

INFORMATION FOR PATIENTS

Thyroid Eye Disease (TED)

What is TED?

Thyroid Eye Disease (TED) is also known as:

- Thyroid Associated Ophthalmopathy (TAO)
- Graves' Disease (GD)
- Graves' Orbitopathy (GO).

Different specialists may refer to your condition with different names, but they all mean the same thing.

Who can be affected by TED?

TED mainly affects hyperthyroid patients (overactive thyroid).

In rare cases it can affect those patients that are hypothyroid (underactive thyroid) or euthyroid (normal thyroid function).

What to expect with TED:

- **Redness, dry/itchy/sore and watery eyes** - the conjunctiva (the white part of your eye) can become red and feel itchy. Your eyes can also water more because of the eye not being able to close very well. Lubricant eye drops can be prescribed to help with these symptoms.
- **Double vision** - TED can cause swelling of your eye muscles, eye tendons, soft and fatty tissue. This can cause a change in the alignment of your eyes resulting in seeing two of things. If this is a problem, orthoptists can help alleviate this with additional prisms for your glasses or by temporarily covering one of your eyes.

- **Changes to your eyelid position** - with TED your eyelids can pull back a little bit meaning they don't always close properly. This can lead to the dry eyes and soreness mentioned above. Using eye drops and gently taping your lids down at night can help with the side effects of this problem.
- **Appearance of protruding eyes** - the swelling mentioned above can lead to protrusion of your eyes. This protrusion combined with changes in your eyelids can again lead to the redness and watery eyes.
- **Swelling around the eyes** - the skin around your eyes can become puffier and more inflamed with TED. Whilst it is unlikely to cause any symptoms it is still a noticeable change to your appearance.
- **Changes to your quality of vision (in extreme cases)** - due to the swelling and the increased exposure to the front of your eye some TED patients are more at risk of a reduction in their quality of vision or changes to their colour vision. This is due to all the swelling happening around your optic nerve.

If you do notice a sudden reduction in your vision, please contact the eye department urgently (contact details towards the end of this leaflet) or attend your nearest Emergency Department.

What to expect at your eye clinic appointments:

- **Vision test** - you will read the letters on the chart. This tests your central vision which is the part of your vision that you use when looking straight ahead in the distance.
- **Colour vision test** - you will be asked to read the numbers on the colour vision test.
- **Visual fields** - a machine where you press the button when you see the flashes of light. This tests your peripheral or outer vision.
- **Orthoptics** - this is often a 40-minute assessment of eye coordination and is used in the management of double vision. This may be done on a different day to your appointment with the ophthalmologist (specialist eye doctor) as not everyone has double vision with TED.
- **Eye drops** - these are used to dilate the pupils (the black part of your eye). This means that it will be unsafe to drive for a few hours after your appointment, but this is essential to check the health of the back of the eye.
- **Scans** - these are photographs and images of the internal structures of the eye.
- **Consultation with the ophthalmologist** – the ophthalmologist will assess the back of the eye and review your test results. This is to decide if any treatment is needed. They will then discuss this with you and agree what investigations or treatment(s) may be required.

Our team

We have a multi-disciplinary team consisting of:

- Ophthalmologists
- Orthoptists
- Photographers/medical imagers
- Ophthalmic nurses
- Healthcare assistants.

All these specialists work together within the eye clinic to perform the tests that you require to assess your eyes and help manage your symptoms of TED.

We also work very closely with your GP and endocrinologist in managing your thyroid function.

The team can also refer you to Nottingham or Sheffield hospitals for any additional treatment you may require that we may not be able to provide at this Trust.

Further investigations and treatments

Most tests and symptoms of TED can be managed in our clinics. However, sometimes we may need to refer you for further tests or treatments that cannot be done in the eye clinic. These can be the following:

- The doctor may request an MRI of your eyes due to the swelling that can occur. This gives us an in-depth image of the eye and allows us to monitor the size and extent of any swelling of the muscles, tendons, soft and fatty tissue.
- You may need surgery on your eyes if the ophthalmologist identifies that pressure is being put on the optic nerves in order to reduce or stop this. This operation can be done at Queen's Medical Centre in Nottingham or The Royal Hallamshire Hospital in Sheffield.
- You may require surgery to correct any misalignment of your eyes. This would be to try and reduce any double vision that you may have. For this correction you would need a referral to Nottingham or Sheffield.
- You may also require surgery to correct any eyelid abnormalities that can result from TED. Again, this surgery is performed at either Nottingham or Sheffield.
- You may need intravenous (IV) steroids in cases with extreme inflammation.

This is done at this Trust by administering steroids directly through a drip over a 20 minute period during which you will be monitored.

- If your endocrinologist advises radioactive iodine treatment to manage your thyroid hormone level. It is important to be aware that this can cause an episode of TED. Therefore, you will need an appointment to be made with the eye department for this to be monitored.

What you can do to help:

- **Keep good control of your thyroid** - engaging with your GP and/or endocrinologist to ensure the best management of your overall thyroid function. This is done with regular blood testing.
- **Stop smoking** - this can adversely affect the course of TED. Medical research shows us that smokers are less likely to respond to treatment for their TED and are likely to have poorer long-term control of their condition. Our clinicians will advise you to stop smoking and if you would like help with that, we can refer you to the hospital's stop smoking service. Alternatively, you can speak to your GP or local pharmacy for help.
- **Selenium supplements** - the ophthalmologist can prescribe you a selenium supplement. Selenium is a mineral that can help reduce the symptoms of TED by ensuring that your thyroid is working and processing your thyroid hormones effectively. If you have any difficulties in getting this on a repeat prescription, selenium supplements can be purchased from your local health food store. The recommended dose is 100-200 microgram daily for 6-12 months.
- **Lubricants** - the doctor or consultant can prescribe you some lubricants to help keep the front surface of your eye from drying out. These can also be purchased over the counter at your local pharmacy.

- **Regular sight tests** - it is important to keep all aspects of your eye health up to date.

Regular sight tests with your optician and keeping your glasses in good condition means that when you come to the hospital, you'll have the best possible sight for your examination.

Support services:

- **The British Thyroid Foundation (BTF)**

Website: <https://www.btf-thyroid.org/>

Telephone: 01423 810093

The British Thyroid Foundation website has a wealth of knowledge and advice about Graves' Orbitopathy and thyroid conditions in general. The support section of their website has links to different people's experiences and stories.

- **Thyroid Eye Disease Charitable Trust (TEDct)**

Website: <https://tedct.org.uk/>

Telephone: 07469 921782

Like the BTF, the TEDct provides great support and insight but this time their focus is purely on Graves' Orbitopathy. The website is run by medical professionals that you may meet after your Graves' Orbitopathy diagnosis. They have created an environment dedicated to the eye symptoms that can come from a thyroid condition. The website has a great section covering frequently asked questions, a medical dictionary of terms and links to other useful resources.

- **Changing Faces**

Website:

<https://www.changingfaces.org.uk/>

Telephone: 0300 012 0275

The website has a wide range of support services that cover many differences of appearance.

One area that they focus on is eye conditions.

The support and advice line can also refer you on to a counselling programme to help you adjust to the changes to your appearance.

If you have any trouble accessing the information listed above, then please let one of the specialists in the eye clinic know so they can help you with this.

Contact details

If you have any queries or notice any changes to your eyes that you think are TED related, please call the Ophthalmology Department at King's Mill Hospital:

- **01623 622515. extension 3366** for general TED symptoms.
- **07768 615247/07825866704** for double vision symptoms.

Further sources of information

NHS Choices: www.nhs.uk/conditions

Our website: www.sfh-tr.nhs.uk

Patient Experience Team (PET)

PET is available to help with any of your compliments, concerns or complaints, and will ensure a prompt and efficient service.

King's Mill Hospital: 01623 672222

Newark Hospital: 01636 685692

Email: sfh-tr.PET@nhs.net

If you would like this information in an alternative format, for example large print or easy read, or if you need help with communicating with us, for example because you use British Sign Language, please let us know. You can call the Patient Experience Team on 01623 672222 or email sfh-tr.PET@nhs.net.

This document is intended for information purposes only and should not replace advice that your relevant health professional would give you.

External websites may be referred to in specific cases. Any external websites are provided for your information and convenience. We cannot accept responsibility for the information found on them.

If you require a full list of references for this leaflet (if relevant) please email sfh-tr.patientinformation@nhs.net or telephone 01623 622515, extension 6927.

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