



## **Patient information leaflet**

### **Orbital decompression for thyroid eye disease (with particular reference to ‘balanced’ two-wall and 3-wall orbital decompression)**

#### **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 may be reduced. 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 “throttle” 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 “throttling” 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, where extra space is created by removing part of the outer (lateral) wall of the orbit; removing this wall has the lowest rate of complications and, in most cases, provides a useful reduction in the signs of TED. Where proptosis is minimal, decompression might be best avoided and, instead, squint surgery (surgery on the eye muscles) may be used to improve any double vision, or eyelid surgery may be needed 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 three-wall orbital decompression and what is “balanced” two-wall decompression?**

This is where three of the four bony walls of the orbit are removed surgically, allowing considerable backward movement of the globes in the eye-sockets – between 6mm and 15mm are typical values. The surgery is performed under general anaesthetic, through a small incision at the outer angle of the eyelids and the scar rapidly fades into the natural creases.

With “balanced” two-wall decompression, we avoid removing the orbital floor (reducing the chance of double vision after surgery) and we use this for lesser degrees of proptosis.

The surgery is a 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 a night, a general anaesthetic, and about 2-3 hours of surgery. There is some bruising, swelling and relatively mild discomfort after surgery, and it is necessary to take time off work – in some cases this time off can be quite long if double vision is troublesome (see below).

If you are on aspirin or any other drug to “thin the blood”, these drugs need to be stopped before surgery (with agreement from your General Practitioner or Cardiologist. Likewise, anti-inflammatory drugs - such as Neurofen or Ibuprofen (Brufen) - need to be avoided for at least 2 weeks prior to surgery and the dosage of anticoagulants (Warfarin) will need to be adjusted.

After surgery, the operated eye will be firmly padded overnight and there will be a small drain in place, to help prevent significant swelling and bruising. The dressing and the drain are normally removed the morning after surgery and patients usually return home after that (they must be accompanied on the way home). Activities of daily living can be continued as normal, with usual washing, showering, but vigorous exercise should be avoided for 2 weeks after surgery.

### **What are the Risks and Side Effects with this Surgery?**

There are risks and side effects with a major procedure like orbital decompression. Most side effects are either temporary or can be treated by further medications or surgery. Some risks, although extremely rare, may be irreversible and lead to a permanent disability.

The most important risk is loss of eyesight: although many orbital decompressions are done for patients with poor vision due to thyroid optic neuropathy, there is a risk of loss of some, or even all, vision with any surgery on the eye socket. With an experienced surgeon the risk of loss is, however, extremely low – probably less than 1 in 3000 for one eye and, thus, less than 1 in 10 million for complete blindness in both eyes.

With 3-wall decompression (but almost never with 2-wall), almost everybody will develop postoperative numbness of the cheeks and upper front teeth, because the nerve supplying the “feeling” is exposed during surgery. In most cases it will recover over some months, but in about 5% a partial or complete numbness will persist. This numbness does not affect facial appearance or movement.

Some double vision (“diplopia”) is common immediately after surgery (due to increased swelling of the eye muscles) and typically settles over a few days or weeks. If persistent, we can often help by fitting a temporary (“stick-on”) prism to your glasses, or by occlusion of one spectacle lens (to blur out the image). If double vision persists long-term, squint surgery or special glasses may be necessary when the eye movements have settled (frequently by 4 – 6 months after decompression).

With TED there is often double vision before any surgery. It can, however, occur for the first time (or be worsened) after orbital decompression and it is most important to realise that diplopia has a major effect on lifestyle, for example, the ability to drive, and may prevent early return to work. **Your preoperative preparations must take this risk into account.**

Despite major reduction in proptosis with orbital 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.

Patients will, rarely, have problems with recurrent sinusitis (or sinus ache) after surgery – although this typically settles over 3 – 6 months. This disruption of the facial sinuses during orbital decompression means that there is a risk of major sinus pain during air travel and such travel should probably be avoided, if possible, for about 2 weeks after orbital decompression. In

some cases the sinus drainage may need surgical correction at a later date, particularly if it leads to an over-correction of the orbital decompression.

There are some other very rare (under 2%) risks: a very slight “wobble” of vision whilst chewing (which is reported as not to be a great problem); some weakness in closing the upper lid and/or raising the eyebrow; asymmetrical or over-correction of proptosis, with one eye set too far back, or too low, within the orbit.

The authors are aware of reports of major neurological complications, and one death, associated with this procedure – although to date, have never witnessed such a devastating complication. The possibility of such a severe complication must, however be recognised.

### **Acknowledgment**

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