

Thyroid eye disease (TED)



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Synonyms:

Graves' ophthalmopathy, thyroid ophthalmopathy, thyroid associated ophthalmopathy

This information leaflet briefly covers the following issues in TED:

What is TED?

When does TED occur?

What are the symptoms of TED?

What is the treatment of TED?

Surgery in TED

Details, indications, recovery and risks

(See also [information leaflet on Orbital Decompression](#))

Summary of treatment options

Support for patients with TED

Qu: What is thyroid eye disease?

Abnormal activity of the thyroid gland (be it over- or under-action), may lead to inflammation in the delicate tissues within the orbit (eye socket). This inflammation is a form of immune 'auto-reactivity', but the exact factors which link thyroid disease and TED remain uncertain. TED usually affects both eyes (although may be asymmetrical in degree), with women being affected more often than men. The diagnosis and severity of TED is made by detailed clinical examination; there is no investigation which alone allows the clinician to diagnose or monitor disease.

Qu: When does TED occur?

The inflammatory period in TED can last up to two years, and may occur:

- (i) any time after a diagnosis of thyroid imbalance, or:
- (ii) before any thyroid changes are diagnosed, and, rarely:
- (iii) without there *ever* being evidence for abnormal thyroid function

Qu: What are the symptoms of TED?

Most patients with TED experience only mild symptoms, such as dryness or surface irritation, and others with the mildest form of TED may be unaware of any ocular involvement at all. In those with significant inflammatory changes, the following symptoms may occur:

1. Uncomfortable eyes
2. Watery eyes
3. Red eyes
4. Puffy upper or lower eyelids
5. Deep orbital ache
6. A 'staring' appearance due to retraction of the upper eyelid, a bulging eye (proptosis), or both.
7. Double vision, 'ghosting' of images, or eye ache with eye movements.
8. Reduced depth of colour (reds appearing 'greyish')
9. Visual loss or blurring

Qu: What is the treatment of TED?

Mild disease

In the great majority of people, TED follows a mild course and topical lubricants and / or anti-inflammatory drops alone may suffice. In all patients, thyroid control should be optimised, and smoking – a known risk factor for severe disease – should be stopped. Oral Selenium is now considered beneficial in mild forms of disease.

Significant 'active' disease

Although the inflammatory phase in TED is typically self-limiting, lasting between one and two years, active orbital inflammation must be treated to avoid debilitating long-term complications (these including eyelid retraction, double vision, proptosis and loss of vision). Current treatments to 'quieten down' active orbital inflammation include oral or intravenous steroids (or other immunosuppressants such as Azathioprine), and low dose orbital radiotherapy, which is considered to reduce the need for (and therefore risks of) systemic immunosuppressive treatment.

Sight-threatening TED

A very small proportion of patients suffer with marked inflammation and do not respond adequately to the treatments mentioned above. In these patients, urgent surgical intervention (within days to weeks) may be necessary to protect vision. This surgery is called 'orbital decompression', because it relieves the inflammatory pressure around the eye and the optic nerve behind the eye.

Stable changes in TED

Other surgery, including operations to treat bulging eyes (proptosis), double vision and abnormal eyelid height or fullness, are usually performed once the disease has settled. Since orbital decompression surgery (to treat stable proptosis) can affect both double vision and eyelid appearance, this surgery, when required, should be performed before muscle or eyelid surgery.

Qu: When is orbital decompression required?

Orbital decompression is indicated in the following circumstances:

1. Optic neuropathy (visual loss) not responding adequately to immunosuppression – urgent surgery may be required.
2. High orbital pressure with engorged blood vessels and raised intraocular pressure (secondary glaucoma) – surgery for the ‘hydraulic orbit’ may be required within a matter of months.
3. Stable proptosis (‘bulging’ eyes) – if desired, ‘aesthetic’ decompression surgery is planned once the degree of proptosis is stable for a minimum of six months, with optimum thyroid control and cessation of smoking.

Qu: What does orbital decompression surgery involve?

The purpose of surgery is to relieve orbital pressure (and thus improve orbital blood perfusion), and increase the available space for the orbital contents (allowing the eye to settle back to a more normal position within the socket).

Surgery is performed under general anaesthetic, typically with one to two days stay in hospital following surgery before being discharged home. The amount of surgery required is influenced by the severity of disease and degree of proptosis. Of the four ‘walls’ of the orbit, the medial (inner), lateral (outer) and inferior (floor) can be decompressed. A ‘medial’ decompression is usually done with a very fine incision lying between the skin of the inner part of the eyelids and the eyeball. The outer wall and floor can be decompressed via a 10 – 15 mm incision in the skin of the outer corner of the eyelids, this being placed within the natural skin creases.

Qu: What is the rate of recovery after orbital decompression?

Orbital decompression is a *major* operation, and the scale of surgery should not be judged by the small incisions involved. Thus, although the skin incision settles over a few weeks, natural repair of the deeper tissues can take up to 9 months, and accounts for occasional deeper ache or discomfort during this healing phase.

Immediately after surgery a firm pad is placed over the eye(s), and is removed by the doctor or nurse the following morning on the ward. Oral antibiotics, a tapering course of oral steroid tablets, and eye drops are provided before the patient goes home, typically one to two days after surgery.

Swelling and some bruising of the eyelids can develop in the week following surgery, and this can take up to a month to settle completely. As the natural drainage of tissue fluid occurs from the outer corner of the eyelids, fullness of both the upper and lower eyelids is more common after surgery to decompress the lateral wall or the floor.

Finally, double vision may occur, or worsen, during this healing period, and can require subsequent surgery to align the eyes. Thus, driving and working following

surgery may be delayed by several weeks, and this should be taken into account when planning treatment.

Qu: What are the possible complications of orbital decompression? (see also leaflet on Orbital decompression)

As with all surgery, side effects of orbital decompression include infection, scarring, and swelling. Specific side-effects can include a decline in vision, double vision and a change in lid height or position.

With lateral wall decompression, hollowness over the bony lateral wall and a sensation of ‘movement’ with eating can rarely occur – these tend not to require intervention.

With decompression of the orbital floor (this being undertaken only in patients with more severe proptosis), numbness over the upper cheek and upper front teeth can occur, and in the great majority of patients (over 90 %), this recovers completely.

All forms of decompression surgery carry a risk of permanent visual loss, the risk of this (per eye) being in the region of 1 in 1000. In patients with visual loss *before surgery* visual recovery may be incomplete.

The following applies to 2- and 3-wall decompression only:

Because drainage of the air sinuses around the eye may be temporarily affected, nose blowing, flying and scuba-diving **MUST** be avoided for at least 3 weeks after surgery. Rarely, surgery to improve sinus drainage is required after orbital decompression where medical treatments do not help.

With all surgery, there remains a *minute* risk of neurological injury, and indeed to life itself, this either due to anaesthesia, surgery, or a combination of both. Such devastating complications have not occurred to patients undergoing decompression surgery at Moorfields Eye Hospital, but, as with all surgery, the possible risks and benefits are very carefully considered with each and every patient before surgery is scheduled.

Summary of treatment options for patients with symptomatic thyroid eye disease

Note: The great majority of people with TED have only mild disease, and may require only topical medication as outlined below.

(LA = local anaesthetic (which may include sedation), GA = general anaesthetic)

Thyroid control and cessation of smoking in all cases

Mild surface inflammation

- Topical lubrication
- Topical steroid drops (tapering short course)
- Oral Selenium

Orbital inflammation

- Oral or intravenous immunosuppression
- Low dose orbital radiotherapy
- Orbital decompression for visual loss if above measures inadequate (GA)

Stable proptosis (GA)

- Lateral wall decompression (single wall)
- Lateral and medial wall decompression (2 wall)
- Lateral, medial and floor decompression (3 wall)

Double vision

- Immunosuppression and low dose radiotherapy during the active phase
- Incorporation of an optical 'prism' within the glasses for small degrees of stable squint.
- Botulinum toxin injection to align muscles (LA)
- Squint surgery in stable cases (GA).

Stable eyelid changes

(i) Bulky upper or lower eyelids:

- Debulking of abnormally bulky tissues (once proptosis addressed – LA or GA)

(ii) Upper eyelid retraction:

- Eyelid lowering (LA)

(iii) Lower eyelid downwards displacement (excess 'white' above the lower eyelid):

- Decompression if proptosis present (*GA*)
- Elevation of the eyelid with a graft from the hard palate (if displacement persists even after decompression performed) (*GA*)
- Elevation of the eyelid using specific biological materials (*LA or GA*)

LINKS

I suffer from TED - who else can I talk to?

(1) Thyroid Eye Disease Charitable Trust

The Thyroid Eye Disease Charitable Trust is run by patients and clinicians, providing information, care and support to those affected by thyroid eye disease.

Contact Details

<http://www.tedct.co.uk>

ted@tedct.co.uk

PO BOX 1928, Bristol, BS37 0AX, UK

0844 800 8133

(2) British Thyroid Foundation

The British Thyroid Foundation (BTF) supports people with thyroid disorders and is for anyone who wants to know more about thyroid disease in general.

Contact Details

www.btf-thyroid.org

info@btf-thyroid.org

British Thyroid Foundation, 2nd Floor, 3 Devonshire Place, Harrogate, HG1 4AA, UK

01423 709707 / 709448

(3) Thyroid federation international

Thyroid federation international (TFI) is an umbrella organization for thyroid patient organisations all over the world.

Contact Details

www.thyroid-fed.org

tfi@thyroid-fed.org

P.O. Box 471, Bath ON K0H 1G0, Canada