

THYROID EYE DISEASE **PATIENT INFORMATION**

What is thyroid eye disease?

Thyroid eye 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. In the case of thyroid eye disease, the damage is directed to fatty tissue 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 ('starey eyes', 'proptosis'). 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.

Does it have any other names?

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

What causes it?

We do not know yet. One theory is that it follows infection with a virus that has molecules which look to the body very like the ones behind the eye. The body then makes antibodies and white cells to get rid of the virus but the reaction spills over onto the cells behind the eye. The body successfully removes the virus but is left with an 'autoimmune' reaction against the eye which continues. This remains just a theory as the virus, if there is one, has not yet been found. However, we do know that thyroid eye disease, as its name suggests, is closely connected with autoimmune thyroid disease and that it is more likely to happen in smokers. It has only a slight tendency to run in families.

Are there any other 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 'starey' and drying of the eyes or too much tears can cause blurry vision, which may come and go. You should consult a specialist urgently if your vision is getting worse all the time, rather than just on and off.

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. Note that 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 make the eyes better or worse?

In general, no. 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 **DETERIORATION**. 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 **OVERTREATED** and your thyroid becomes **underactive** (hypothyroid) this can worsen any eye problems.

Can thyroid eye disease be prevented?

To some extent. Giving up smoking and careful checks of thyroid blood level to avoid underactivity may help prevent the eye problems getting worse although they are not the full answer.

Will my eyes get worse?

In most people, thyroid eye disease only causes irritation of the eyes, a little stareyness and some puffiness around the eyes. This carries on usually for a few months, occasionally one to two years, and then settles down by itself. In about 1 in 10 people the eyes get worse. This usually happens within a few months of the problem starting so that if your eyes have been the same for more than six months, it is unusual for them to get worse.

What can be done about thyroid eye disease?

a. Irritation and redness of the eyes

Simple eye drops such as 'artificial tears' ('viscotears' or 'hypromellose eye drops') will usually give relief. These drops are harmless and can be applied as often as required, even as much as hourly. For longer effect Lacrilube Ointment may be used during the day or night.

b. Puffiness around the eyes

This is more difficult to treat. The puffiness is unsightly but not dangerous. It is worse in the morning after lying flat and 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.

c. Starey eyes

If mild, this problem usually gets better with 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 very much 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.

d. Double vision

If this only occurs from time to time and/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. Plastic prism lenses added to glasses can improve the double vision. At a later stage, if the double vision remains, surgery as for squints in children can be done to realign the eyes. However, if the double vision is getting worse you may need 'immunosuppressive treatment' (see below).

e. Deteriorating vision

If this happens more than just occasionally and cannot be corrected by new spectacles, 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 as soon as possible may be necessary. Sometimes the problems with vision are 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.

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.

Some specialists also use another tablet called Azathioprine along with the steroids so that the same degree of treatment can be achieved with a lower steroid dose. This medication is used in combination with radiotherapy and it is hoped that by treating the disease early the severe complications of thyroid eye disease and the need for surgery can be avoided.

Once the thyroid eye disease reaches the stable uninflamed state, these treatments are not effective.

Will the eyes go back to normal?

Occasionally, yes, especially if they were only mildly affected. 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.

Should I see an eye specialist (ophthalmologist)?

Yes. If you have more than minor symptoms this is advisable. The eye specialist will want to see your eyes as soon as possible in case anything can be done to prevent later problems.

Am I likely to lose my sight?

No. 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.

The changes in my face have affected me badly. 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.

More research is needed into the psychological effects of changes in people's appearance in thyroid eye disease and also on the treatments aimed at rehabilitation. Certainly an increasing number of specialists are aware of these problems and are prepared to tackle them if there is significant disfigurement and once the disease has reached the stable uninflamed stage. The surgical plan will be tailored to meet the individual's needs but it is fair to say that the surgery is not easy and often more than one operation is needed.

Can I make contact with fellow sufferers?

Yes. 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 the Thyroid Eye Disease (TED) self-help group who have produced this leaflet.

There may be a local TED group near you.

Thyroid Eye Disease (TED) Head Office,
Solstice,
Sea Road,
Winchelsea Beach,
East Sussex
TN36 4LH
UK

(e-mail: tedassn@eclipse.co.uk, Phone/Fax 01797 222 338)