

## Patient information leaflet

# Orbital Decompression for Thyroid Eye Disease (TED) (with particular reference to lateral wall orbital decompression)

These notes are intended for your guidance and answer many of the questions asked by people with thyroid eye disease (TED). If any of your questions remain unanswered, feel free to ask Miss Mellington in the clinic.

## What is Thyroid Eye Disease?

This is a condition of the eyes characterised by a tendency for the eyelids to open too far (lid retraction) and for the eyes (globes) to be pushed forwards (so-called "proptosis"). It is often associated with red and irritable eyes that tend to water. Eye movements can also be reduced and this can cause double vision, either intermittently at the extremes of gaze or (more rarely) in all positions of gaze. In a few cases the optic nerve, carrying the visual signals back to the brain, can be compressed and this leads to reduced vision.

The eye changes are generally similar on the two sides, but very rarely one side can be affected much more than the other. Although most people with TED have a history of an over- or an under-active thyroid gland, this is not always the case and some people with characteristic eye disease never have an abnormal blood test.

## Why do the Changes Occur in Thyroid Eye Disease?

Inflammation of the tissues in the eye-socket (orbit) causes the signs of TED, but the reason for the inflammation is unclear. Inflamed tissues become swollen and congested and, within the orbit, this causes the proptosis and sore/red eyes. Swelling of the eye muscles reduces their

ability to shorten and lengthen, thereby affecting eye movements. If the muscles get very swollen, they can compress the optic nerve at the back of the orbit and the eyesight will gradually fade away.

## What Can I Do to Help Prevent or Improve the TED?

At present there are four factors known to affect the outcome for TED: Two of them (age and sex) are hard to affect! The other two factors – which can be controlled – are the degree of control of the thyroid gland activity (needs regular checking by blood tests) and smoking.

In recent years it has become evident that smoking seriously worsens the outcome for TED and carries a significant risk of blindness. If you smoke, you should stop (or

at least drastically reduce) this habit and please see your General Practitioner if you need help with this.

## How can TED Treated?

Mild TED eye disease might require no treatment, or just some lubricant eye drops to reduce discomfort of the eyes. Most cases of TED are mild and self-limiting over a few years.

Severe inflammation may need to be damped down as it can otherwise lead to problems both during the inflamed phase and with scarring of tissues as the inflammation settles. The inflammation can be reduced by the use of powerful drugs, such as steroids, or by low doses of radiotherapy (X-ray therapy). Radiotherapy is similar to that used for treatment of tumours but, with TED, is used at a much lower dosage and so side effects are almost unknown.

If the eyesight is impaired due to pressure on the optic nerve (so called "optic neuropathy"), it may be necessary to perform urgent orbital decompression to prevent permanent loss of vision. Orbital decompression involves removal of some bony walls of the orbit (they do not need to be replaced) and their removal creates more space for the inflamed orbital tissues in most cases, relieving the compression of the optic nerve and allowing a recovery of sight.

Mild proptosis (and/or marked fullness of the lids) can be treated with lateral wall decompression. Here extra space is created by removing part of the outer (lateral) wall of the orbit. Decompression is best avoided where proptosis is minimal and instead, squint surgery (surgery on the eye muscles) can be used to improve any double vision, or eyelid surgery may be used to improve the appearance or the eyelid closure.

Two or three-wall orbital decompression is of particular value in improving the appearance where there is significant proptosis or gross thickening of eyelid tissues in a "tight" orbit – even where there is no visual loss due to optic neuropathy

## What is Lateral Wall Orbital Decompression?

This is where part of the outer bony wall of the orbit is removed surgically, allowing some backward movement of the globes in the eye-sockets – between 2 to 4 mm are typical values. The surgery is performed under a general ("full") anaesthetic, through about a 12mm incision at the outer angle of the eyelids and the scar rapidly fades into the natural creases. If removal of the lateral wall is not sufficient we will, in some cases, proceed to remove the inner wall of the socket to increase the reduction of proptosis – although this "balanced" two-wall decompression is associated with a higher rate of diplopia (double vision) after surgery.

Any decompression surgery is a fairly major procedure and the small size of the incision must not give the idea that this is a minor operation. It involves admission to hospital for 1 night, general anaesthesia, and about 1.5 hours of operating time for

each side. There will be some bruising, swelling and relatively mild discomfort after surgery and it will be necessary to take a painkiller such as paracetamol.

Rarely there can be slight double vision (diplopia) immediately after surgery – due to swelling of eye muscles – but this almost always settles within a few days. The almost complete absence of persistent new diplopia as a complication of surgery is the major benefit of lateral wall decompression.

Despite a reduction in proptosis with decompression, any tendency to upper eyelid retraction tends to persist after surgery. This persistent retraction may require the use of lubricant eye drops or later eyelid surgery, which is typically performed as an outpatient under local anaesthesia. A very rare complication of surgery is some weakness in closing the upper eyelid and/or in raising the eyebrow. Very rarely there can be a significant asymmetry in the result of decompression, or an over-correction with one eye set too far back within the orbit.

# **Further information**

# 1. Thyroid Eye Disease Charitable Trust

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

PO BOX 1928, Bristol, BS37 0AX, UK Website: <u>http://www.tedct.co.uk</u> Email: <u>ted@tedct.co.uk</u> Tel: 0844 800 8133

# 2. British Thyroid Foundation (BTF)

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

British Thyroid Foundation, 2<sup>nd</sup> Floor, 3 Devonshire Place, Harrogate, HG1 4AA, UK Website: <u>www.btf-thyroid.org</u> Email: <u>info@btf-thyroid.org</u> Tel: 01423 709707 or 01423 709448

# 3. Thyroid Federation International (TFI)

Thyroid Federation International is an umbrella organisation for thyroid patient organisations all over the world. PO BOX 471, Bath ON K0H 1G0, Canada. Website: www.thyroid-fed.org Email: tfi@thyroid-fed.org

# 4. EUGOGO- European Group of Graves Orbitopathy

Website: www.eugogo.eu

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## Acknowledgment

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