



**The Leeds
Teaching Hospitals**
NHS Trust

Thyroid Eye Disease

Information for patients



Leeds Centre for
Ophthalmology

Welcome to the Joint Thyroid Eye Disease Clinic. We hope you find the following information useful.

“Who’s who?”

The clinical team is led by Professor Ramzi Ajjan, Consultant Endocrinologist and Professor Bernard Chang, Consultant Ophthalmologist. An Orthoptist, a nurse and other doctors frequently assist in clinic.

In the joint TED clinic, you will be seen by an **Endocrinologist** who will manage problems related with your thyroid gland and an **Ophthalmologist** who will manage problems related to your eyes. You may also be seen by an **Orthoptist** who can provide advice and treatment for any double vision or eye movement problems you may have.

What is Thyroid Eye Disease (TED)?

Thyroid Eye Disease (TED) may also be referred to as Graves ophthalmopathy, dysthyroid eye disease or thyroid ophthalmopathy. It is an eye condition where the tissues around the eye including the eye muscles and lids become inflamed. It occurs when the thyroid gland malfunctions due to an auto-immune disease. The antibodies released by the immune system not only attack the thyroid gland but also the tissues around the eyes resulting in TED. It usually occurs for patients with overacting thyroid function but can also occur for those with underacting or normal function.

This condition has an active phase that should be closely monitored and treated appropriately to avoid long-term problems. Some patients will require minimal input, whereas others may need steroid therapy and rarely, urgent surgery.

How long will it last?

The “active” phase of TED usually lasts between 1-3 years although individuals can vary. Eventually, the disease will reach a “burnt-out” or stable phase. Some people who have had a severe case of TED may still be left with the signs and some degree of symptoms because of the residual scarring of tissues.

Signs and symptoms of Active Thyroid Eye Disease

- Dry, red, or irritated “gritty” eye sensation.
- Ache behind the eye especially when looking up.
- Watery eyes.
- Light sensitivity.
- Eyes look more bulgy (proptosed).
- Eyelid retracted (more white of the eyeball showing).
- Eyelids more puffy (increased eye bags with redness).
- Double vision due to strabismus (change of eye position).
- Eye itself looking more red and inflamed.
- Loss of vision including change in colour vision.

Any deterioration experienced in your signs and symptoms should be reported to your clinic doctor or GP

If you experience any loss of vision you should go to eye casualty as soon as possible

What is the treatment?

There is no single treatment for TED, but at the Leeds Joint Thyroid/Eye Clinic, we aim to treat signs and symptoms as early as possible to give you the best possible outcome. There are some things that you can do to improve the chances of a successful outcome.

Smoking is known to have a significant effect on TED. Smoking not only increases an individual's chances of getting TED but is also associated with faster disease progression, deterioration of symptoms and poorer responses to treatment. Promptly stopping smoking is encouraged for all those with TED. Please speak to a clinician in clinic or GP if you require any assistance. You are four times more likely to quit smoking with NHS support.

It is important that during the active phase every effort is made to preserve eyesight and protect the eye. Treatments may include: dry eye drops, supplements such as selenium for mild cases, anti-inflammatory drugs (including steroids) and in extreme cases, radiotherapy or surgery. These treatments do not apply to everyone and depends on the severity of the disease. If you are prescribed medication please take as advised, If you experience any problems please contact the clinic or GP.

Some patients will have double vision because the inflammation of the eye muscles causes a change of the eye position and results in the inability to use both eyes together as a pair. The orthoptist may be able to restore single vision with prisms during this period and will be able to advise how best to cope with any double vision. Any change in your eye position will be monitored; once TED is stable and inactive some patients may opt for surgery to realign the eyes.

What will happen at my visit?

When you have checked in at reception, you may have your weight and blood pressure checked. You may also have your vision checked at this time as well. Depending on your symptoms, you may only need to see one or all members of the team. Whilst we endeavour to keep the appointments to time, some patients require longer consultations than others for a variety of reasons and this sometimes leads to delays. If you feel you have been waiting longer than you should for your appointment, please ask at reception and we will do our best to find out why.

Some patients may require further tests such as blood tests, and you may be able to get some of them done on the day. Some tests may be done by your own GP; more specialised tests may require another appointment.

Before you leave, you will be given a follow-up appointment or discharge letter as appropriate which will be copied to your GP.

We would encourage you to ask any of the Joint TED team about any concerns you may have about any aspect of your treatment or symptoms during your visit.

Contacting us

If you need to cancel an appointment, please call:

Referral and Booking Service

Tel: **(0113) 206 4819**

If you would like to speak to someone on the day of your appointment, please call:

Tel: **(0113) 206 4765 / (0113) 206 4764**

(2nd, 3rd and 4th Fridays only, 8.30 am - 12.30 pm)

If you would like to contact the orthoptist, please call:

Tel: **(0113) 206 4736**

(Monday - Friday, 8.30 am - 4.30 pm)

Email: **leedsth-tr.orthoptics@nhs.net**

Professor Chang's Secretary

Tel: **(0113) 206 6219**

Professor Ajjan's Secretary

Tel: **(0113) 206 4963**

Useful contacts:

British Thyroid Foundation

Website: www.btf-thyroid.org

Helpline: (01423) 810 093 (Mon-Thurs 10am -4pm)

Email: info@btf-thyroid.org

TEDct - Thyroid Eye Disease Charitable Trust

Website: www.tedct.org.uk

Helpline: 07469 921 782

Email: info@tedct.org.uk

RNIB (Thyroid Eye Disease)

Website: www.rnib.org.uk

Helpline: 02073 913 299

Email: eyehealth@rnib.org.uk



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