



newsletter
AUTUMN 2020



Thyroid Eye Disease
Charitable Trust

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Associated with the *British Thyroid Foundation*

*Introduction by
Rebecca Ford*

We're very sorry that we haven't had a newsletter for some time. This has been due to a reduced number of active volunteers and article writers. We try to keep information flowing via Twitter @thyroideye and Facebook, and hope to be back on track with newsletters next year.

News from this year includes:

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If you have any TED-related events or news you would like to see on our social media please email us at **info@TEDct.org.uk**

Thanks to Rebecca Ford & Eva Tunstall for content & editing & Becky Jaggs for design

COVID-19 and TEDct

The COVID-19 pandemic has been a difficult time for everyone, especially for those with chronic health conditions and medical staff. The main impact on TEDct has been the need to suspend our plans for face-to-face patient information meetings. We hope to remedy this with our new plan for a series of online webinars. Medical conferences have also been shut down or moved online, so our usual work of publicizing the charity and educating healthcare professionals about TED at conferences has also paused.

I did make it to the Optometry Tomorrow conference in Telford not long before the lockdown and did a lecture about thyroid eye disease for a large audience of optometrists. It was good to raise awareness with them, since people with eye conditions often consult their optometrist before any other health professional.

I was also invited to submit an article to the Optometry in Practice journal based on this lecture, so hopefully this will go some way towards one of TEDct committee's goals for this year, which was to educate optometrists about TED.

*By
Rebecca Ford,
TEDct
Committee
Chair*

The pandemic closed elective eye clinics and postponed planned surgeries, but hospitals are starting the recovery process. Doctors and nurses have had to learn what we can and can't do with video and phone-based clinics but we hope that enough access to care and advice has continued for people who need it. We hope our 'COVID-19 and TED' FAQ sheet has been useful. It can be found on our website. Gillian, the TEDct helpline counsellor, tells us she has not been receiving quite as many phone calls throughout the pandemic as usual. We hope this means that patients have been able to get advice from their own healthcare teams. Now that things are improving and hospitals have adapted with social distancing, PPE, etc; patients are less likely to miss out on any important appointments due to safety fears.

During the pandemic, TEDct joined with a group of other patient support organisations involved with endocrine related conditions to share ideas. We found that, as a volunteer-led charity with no premises and employees, our situation is better than many charities who have had to furlough workers and close offices. We hope to bounce back quickly and

feel, keeping up this link with other patient support groups and their experiences, might help us with new ideas in future.

Vickie Lee, consultant ophthalmologist from the Western Eye Hospital in London, has kindly agreed to tell us in more detail of her experience keeping up TED & eyecare services in a hospital at the heart of the pandemic.

We look forward to this talk and others in our forthcoming webinar series.

I hope all our members and supporters have been keeping safe and healthy during this trying time!

TED personal experience story

Becky is responsible for the look of our newsletter and does a great job with the graphic design. In this article, she tells us about her own experience with TED, culminating in orbital decompression surgery recently with great results!

I was first diagnosed with an overactive thyroid in 2002 with most of the classic symptoms of hyperthyroidism - feeling cold, shaking hands, weight and hair loss, racing heart, itchy shins (what is that about?!). I was prescribed carbimazole and over the years I had my TSH levels checked regularly. The

By
Becky Jaggs

treatment worked well for me. I didn't feel quite myself but I didn't have any other side effects. After about 10 years I tried to reduce and stop carbimazole to see if my thyroid levels had normalised. Sadly, that didn't work, so I restarted carbimazole and continued having my TSH levels checked.

In 2014 my children had grown up and so radioiodine treatment became an option. Whilst carbimazole was working, I was concerned that taking the drug for many more years was not a good idea. After consulting with my GP, I decided to go for the radioiodine treatment.

All went well after the treatment, however after 6 months I started having trouble with my eyes. They became very puffy and sore. I began to develop proptosis and double vision very quickly. My GP referred me to a consultant at Bath RUH with the first available appointment being 3 months away. Given the pace of the condition I decided instead to book a private consultation with Dr M. Potts in Bristol. Dr Potts confirmed the diagnosis of thyroid eye disease and recommended I get immediate and aggressive treatment.

This consultation helped start the treatment of 10 sessions of radiotherapy and 15 weeks intravenous steroid treatment throughout the summer of 2015. During the steroid treatment I took Azathioprine, Levothyroxine and Selenium daily. And after took Alendronic Acid, Omeprazole & Calceos for a short time.

Looking back at this traumatic time, perhaps the process of a TSH testing schedule post radioiodine and might have potentially limited the impact for me.

Post TED treatment my proptosis stabilised. With the help of special prisms on my glasses, I was very lucky to be able to carry on my graphic design work. Because my eyes protruded I had to put little pads on my glasses to hold them further away from my eyes, which were incredibly sensitive. I used eye drops to keep them moist. They watered a good deal, and I had double vision without the aid of the prisms. After about a year my eyes had settled down and in the summer of 2016 my TED was inactive (taking 75mcg levothyroxine daily).



*Before &
after*

Living with the difficulties with my eyes was challenging. Work was much more tiring and I was also very self-conscious about their appearance. Fortunately, I had glasses to hide behind, but I really wanted further treatment to alleviate the discomfort and double vision. Hopefully, this could help with their appearance.

It took two requests to the NHS and eventually I had a consultation which led, in August 2018, to me seeing Mr Raman Malhotra, ophthalmic and oculoplastic surgeon at QUH, East Grinstead, to discuss orbital decompression surgery. I decided to have the surgery, opting to have both eyes corrected at the same time. This is more unusual, but for me, living many miles away but with great family support, I felt it was the right decision.

It was a scary time, and I was worried about the very real risks. Thankfully the surgery went well, although I did look grim for some time. It took several months for the swelling to go down. But once the swelling had reduced, my eyes were much more comfortable. The proptosis had been almost completely corrected. I was left with squint

in my right eye, which over the course of the following year has reduced, so that I have only a minor squint. I no longer feel quite so self-conscious about the way I look.

I am very happy with the outcome of the surgery. Most of the problems that I had as a result of TED have gone. My next challenge is that I have been left with very heavy eyelids! I find I have to raise my eyebrows all the time to help keep my eyes open, which can give me a cracking headache! I'm not sure if my lids are not sufficiently bad to be eligible for NHS treatment, but once the current COVID-19 situation has passed, I'm hoping to get a consultation to find out.

If this experience has taught me one thing, it's to listen to your body. If something feels strange, don't wait to go and see your GP. Take responsibility and do everything in your power to find a solution.

Stay safe, Becky x

A TED specialist's comments on this article:

A big thanks to Becky for sharing her experiences! Radioiodine can be a good option for long term control of hyperthyroidism, but patients have to stay

By
Rebecca Ford,
Consultant
Oculoplastic
Surgeon 9

away from children for a week after treatment which may be difficult for parents. However, in some cases it may contribute to triggering thyroid eye disease, so patients having radioiodine therapy should be aware of the need to report eye symptoms promptly. Becky had good immunosuppressive treatment which probably reduced the impact of the disease. It should be noted that even with such treatment, patients do not always avoid surgery.

Decompression surgery can be done on both eyes at once or one at a time. Many surgeons will let the patient decide which they prefer. Having both together is a long surgery, with both eyes swollen and perhaps blurry during recovery. However, it gets everything done in one go so I think most patients would prefer this.

Becky says it took some months before the swelling went down after her surgery. This is to be expected. I always try to make sure that patients understand that recovery from these procedures does take time. Becky did experience a squint (strabismus) after the surgery. This is not uncommon, though the risk will depend on individual circumstances as

well as the type of decompression performed. In general, the more walls of the orbit that are decompressed, the more decompression can be achieved but the higher the risk of double vision afterwards. If the double vision does not settle, it may be possible to correct it with prisms on the glasses or with squint surgery if needed.

I think Becky looks fantastic after her surgery, but she does note that she still has a bit of excess tissue in her upper lids. I hope she will get funding from her local Clinical Commissioning Group (CCGs) to have blepharoplasty surgery to correct this. Samantha Hunt's article in this issue tells us a bit more about the difficulties involved in securing funding for such surgery.

CCG funding of eyelid surgery related to thyroid eye disease

Samantha is a senior surgical trainee in oculoplastics. She has recently undertaken a big project looking at funding for oculoplastics surgery in England, and tells us in this article what she found out about funding for TED-related eye surgery in particular. We hope the full report will be in the medical press soon,

*By Samantha
Hunt,
Oculoplastics
Fellow, Bristol
Eye Hospital*

but TEDct members are getting a preview of the findings most relevant to us.

Clinical commissioning groups (CCGs) are responsible in England for allocating funding resources for all clinical activity in their local regions, taking over from Primary Care Trusts in 2013. To prioritise funding for those with the greatest clinical need, many CCGs have created policies restricting access to certain procedures that they deem to be of 'low clinical value'. Oculoplastic (eyelid) surgery is one area that has been particularly affected by these restrictions, with strict criteria applied in many cases to determine who the CCG deems eligible to receive funding for their eyelid procedure.

In 2018, there were 206 CCGs in England, each capable of creating their own policies and applying their own criteria. It was this potential for 206 different policies that has often been reported in the media as creating a 'postcode lottery', whereby a person's eligibility to have a certain operation done on the NHS may be affected simply by where they live, as opposed to their medical need.

Some individuals with TED benefit from having eyelid surgery once their disease is

stable to remove excess eyelid skin, or lower retracted upper eyelids, for example. When we reviewed all the policies in place in 2018, just over a third of CCGs mentioned TED in at least one eyelid surgery policy, with 10 CCGs (just under 5%) having a specific TED policy. All 10 specific TED policies stipulated that surgery to correct bulging of the eyes (proptosis) or eyelid position could only be undertaken if the patient has tried using lubricating eyedrops for 6 months and this treatment has 'failed' i.e. the drops did not provide adequate relief of the symptoms.

Outside of specific policies, TED was usually mentioned in blepharoplasty policies (for surgery where excess skin is removed from the eyelids). The majority of these policies would fund all patients with TED for this procedure where appropriate, but a small number mentioned that their excess eyelid skin must be the result of their TED as opposed to ageing, or that the TED must be 'burnt out' i.e. inactive and stable. In CCGs without a specific TED policy, funding for blepharoplasty depends on demonstrating that the vision is affected, usually by showing in a visual field test that the eyelid skin blocks

part of the peripheral vision. Unfortunately this means that in many regions, blepharoplasty will not be offered on the NHS for swollen or thickened eyelids unless vision is affected, even if the patient feels disfigured by the eyelid changes.

A few policies only discussed lower eyelid blepharoplasty rather than the more common upper eyelid blepharoplasty, but all such policies would fund patients with TED for this. Some CCG policies are designed to apply to more than one procedure, with lifting of the whole upper eyelid, or the eyebrow, being considered together with blepharoplasty. Where this was the case, any patient seeking these operations would have to meet the same criteria as applied to blepharoplasty surgery.

It is important to note that all CCGs will consider funding surgery for patients who do not meet the criteria they have outlined in their policies in 'exceptional circumstances'. In these situations, funding must be applied for via an Individual Funding Request (IFR) outlining the reasons why the procedure is necessary. These applications are not always successful. Thankfully, improvements in

medical care for Graves and TED mean that fewer people find themselves with severe TED requiring surgery to correct their eyelid position or to remove excess skin, but quite a number of patients still do. Unfortunately, restrictions upon who can obtain funding for such procedures may increase in future as NHS resources become further stretched and more CCGs become aware of the policies that exist in other areas.

Notes from Rebecca Ford, TEDct chair:

Samantha has found that there is still something of a 'postcode lottery' for eyelid surgery provision. We at TEDct, as well as many surgeons from the British Oculoplastic Surgical Society, do not agree with the classification of lid surgeries as 'procedures of limited clinical value', especially for patients recovering from TED. Clearly the NHS does require a mechanism to prevent people abusing the system to get cosmetic surgery on the NHS. Due to the psychosocial impact of TED on patients, the correction of eye lid changes should be seen as rehabilitative rather than cosmetic.

The Exophthalmometer: What is this instrument for and how does it work?

*By
Rebecca
Ford,
Consultant
Oculoplastic*

If you have attended the thyroid eye clinic, the chances are that you may have had your eye positions measured with an exophthalmometer. The original version of the Hertel exophthalmometer that we commonly use was invented in Germany in 1905 by Emil Hertel (1870-1943), a professor of ophthalmology who was especially interested in optical instruments. This device is designed to measure the amount of protuberance or proptosis of the eyes. It is measuring how many millimetres the eye protrudes in front of the bony rim of the eye socket. This measurement helps us to keep track of the severity of the proptosis. It can also show whether the disease has improved or deteriorated after treatments such as decompression surgery.

The doctor will sit the exophthalmometer resting on the rims of the orbits. This can produce an uncomfortable pressure but it should not hurt. The doctor uses just one eye for the examination. The patient should look straight at the doctor's open eye. The

device has a mirror set at 45 degrees to the direction of vision, so that the doctor can see the patient's eye as if looking from the side. This arrangement allows relatively accurate measurement and comparison of the two eyes. Most people's eyes have an exophthalmometry reading between 14mm and 20mm, though black people tend to have slightly higher readings as opposed to people of Chinese race that often show lower readings than average.

I hope this piece helps you understand this instrument and why we use it.

Fig 1: Examining the eyes with an exophthalmometer.

Fig 2: Examiner's view into the mirror of the exophthalmometer. The two red lines should be lined up and then the measurement can be read off the scale at the top of the mirror

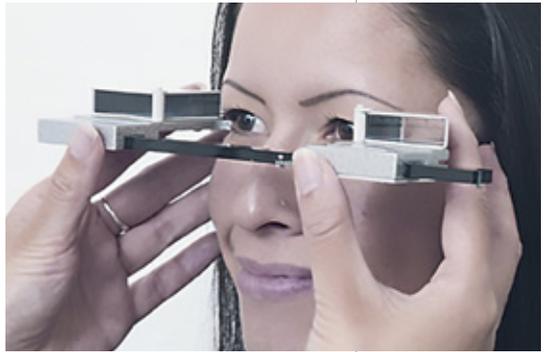


Fig 1:



Fig 2:

TEDCT WEBINARS

COVID 19 AND THYROID EYE DISEASE

Vickie Lee
Consultant Ophthalmologist,
London

**LATEST RESEARCH IN
THYROID EYE DISEASE**

Colin Dayan
Professor of Endocrinology, Cardiff

**Thursday October 22nd
6pm-7.30pm**

For information about how to join
this online event please email
info@TEDct.org.uk

Announcing the TEDct Patient Information Webinar Series. Since COVID has prevented us from holding our usual face-to-face patient information events, we thought we should try something different. We have therefore planned a series of webinars, covering topics of interest to patients and their families. If you would like to join any of these events, they will be held in evenings from 6-7.30pm via Zoom. Please email info@tedct.org.uk to register and receive the link to join.

The topics and speakers will be:

Thurs 22nd Oct:

What's new in TED?

Webinar 1 *Vickie Lee (Consultant Ophthalmologist) - COVID 19 and Thyroid Eye Disease*

Colin Dayan (Professor of Endocrinology) - Latest research in TED

Weds 18th Nov:

TED & your thyroid

Webinar 2 *Rebecca Ford (Consultant Ophthalmologist) - Why do people get TED?*

Bijay Vaidya (Professor of Endocrinology) - Endocrine management in TED

Tues 8th Dec:

TED & your quality of life

Webinar 3 *Tessa Fayers (Consultant Ophthalmologist) - How does TED affect quality of life and how do we measure the impact on people?*

Duncan Harding (Consultant Psychiatrist) - Coping psychologically with chronic diseases like Graves' and TED

Weds 13th Jan:

Surgery for TED

Webinar 4 *Anne Cook (Consultant Ophthalmologist) - Orbital decompression surgery*

Gill Adams (Consultant Ophthalmologist) - Squint surgery for TED (TBC)

Samantha Hunt (Oculoplastics Fellow) - Eyelid surgery for TED

some useful contacts

British Thyroid Foundation (BTF)

Suite 12, One Sceptre House Hornbeam Square
North Hornbeam Park Harrogate HG2 8PB
01423 810093 www.btf-thyroid.org

British Thyroid Association (BTA)

www.british-thyroid-association.org

Helpline

Gillian Barron is the helpline TEDct helpline volunteer with personal experience of the condition. You can speak to her directly on **0746 992 1782** or leave a message and she will ring you back.

Getting social

Follow us on Twitter **@thyroideye**

Find us on Facebook

TEDct: Thyroid Eye Disease Charitable Trust



PO BOX 1928 BRISTOL BS37 0AX
07469 921782 info@TEDct.org.uk

TEDct aims to provide information, care & support to those affected by thyroid eye disease. An optional annual membership is £12 / overseas £20. If you would like to make a donation, please state if you are a UK taxpayer as TEDct can reclaim 25p in the pound from HMRC.