# Thyroid eye disease

Thyroid eye disease (TED) is an eye condition that usually occurs when you have a problem with your thyroid gland. It causes the eye muscles, eyelids, tear glands and soft tissues in and around your eye socket to become inflamed. The period of inflammation and swelling of these tissues is called the “active stage”. The active stage may resolve on its own, but sometimes needs treatment so it’s important to have any symptoms of TED checked early. It commonly lasts about six months to two years. After this, the inflammation settles, and this is known as the “inactive” or “burnt out” stage.

It may also be called thyroid associated ophthalmopathy (TAO), thyroid orbitopathy, Graves’ orbitopathy or Graves’ ophthalmopathy (GO).

## Your thyroid gland

Your thyroid gland is located in your neck and produces thyroid hormones that help regulate metabolism (the speed with which the cells of your body work). Occasionally it can produce too much thyroid hormone (overactive thyroid) or too little (underactive thyroid). If too much thyroid hormone is produced, the increased activity of your body cells or body organs may lead to, for example, quickening of your heart rate or increased activity of your digestive system. If too little thyroid hormone is produced, the cells and organs of your body slow down so that, for example, your heart rate may be slower than normal, or your digestive system works sluggishly.

TED most commonly occurs when you have an overactive thyroid but can also occur with an underactive thyroid or even when the thyroid is working normally.

## Autoimmune disease and the thyroid

The most common cause of an overactive thyroid gland is Graves’ disease, which is an autoimmune condition. Our immune system normally makes small proteins (antibodies) to combat bacteria and other ‘germs’ that are foreign to us. If you have an autoimmune condition, your immune system acts against normal tissues of your body. The reason why this happens isn’t entirely clear at the moment.

In Graves’ disease, an autoimmune response produces antibodies that cause the thyroid gland to make more of its hormones. At the same time, the antibodies attacking your thyroid gland also attack the soft tissues behind your eyes (orbital contents), leading to swelling and inflammation.

Further information about thyroid problems and how they can affect your body is available from the British Thyroid Foundation (their contact details can be found at the end of the factsheet).

## How can TED affect my eyes?

The way that TED can affect your eyes can vary between different people. The most common way TED affects the eyes is by causing symptoms of watering, grittiness, and soreness. You may also find that bright lights are uncomfortable.

These symptoms are caused by inflammation and dry eye. Dry eye can happen when your lacrimal gland, which produces the tears in your eyes, is affected by TED.

Your eyes may also look more prominent. In particular, the upper eyelid rises to a higher position than normal, known as eyelid retraction. This can make more of the white of your eye visible, giving a ‘staring’ appearance. Because your eyes are more exposed, this can also cause symptoms of dry eye.

If the soft tissues around your eye become inflamed, they become red and swollen and cause some changes to your eyes:

* Your eyelids can become puffy and red (lid swelling), which is often more obvious in the morning.
* The muscles and fat (the soft tissues) behind your eyeball can swell, pushing your eyes forward so that they ‘bulge’ (called ‘exophthalmos’, or ‘proptosis’).
* Both eyelid retraction and exophthalmos can make your dry eye symptoms worse. This is because more of your eye’s surface is exposed and also because these changes can mean that your eyelids are unable to blink or close fully.
* If the muscles that move your eyeball become swollen, this can mean your eyes are unable to move together and equally as they should, causing double vision (diplopia). You may only have double vision when looking in one particular direction or you may have double vision all the time, whatever direction you are looking.
* Your orbits (eye sockets) may become painful, particularly when your eyes move.

Most people only get a mild form of TED, although the symptoms can be difficult to cope with. You may have dry eye which can usually be managed well with lubricating eye drops. You may have some eyelid retraction or exophthalmos and any double vision you have may come and go.

Many people may only experience these changes mildly and they can be temporary and short-lived. However, they can still affect your quality of life. Often the symptoms of TED get worse for six months to a year, but after that the appearance of your eyes should improve.

For some people, it can take up to two years before the inflammation has completely gone. The longer the active stage lasts, the less likely it is for the appearance of your eyes to go completely back to normal again and some other symptoms such as double vision may persist in the long term.

## How can TED affect my sight?

If the muscles that move your eyeball become swollen this can affect how well your eyes are able to move together. This can cause a squint (where the eyes do not look in the same direction as each other) and double vision (diplopia). If your eyes don’t quite point in the same direction, then each eye sends a slightly different visual message to your brain. Your brain isn’t able to combine the different pictures and “sees” two of everything. These two images may not be completely separate but may overlap slightly on top of each other. Double vision can make activities like reading difficult and makes driving dangerous.

It’s illegal to drive with double vision that isn’t controlled. If you develop double vision, then you need to inform the Driver and Vehicle Licensing Authority (DVLA) and usually they will contact your ophthalmologist for a medical report. If your double vision becomes controlled with prisms in your glasses at a later date, then the DVLA may say it’s OK for you to drive again. If you don’t inform the DVLA of your double vision it could invalidate your insurance and you would also be driving illegally.

In severe TED, the pressure inside the orbits increases, causing a dull ache. This pressure can squash (compress) the optic nerve. Your optic nerve carries the messages from your eye to your brain and if it is compressed it can cause problems with your sight. Optic nerve compression can cause blurred vision and dimming of your sight. It may cause colours to begin to look “washed out” or dull, and your visual field (your side, or peripheral, vision) may close in to create tunnel vision.

If you notice these changes in your vision it’s important to get medical attention straight away, so that the pressure on your optic nerve can be reduced quickly, before permanent damage occurs. Very few people (about 5%) develop this more advanced stage of the TED condition.

In very severe cases of TED, your eye may become exposed or dry for a long time, which can cause your cornea (the clear front surface of your eye) to become damaged. This is known as exposure keratopathy and can cause reduced vision, but this is rare.

## How is TED diagnosed?

If you have a problem with your thyroid, especially if you have an over-active thyroid, it’s important to be aware of the possibility of developing TED and its symptoms. TED may not happen at the same time as your initial thyroid problem is diagnosed. It can develop at any time afterward or sometimes even before your thyroid problem has been found.

Most people with a thyroid problem will only ever develop mild symptoms of TED. If you have signs of TED, you should be referred to an ophthalmologist (hospital eye doctor) who may work with your endocrinologist (a specialist in the hormone systems of the body) to help manage your condition.

Your ophthalmologist may be able to diagnose TED just by examining your eyes but sometimes you may also need a scan of your orbits to check for any swelling. If at any time you begin to notice your sight getting worse, you should have your eyes checked at the hospital straight away.

## Can treatment for my thyroid problem affect my eyes?

Your thyroid problem will normally be looked after by an endocrinologist and you will be given treatment to keep your thyroid hormones at the correct level. An over-active thyroid is firstly treated with anti-thyroid drugs, which may be followed by surgery or radioactive iodine treatment. Your eyes can be affected by both overactivity and underactivity of the thyroid gland, so it is important that your hormone levels are kept as normal as possible if you have TED.

Anti-thyroid medication and surgery don’t usually affect what’s happening with your eyes, provided your thyroid function remains well controlled. Some evidence suggests that if you have active TED, radioiodine treatment for an over-active thyroid may make any eye problems worse. This is why this treatment option may not be suggested to you if you have active TED. If you have active TED or are felt to be at risk of TED, then you might be given a course of steroid medication around the same time as your radioiodine treatment to help prevent any worsening of eye problems. If you don’t have TED, then radioiodine treatment is a very successful treatment option for your over-active thyroid.

Sometimes even though your thyroid hormone levels become stable, your TED may not improve. This is because, in most cases, both your thyroid condition and your TED will run their own separate course.

## How can TED be managed during the active stage?

During the active stages of TED, the treatments are aimed at improving your symptoms and protecting your eye while the active stage of the condition runs its course. Symptoms can fluctuate during the active phase, which can last months or a couple of years. If you smoke, your team will encourage you to stop (more information can be found in the section below “What can I do to help?”).

Most commonly, during the active stage, treatment involves treating dry eyes or double vision. For most people, this is all the treatment they will need at this stage and the condition won’t get any more advanced than this.

Much less commonly, where vision is at risk, your ophthalmologist may recommend ‘immunosuppressant’ treatment, usually steroids, to help reduce the inflammation. This will usually be given as a weekly steroid infusion into a vein over a period of 3 months, but may also be given in the form of daily tablets. Other immunosuppressive medication may also be needed. Orbital radiotherapy treatment may also be considered to treat the tissues around the eyeball and prevent optic nerve damage. The earlier these treatments can be given, the more they can help prevent the condition from progressing and protect your sight.

In very severe cases, emergency orbital decompression surgery may be needed – this operation involves removing some of the bone and/or fat in your eye socket to provide more room for the swollen muscles, and to take the pressure off the optic nerve.

All these treatments aim to avoid permanent damage to the optic nerve. Very few people have TED that progresses to a stage where these treatments are needed.

### Managing dry eye

Dry eye can cause your eyes to feel dry and gritty. Lubricating eye drops, also known as artificial tears, can help to make your eyes feel more comfortable and help to prevent your cornea becoming damaged from being dry.

Thicker gel type drops can be used to help lubricate the eyes for longer and ointments can help lubricate the eyes overnight. If your eyelids aren’t able to close fully, your ophthalmologist may suggest gently taping your eyelids closed at night to prevent your eyes from drying out. Although your eyes may be described as ‘dry’, they can sometimes be watery. Using artificial tears can make your eyes feel more comfortable as well as reducing the watering.

### Managing double vision

An orthoptist is an eye professional who specialises in double vision and they will usually be involved in your treatment if you develop this. Different treatments such as occlusion, prisms and surgery may be used depending on whether your TED is active or inactive and how severe your symptoms are.

#### Occlusion

One of your eyes can simply be covered up with an eye patch or an opaque filter that can be placed on your glasses so that the brain only receives an image from one eye. This is usually used as a temporary solution during the active stages of TED, where the double vision may be unstable.

#### Prisms

Prisms work by bending light in a direction which compensates for the angle between the eyes. They can be tailored to match the angle between your eyes, and fixed to spectacles.

Temporary stick-on prisms, known as ‘Fresnel’ prisms, may be used until the angle is stable, at which point prisms can be incorporated into your normal spectacles by an optometrist.

During the active stages of TED, your double vision may be temporary and unstable, so prisms and occlusion may be the only treatments possible. As TED becomes inactive you might have some double vision that remains, and this may be treated with surgery to re-align the eyes so that they point in the same direction and give you single vision.

### What can I do to help?

During the active stages of TED, there are some things you can do that might help your symptoms.

Puffiness around the eyelids tends to be worse in the mornings after lying flat. Sleeping propped up on extra pillows can help reduce the puffiness and congestion around your eyes.

#### Use artificial tear eye drops

Symptoms of dry eye can be managed by using eye drops to moisten your eyes and they can usually be used frequently or as much as needed.

Also trying to avoid, or protect your eyes in windy or dusty environments, can help, as these conditions might irritate your eyes; this can be done by wearing glasses or protective eyewear.

You may also find that taking regular breaks when doing activities such as reading, watching television and using computer screens can help keep your eyes feeling more comfortable.

#### Keep control of your thyroid condition

Even though treatment for your thyroid condition may not prevent or improve TED, it’s important to keep your thyroid hormone levels at the correct levels. 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.

#### Stop smoking

Smoking increases your chances of developing TED and can also make it dramatically worse. Also, treatment is less effective in people with active TED who smoke. Because e-cigarettes also contain nicotine, these are also thought to increase your risk. Talk to your GP about getting help to quit. This is probably the most important thing you can do if you are a smoker.

#### Selenium supplements

Some evidence suggests that taking selenium supplements (200 micrograms daily) may help people with mild thyroid eye disease. It’s important to check with your GP whether taking supplements is safe for you, especially if you are taking other medications as well.

#### Wearing sunglasses

If you find bright lights uncomfortable, reducing the amount of light entering your eyes by wearing sunglasses or tinted eye shields can help.

## How can the long-term effects of TED be managed when it has ‘burnt out’?

In most people, the active inflamed stage of TED resolves (burns out) within about two years. In a few people, active TED can recur again after it has burnt out, although this becomes less likely the longer that the condition has been inactive.

Treatment after TED has burnt out is aimed at dealing with any remaining double vision, providing better eyelid protection for your eyes and improving the appearance of your eyes.

The swelling caused by TED can often improve once the active stage has passed, meaning there can be some improvement in the appearance of your eyes. However, you might be left with some changes caused by the swelling, such as eyelid retraction (where the upper eye lid is pulled upwards causing a staring appearance), exophthalmos (bulging of the eyes), large eyelid bags or double vision. This is because the tissues that have been inflamed are often less flexible once the active phase of the condition has passed, and they’re not able to return to their original position.

If this is the case, then you may wish to decide whether or not to have further surgery to help improve these changes. Sometimes the problems that are left may only be minor and you may feel treatment is not necessary, or that the risks of the surgery outweigh the problems that you have.

If surgery is needed, it is usually done in a particular order, so orbital decompression surgery to reduce the amount of proptosis (if needed) is the first priority, then surgery for double vision, and lastly eyelid surgery (for lid retraction, for example). It’s important to understand that often several surgeries will be required to manage the changes of TED and typically these operations are carried out over about 18 months to two years.

Orbital decompression surgery allows the eyes to rest further back in your eye socket. This can improve the appearance of ‘bulging’ or exophthalmos. Bone, and occasionally fat, within the eye socket is removed. One of the main risks of this surgery is the development or worsening of double vision, so you may expect to need surgery to your eye muscles as well after this. There is also a small risk of serious sight problems developing as a consequence of this surgery. Your ophthalmologist will explore the risks as well as the benefits of this surgery with you.

If you are left with stable, persistent double vision, surgery on the muscles that move the eyes can help improve the alignment of the eyes and reduce or get rid of double vision. Eye muscle surgery may alter the position of the eyelids so you may need lid surgery as well after eye muscle surgery.

Lid surgery will aim to correct the position of the upper and lower eyelids, allowing them to close properly and protect your eyes as they should. TED can also often leave unsightly bags around the lower and upper eyelids and these can also be removed surgically.

In order to have surgery for TED, it’s important that the active stage of your condition has burnt out and that your thyroid condition itself is stable. The surgery offered for TED aims to restore the position and appearance of your eyes to as near to normal as possible.

## Coping with changes to your appearance

It is well known that TED can affect your 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. Your mood can also be affected by medications you may be taking, such as steroids. 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.

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.
* The British Thyroid Foundation 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 also offers a support service for anyone experiencing a condition or injury that affects their appearance.
* Our RNIB Counselling and Wellbeing service can offer telephone counselling to anyone affected by sight loss or an eye condition.

## Sources of support

Whether you have just been diagnosed with thyroid eye disease or have been living with it for a while, at RNIB, we are here to help and support you at every step.

**Royal National Institute of Blind People (RNIB)**

105 Judd Street

London

WC1H 9NE

The RNIB Helpline is your direct line to the support, advice and products you need. We'll help you to find out what's available in your area and beyond, both from RNIB and other organisations.

Whether you want to know more about your eye condition, buy a product from our shop, join our library, find out about possible benefit entitlements, be put in touch with a trained counsellor, or make a general enquiry, we're only a call away.

RNIB Helpline  
Tel: 0303 123 9999  
Email: [helpline@rnib.org.uk](mailto:helpline@rnib.org.uk)

**The Thyroid Eye Disease Charitable Trust (TEDct)** can provide information, care and support to those affected by thyroid eye disease.

www.tedct.org.uk   
Tel: 07469921782

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

**The British Thyroid Foundation** provides information and support for people with any kind of thyroid problem, and their families. They have a network of local support groups and telephone support volunteers that can talk to you. They also have Closed Facebook groups for people with TED and hyperthyroidism.

www.btf-thyroid.org

Tel: 01423 810093

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

**Changing Faces** supports people who have any condition or injury that affects their appearance.

Support Information & Advice line: 0300 012 0275  
Email: [support@changingfaces.org.uk](mailto:support@changingfaces.org.uk)

## Other useful contacts

**Driver and Vehicle Licensing Agency (DVLA)** can give you advice on sight standards for driving.  
Drivers' medical enquiries  
DVLA  
Swansea  
SA99 1TU

Tel: 0300 790 6806

**British Oculoplastics Surgery Society** have useful information on their website about having surgery on your eyelids and around your eyes.

[www.bopss.co.uk](http://www.bopss.co.uk)

**BIOS (British and Irish Orthoptic Society)**

Orthoptists are professionals who specialise in the diagnosis and management of eye movement disorders.

**www.orthoptics.org.uk**

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