

Thyroid eye disease

What is thyroid eye disease?

Thyroid disease is an autoimmune condition. Autoimmune means that your own white blood cells or antibodies are causing damage to parts of your own body in addition to their normal role of protecting you against infections.

Doctors call this condition many different names including thyroid ophthalmopathy, thyroid associated ophthalmopathy, Graves' eye disease, Graves' ophthalmopathy and Graves' orbitopathy.

In the case of thyroid eye disease, the damage is directed to fatty tissue and muscles behind the eye. Swelling of the damaged tissues behind the eyes can cause the eyes to become red and swelling to occur above and below the eyes. It may also cause the eyes to be pushed forward (staring, wide open eyes, proptosis or exophthalmos).

In more severe cases, the damage at the back of the eye causes swelling and stiffness of the muscles that move the eye, causing double vision especially when you look from side to side, as the muscles cannot keep the eyes exactly in line with each other. Occasionally, the swelling behind the eyes is bad enough to press on the nerve from the eyes to the brain affecting your vision.

What causes thyroid eye disease?

We do not know yet but something triggers the autoimmune reaction. This may be a virus infection, but no specific viruses have been identified as a trigger. Stress is commonly observed as a trigger but we do not know how this works.

The disease can run in families, and genetics play a role. Smoking is a strong risk factor, and stopping smoking is one of the most important things patients can do to help their disease. We do know that thyroid eye disease, as its name suggests, is closely connected with autoimmune thyroid gland disease.

What are the symptoms?

The commonest symptoms are mild soreness and grittiness of the eyes. Surprisingly, one eye is usually affected more than the other. There may also be increased watering of the eyes, a



dislike of bright lights and a feeling of discomfort behind the eyes especially when looking up or side-to-side. Puffiness of the upper eyelid or around the eyes (baggy eyes) is also common and is worst first thing in the morning. The eyes often appear staring and wide open, and drying of the eyes or too many tears can cause blurry vision, which may come and go. You should consult a specialist urgently if your vision keeps getting worse.

What is the connection with thyroid disease?

In addition to the antibody or white cells that cause the eye problem, 90% of people with thyroid eye disease also have an antibody in their blood which causes an overactive thyroid gland. The overactive thyroid gland is called Graves' Disease, after Dr Graves who first recognised it 200 years ago. The reason the autoimmune condition affects both the eyes and the thyroid, seems to be that they share a common molecule, the TSH receptor. The eyes and thyroid are not always affected at the same time. For example, the thyroid overactivity can come first and then the eye disease can develop even after the thyroid has been treated. Also, treatment of one does not treat the other. A small number of people who develop thyroid eye disease have no thyroid disturbance and some have an underactive thyroid.

Will the treatment for the thyroid affect the eyes?

Treatment of the thyroid overactivity with tablets or surgery rarely affects the eye. However, studies have suggested that radioactive iodine treatment for the thyroid may make the eye problems worse. Since the eye and thyroid problems, although connected in some way, run their own separate courses, worsening of the eyes after thyroid treatment is often a coincidence rather than a direct effect of the thyroid treatment. Nonetheless, it is **strongly recommended** that patients with severe eye disease avoid radioiodine. If you have milder problems, you should receive a three month course of steroids starting on the day of radioiodine to prevent the eyes becoming worse. If you have no eye problems then radioiodine is an excellent treatment.

Treatment for the thyroid may also affect the eyes in one other way - if the thyroid is over treated and your thyroid becomes **underactive** (hypothyroid) this may worsen any eye problems.



Can thyroid eye disease be prevented?

Thyroid eye disease can be prevented to some extent. Giving up smoking and careful checks of thyroid hormone blood levels to avoid underactivity may help prevent the eye problems getting worse although they are not the full answer.

What is the normal course of action with thyroid eye disease?

In most patients with the milder form of thyroid eye disease, the eye problems settle after a period of time, but this may take from 6 to 18 months. More severe forms of the condition may initially deteriorate over some time, then stabilize and then improve over a similar time frame, but often the eyes do not return to normal when the disease has been more severe. Once the eyes have stabilized, then surgery can be considered to improve their appearance, comfort and to improve any double vision that might persist. If your eyes have been the same for more than six months, it is unusual for them to get worse.

How to manage symptoms

Selenium supplements

There is good evidence that taking selenium supplements (200 micrograms a day for 6 months, available in health food stores and pharmacies) is helpful in mild to moderate forms of thyroid eye disease, helping to reduce symptoms and signs of inflammation.

Irritation and redness of the eyes

Simple eye drops such as 'artificial tears' will usually provide relief. These drops are harmless and can be applied as often as required, even as much as hourly. For longer effect, paraffin ointment may be used during the day or night.

Puffiness around the eyes

Puffiness is more difficult to treat. While the puffiness may be unsightly, it is not dangerous. Given it is often worse in the morning after lying flat, it may be helped by using an extra one or two pillows or bolster to raise your head at night, raising the head of the bed on blocks or using a diuretic (water tablet) at night-time. Usually the swelling does improve after several months as the eyes settle. Surgery is sometimes used to improve the appearance in severe cases.

Staring, wide open eyes

If mild, this problem usually gets better over time as the eyes settle. When it is severe, and has been present a long time, then it may not go away. In this case, the appearance can often be improved by surgery to the eyelids, once the eyes are stable and not



changing any further. Some people find tinted spectacles helpful to disguise the appearance.

Double vision

If this only occurs from time to time or only when you look out of the corner of your eyes then it should not interfere with normal activities and does not require treatment. However, if the double vision occurs more frequently, you need specialist help.

Double vision can be improved with the addition of plastic prism lenses to your glasses. If the double vision remains, surgery to realign the eyes can be performed (similar to squint surgery in children). However, if the double vision is getting worse you may need 'immunosuppressive treatment' (see below).

Deteriorating vision

If this happens more than just occasionally and cannot be corrected by new glasses, urgent expert attention is required as it may mean that there is pressure on the nerve behind the eyes. Immunosuppressive treatment (see below) or surgery to relieve pressure behind the eyes may be necessary.

Sometimes the problems with vision may be caused by drying out of the eyes if they are very prominent and the eyelids do not close fully at night. Surgery may then be required to protect the eye.

Smoking

Stopping smoking or avoiding passive smoking is a positive thing that you can do to stop your eyes getting worse and perhaps help them to get better.

What is immunosuppressive treatment (steroid tablets, radiotherapy)?

When double vision is getting worse or the accuracy of vision is deteriorating, stronger treatment may be used to calm down the immune system (immunosuppressive treatment) and reduce the swelling behind the eyes. Some specialists use low dose radiotherapy to the eyes. This is often effective and side effects (in experienced hands) are minimal.

Currently, standard 'immunosuppressive treatment' involves steroid tablets at high dosage. This treatment is effective but can cause swelling of the face, increase in weight, thinning of the bones, sleeplessness and diabetes. It is therefore reserved for severe cases and must only be used under specialist supervision.



Steroids can also be given intravenously and may be more effective in some patients and have lesser side effects than steroid tablets.

Once the thyroid eye disease reaches the stable un-inflamed state, these treatments are not effective.

Will the eyes go back to normal?

If the eyes were only mildly affected, they may go back to normal, however this may take up to 12-24 months. The longer the eye changes have been present, the less likely it is that they will go away. This is because the swelling turns to scarring and even immunosuppressive treatment will not reduce the swelling. Expert treatment is then required, usually involving carefully planned surgery, and can be very effective in improving the appearance of the eyes.

Am I likely to lose my sight?

It is very rare for the vision to be severely affected. Even when it is, prompt surgery or immunosuppressive treatment can usually improve the situation.

Can I get another attack of thyroid eye disease?

It is very rare to get another 'attack' of thyroid eye disease, and this probably occurs only in about one in every few hundred patients with the disease. If it does occur, it can be many years after the initial 'attack'.

The changes in my face have affected me. Can anything be done about them?

Some of the effects of thyroid eye disease improve with strict medical control and the passage of time. However, in a proportion of sufferers the changes persist long term. Many can camouflage these by simple measures such as growing a fringe or wearing tinted or dark glasses, but some experience considerable psychological difficulties as a result of changes in their appearance. This can result in loss of self-esteem, lack of self-confidence and anger at the changes. Relationships are also affected at many different levels. All this is hardly surprising as the face and particularly the eyes are the most significant point of contact between individuals.

Much can be done with surgery to improve the appearance and comfort of the eyes, but it may require more than one operation.



With surgery, the eyes can often be returned to an appearance more like the eyes were before the disease began.

Can I make contact with fellow sufferers?

Many people find the changes in appearance with thyroid eye disease very distressing and contact with other sufferers who have been through the same thing is very helpful. You can make contact with other people through a Thyroid Eye Disease (TED) self-help group.

Some useful starting points include:

www.thyroid.org.au

www.tedct.co.uk

www.dailystrength.org/c/Graves-Disease/support-group

Reference:

This handout is reproduced in part from the following website:

www.british-thyroid-association.org/info-for-patients/Docs/ptinfo-TED.pdf

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