

# Your guide to Thyroid Eye Disease

**Thyroid Eye Disease (TED) 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 or Ophthalmopathy – is an autoimmune condition. It occurs when the body's immune system attacks the tissue surrounding the eye causing inflammation in the tissues around and behind the eye. In most patients, the same autoimmune condition that causes TED also affects the thyroid gland, resulting in Graves' disease. 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, about a quarter 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. 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 **underactive** 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 hayfever 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 hayfever
- Allergies usually cause itchy eyes, whereas TED does not
- Conjunctivitis usually causes sticky eyes, whereas TED usually does not
- TED is often 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 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.

Further information about the effect that smoking has on TED is available at:

**[www.btf-thyroid.org](http://www.btf-thyroid.org)**

**Avoid fluctuations in your thyroid levels** – particularly hypothyroidism. Make sure 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 make sure that your thyroid levels remain normal and steady, 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** – recent 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.

## **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 the British Thyroid Foundation (BTF), The Thyroid Eye Disease Charitable Trust (TEDct), or your local eye centre for further support.

## What treatments are available for people with TED?

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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 (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 so are commonly used at night but may also be required in more severe cases).

Although the symptoms may worsen for the first six 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 steroids, which can be given by mouth or intravenously. Steroids 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, however, are not very effective in reducing protrusion of the eyes.

Unfortunately, some people with TED are left with permanent double vision or a change in the appearance of their eyes. 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

## What should I do if the symptoms get worse?

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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 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 regular experience of TED, especially if the symptoms become more severe. There should be one in every region of the UK

## TEAMeD

### Thyroid Eye Disease Amsterdam Declaration Implementation Group UK

**TEAMeD** is a project supported by eye specialists, thyroid specialists, the BTF and TEDct. It aims to improve care for people in the UK with TED, by putting in place measures to ensure access to information, early diagnosis, appropriate treatment, and access to skilled professionals – endocrinologists and ophthalmologists offering high standards of joint care. The TEAMeD-5 project makes five recommendations to specialists providing treatment and care. These recommendations are listed below so that patients know what to expect in terms of care:

1. **DIAGNOSE** Graves' disease accurately
2. **SCREEN** all patients with Graves' disease for early symptoms and signs of TED
3. **ALERT** patients with Graves' disease to the early symptoms of TED
4. **PREVENT** – reduce the incidence of TED in Graves' disease by smoking reduction, early induction and maintenance of euthyroidism (thyroid function within the normal range) and avoidance of radioiodine in active TED
5. **REFER** – prompt referral of patients who develop TED directly to a regional multidisciplinary clinic with extensive experience of managing TED.

[www.btf-thyroid.org/teamed-5](http://www.btf-thyroid.org/teamed-5)

Endorsed by the organisations represented in TEAMeD

## Further information can be obtained from:

### The British Thyroid Foundation

Tel: 01423 810093

[info@btf-thyroid.org](mailto:info@btf-thyroid.org)

[www.btf-thyroid.org](http://www.btf-thyroid.org)

The British Thyroid Foundation is a registered charity:

England and Wales No. 1006391, Scotland No. SC046037

### The Thyroid Eye Disease Charitable Trust

Helpline 07469 921782

[info@tedct.org.uk](mailto:info@tedct.org.uk)

[www.tedct.org.uk](http://www.tedct.org.uk)

TEDct is a registered charity: England and Wales

No. 1095967, Scotland No. SC042278

Thyroid problems often run in families and if family 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 the British Thyroid Foundation for further information and support, or if you have any comments about the information contained in this leaflet.

### Endorsed by:

The British Thyroid Association - medical professionals encouraging the highest standards in patient care and research

[www.british-thyroid-association.org](http://www.british-thyroid-association.org)

The British Association of Endocrine and Thyroid Surgeons - the representative body of British surgeons who have a specialist interest in surgery of the endocrine glands (thyroid, parathyroid and adrenal)

[www.baets.org.uk](http://www.baets.org.uk)

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