmune condition that causes TED also affects the thyroid gland, resulting in Graves’ disease. Usually this can be confirmed with a blood test to measure TSH Receptor Antibodies (TRAbs.) Graves’ disease most commonly causes thyroid overactivity (hyperthyroidism) but can also rarely cause thyroid underactivity (hypothyroidism).

TED can occur in people when their thyroid is overactive, underactive or functioning normally. It can also occur after treatment for Graves’ disease. People with TED need to be looked after by an eye specialist (ophthalmologist) and a thyroid specialist (endocrinologist).

What is the chance that I will develop TED?

Overall, up to 40% of people with Graves’ disease develop TED either before, during, or after their thyroid disorder is diagnosed. In most cases, the eye disease is mild and only 5-6% of people with Graves' disease develop moderate to severe TED. If you have no features of TED by the time the Graves’ disease is diagnosed and you are a non-smoker or ex-smoker then your chance of developing TED is less than one in ten. But if you smoke your chance of developing TED is doubled. If you are a heavy smoker, the chances of developing TED is increased **eight times** compared to non-smokers.

What are the symptoms of TED?

These are the most common symptoms. See your doctor if you have any of the following and ask if it could be TED:

- Change in the appearance of the eyes (usually staring or bulging eyes)
- A feeling of grittiness in the eyes or excessive dryness in the eyes
- Watery eyes
- Intolerance of bright lights
- Swelling or feeling of fullness in upper or lower eyelids
- New bags under the eyes
- Redness of the lids and eyes
- Blurred or double vision
- Pain in or behind the eye, especially when looking up, down or sideways
- Difficulty moving the eyes

If you have puffy eyelids and puffy skin around and under the eyes **and** you have a severely **under**active thyroid, this is probably not TED. It should improve once you are adequately treated with levothyroxine (thyroid hormone replacement treatment).

TED can sometimes be difficult to diagnose and patients may be treated for other conditions such as conjunctivitis, allergy or hay fever, sometimes months before the diagnosis is made. The signs that the diagnosis may be TED rather than any of these conditions are:

- Symptoms may occur in the wrong season for hay fever
- Allergies usually cause itchy eyes, whereas TED does not
- Conjunctivitis usually causes sticky eyes, whereas TED usually does not
- TED often is associated with an ache or pain in or behind the eye, especially when trying to look up or sideways, whereas the other conditions mentioned are not
- TED is sometimes associated with double vision, whereas the other causes of eye symptoms are not

Can I do anything to prevent TED from getting worse?

If you are a smoker, give it up – ask your doctor for advice on how to stop, or enrol on a stop-smoking programme. Patients with TED who continue to smoke respond less well to treatments, but this disadvantage seems to disappear soon after giving up smoking. Also non-smokers or ex-smokers are more likely to be cured of their thyroid overactivity after a course of Carbimazole (CMZ) or Propylthiouracil (PTU) treatment, than smokers. There is no research yet on vaping and TED. The safest thing for your TED and your general health is to stop doing either.

Further information about the effect that smoking has on TED

Avoid fluctuations in your thyroid levels – particularly hypothyroidism. Make sure that you have thyroid blood tests regularly, and follow the advice given by your doctor about when and how to take your thyroid medication. This will ensure that your thyroid levels remain normal and steady, and within the normal reference range, which will give your eyes the best chance of healing and improve the way you feel.

Avoid radioiodine treatment if you have active TED – radioiodine treatment can worsen TED, especially in smokers. Discuss with your doctor what special precautions may be required, or whether treatment should be delayed.

Selenium supplements – convincing evidence suggests that patients with mild active TED may benefit from a six month course of selenium supplements at a dose of 100mcg twice daily which you can buy over the counter.

Atorvastatin in patients with co-existing hypercholesterolemia
There is also recent evidence that statins, drugs routinely used to reduce cholesterol levels when needed, may benefit people with both GD and TED.

Can TED affect my quality of life?

Yes, it is well recognised that TED can affect your psychological and social well-being. If you have fluctuating thyroid levels, you may feel anxious and/or irritable and suffer from mood swings until your hormone levels are stabilised.

You may also feel anger, loss of self-esteem or confidence, or socially isolated, because of the change in the appearance of your eyes. Relationships may be affected – both social and at work. This is hardly surprising as the face and eyes are the most significant point of contact between individuals. TED can change your facial appearance and alter your expression which may affect the way people react to you which, understandably, can be difficult to cope with.

Treatment, which may include surgery, can often improve this; and counselling, or contact with others who have TED, can help you find coping strategies. Contact your local eye specialist or your Patients Organisation for further support.

What treatments are available for people with TED?

In mild cases, if your eyes feel gritty, water a lot and feel uncomfortable in bright lights, then artificial tear drops will help your eyes feel more comfortable and help to protect the surface of your eyes.

These can be used in the form of drops (a watery liquid), gels (thicker than drops and last longer) and ointments (oily lubricants that last for the longest time but may cause

some blurring of vision and are therefore commonly used at night but may also be required in more severe cases).

There are a range of preparations available so if the first option does not work discuss others with your doctor. If the eye drops irritate your eyes, you may need preservative-free drops. Remember to apply the eye drops at least 3-4x/day to ensure efficacy of treatment.

Although the symptoms may worsen for the first 6 to 12 months or so, after that your eyes should become stable or improve. It can take up to two years before the inflammation has gone. Significant inflammation may need treatment with anti-inflammatory drugs, e.g. steroids, which can reduce double vision by helping inflamed eye muscles to move more freely. They can also reduce redness and swelling of the eyes and eyelids. In severe cases steroids can help restore eye sight.

Steroid treatments are sometimes combined with other treatments such as immunosuppressive agents and/or radiotherapy for more effective control of the condition and to avoid relapse. Steroids can be given as tablets but they are more effective and cause less side effects when given intravenously. Unfortunately, however, steroids are not very effective in reducing protrusion of the eyes.

Further information about treatments for TED.

Even after optimal medical treatment of the active stage of TED, some people with TED are left with permanent double vision or a change in the appearance of their eyes in inactive TED. Rehabilitative surgery may help once the inflammation has settled including:

- ‘Decompression’ surgery to create more space behind the eyes when there is pressure on the nerve, or if there is a lot of protrusion of the eyeballs, to allow the eyes to close better and to protect the eyes
- Eye muscle surgery to treat double vision if this cannot be controlled with prisms; and/or
- Eyelid surgery to protect the eyes

Other treatments for TED include prisms attached to spectacles (to help the double vision) or a patch may be required temporarily to cover one eye to alleviate double vision

New treatments for TED

There are also several newer treatments being developed but these are not yet available in most European countries. Many of these treatments have not yet been compared to steroid injections and they are much more costly than steroids, so ongoing research is still needed to understand their place in treating TED. You should ask your specialist doctor if you may be eligible to take part in any clinical trials for these newer treatments.

Other targeted treatments (sometimes called biologic agents), including Teprotumumab (IGF-1 Receptor-blocker), Rituximab (a B-cell–depleting monoclonal

antibody) and Tocilizumab (an interleukin-6 receptor antagonist), widely used in other inflammatory conditions have also been investigated for TED, with varying degrees of clinical efficacy.

Even though these treatments represent progress in the options that are available, they do have limitations, including:

- high cost
- restricted country specific availability outside specialist centres
- potential for significant side effects, including infections, high blood sugar levels (hyperglycaemia) and hearing loss associated with IGF-1R inhibition.

This may mean the treatments remain difficult to access and are not the best choice for all patients. In addition, because these treatments are relatively new, long-term data regarding their safety and lasting effectiveness remain limited. For this reason, clinicians will continue to monitor closely how they work in routine clinical practice. This ongoing review will ensure the treatments remain safe and effective for patients over time.

What should I do if the symptoms get worse?

In less than 5% of people TED becomes very severe. You might experience disabling double vision; the delicate window at the front of the eye known as the ‘cornea’ can develop ulcers if the eyelid cannot close completely and these ulcers can interfere with vision; and, rarely, the ‘optic nerve’ carrying messages to the brain can be compressed, leading to loss of vision. If these complications are diagnosed early, then treatment can be successful.

If you develop any of the following symptoms you should see your doctor without delay and ask for **immediate referral** to a specialist eye centre with experience of treating TED:

- Your symptoms get increasingly worse over a period of several days or weeks
- You have blurred vision which does not improve by blinking or covering each of the two eyes in turn
- You become aware that colours do not appear as bright as they used to, or there is a difference in how bright colours seem when you compare one eye with the other
- You see double when looking forwards or downwards
- You have to keep your head tilted sideways or backwards to avoid seeing double

Some important points….

- There is a lot that can be done to help people with TED, from artificial tear drops to surgery
- Smoking increases your chance of getting TED. Patients with TED who continue to smoke respond less well to treatments. Ask your doctor for advice on how to stop
- Avoid fluctuations in your thyroid levels. Have regular blood tests, aim to keep your thyroid levels within the normal reference range and take your medication regularly
- TED can affect your psychological and social well-being. Don't hesitate to ask your doctor for advice
- Ask your doctor to refer you to a specialist eye centre which has experience of TED, especially if the symptoms become more severe. There should be one in your region

Thyroid problems run in families and if families members are unwell they should be encouraged to discuss with their own GP whether thyroid testing is warranted.

If you have questions or concerns about your thyroid disorder, you should talk to your doctor or specialist as they will be best placed to advise you. You may also contact your local Patients Organisation for further information and support.

© 2026 British Thyroid Foundation (BTF) and the Thyroid Eye Disease Charitable Trust (TEDct). This document is the property of the BTF and TEDct and has been updated and reproduced for use by EUGOGO with permission.

British Thyroid Foundation

Registered Charity No: 1006391, SC046037

www.btf-thyroid.org

The British Thyroid Foundation is a registered charity: England and Wales No 1006391, Scotland SC046037

TEDct CHARITABLE TRUST

www.tedct.org.uk

EUGOGO

www.eugogo.eu