

# Thyroid eye disease (TED)

Ophthalmology Department

Information for Patients

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## What is thyroid eye disease (TED)?

Thyroid eye disease is an autoimmune disease.

It usually happens if you have an overactive thyroid gland.

It can happen in people with a normal or underactive thyroid gland.

Early in the disease the tissues around your eyes become swollen. This makes your eyes seem to stare or be pushed forwards (also known as proptosis).

In some people the muscles around the eyeballs are also swollen.

## What are the signs and symptoms?

- Starey eyes or proptosis
- Irritation/ grittiness and redness of the eyes
- Double vision (diplopia)
- Blurred vision
- Pain behind your eyes or with eye movement
- Excessive watering of the eyes
- Puffy eyelids

**Health information and support is available at [www.nhs.uk](http://www.nhs.uk)  
or call 111 for non-emergency medical advice**

Visit [www.leicestershospitals.nhs.uk](http://www.leicestershospitals.nhs.uk) for maps and information about visiting Leicester's Hospitals  
To give feedback about this information sheet, contact [InformationForPatients@uhl-tr.nhs.uk](mailto:InformationForPatients@uhl-tr.nhs.uk)

## How can TED be treated?

During the day, lubricating eye drops (for example, artificial tears) can be used to help with gritty eyes. At night an ointment (for example, Xailin night, hylonight or similar) can help.

Using extra pillows at night to raise your head can reduce puffiness around the eyes.

A cool compress can help in the morning.

Wearing sunglasses or tinted lenses can help if your eyes are more sensitive to sunlight.

A wide brimmed hat or cap can also reduce sensitivity.

Double vision can happen when the muscles that move the eye swell and become stiff. This can affect eye movement. We can fit temporary stick on prisms on your spectacles, which may help by joining the 2 images.

If your vision gets worse it may need treatment to ease pressure on the optic nerve. This can involve treatment with high dose steroids, radiotherapy or an operation to reduce the pressure on the nerve (orbital decompression surgery, ([www.bopss.co.uk/public-information/common-conditions/orbital-decompression-surgery/](http://www.bopss.co.uk/public-information/common-conditions/orbital-decompression-surgery/))).

Also, in some cases your doctor will refer you to a specialist to consider the use of immunotherapy to help control your TED.

## Can I do anything to stop TED from getting worse?

### If you are smoker, give it up.

Ask your doctor for advice on how to stop, or join a stop-smoking programme. Patients with TED who continue to smoke respond less well to treatments, but the response can improve soon after giving up smoking.

### Keep control of your thyroid function.

Even though treatment for your thyroid condition may not stop or improve TED, it is important to keep your thyroid hormone levels at the correct levels. Fluctuation in levels can worsen TED

## Prognosis

About 80% of thyroid eye disease cases settle with topical lubricant eye drops. This is known as conservative management.

About 5% of TED cases need IV medications followed by oral tablets (systemic steroids) or immune therapy.

A small number of these also need surgery to keep their vision.

## How does TED develop?

Thyroid eye disease begins with a first phase. It lasts a few months.

The eye disease becomes progressively worse, until it reaches a peak and then it begins to improve.

These changeable phases can last 1 to 2 years until the chronic or “burnt-out” stage, when then further change is highly unlikely.

Once settled, some people are left with eye or eyelid that are not in line and need surgery to improve this. The result can be an appearance that they are more comfortable with and is closer to how they looked before.

## Coping with changes to your appearance

It is known that for some people, TED can affect their psychological and social well-being.

You may feel anger, loss of self-esteem or confidence, or socially isolated, because of the change in the appearance of your eyes.

TED can change your facial appearance and alter your expression. This may affect the way people react to you which, understandably, can be difficult to cope with. Some of the effects of TED can improve with strict medical control and the passage of time, but sometimes the changes are more persistent.

Counselling, or contact with others who have TED, can help you find ways to cope



## More support

Some of the following organisations might be helpful:

- Thyroid Eye Disease Charitable Trust (TEDct) can help put you in touch with other people who have had similar experiences which is often helpful. <http://tedct.org.uk/>
- The British Thyroid Foundation [www.btf-thyroid.org/](http://www.btf-thyroid.org/) has a network of telephone support volunteers that can help. They also have closed Facebook groups for people with TED. You can email them at [info@btf-thyroid.org](mailto:info@btf-thyroid.org) if you would like their support.
- The charity Changing Faces ( [www.changingfaces.org.uk/](http://www.changingfaces.org.uk/) ) also offers a support service for anyone has a condition or injury that affects their appearance.
- RNIB Counselling and Wellbeing team ([www.rnib.org.uk/living-with-sight-loss/community-connection-and-wellbeing/sight-loss-counselling/](http://www.rnib.org.uk/living-with-sight-loss/community-connection-and-wellbeing/sight-loss-counselling/)) can offer telephone counselling to anyone affected by sight loss or an eye condition.

## Contact details

Oculoplastics Team, Leicester Royal Infirmary:

Monday to Friday, 8am to 5pm - Tel: 0116 204 7971

Eye Casualty Department (for advice): 0116 258 6273

Monday to Friday - 8.30am to 4.30pm.

Saturday, Sunday and bank holidays - 8.30am to 12.30pm

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Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

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