

Patient information

Graves' Hyperthyroidism

Diabetes and Endocrinology Department

What is Graves' Hyperthyroidism?

This is a condition caused by your thyroid gland producing too much of the hormone thyroxine. The thyroid gland sits at the front of your neck, just above your collarbone. In normal health it produces enough of the hormone thyroxine to keep you well. Thyroxine hormone helps the body use energy, stay warm and keep the brain, heart, muscles, and other organs working as they should.

This type of overactive thyroid affects women more than men and is usually diagnosed before the age of 40. It is due to an auto immune response. It can also affect your eyes causing them to feel gritty, dry and sore.

What happens to me with Graves' Hyperthyroidism?

You may have some or all of the following:

- A general feeling of nervousness or anxiety.
- Shakiness.
- Mood swings.
- Sweating and being unable to tolerate heat.
- Weight loss even with a good appetite.
- General tiredness and weakness.
- Increase in bowel movements, maybe even diarrhoea.
- If you are a woman your periods may become irregular or even stop.
- The gland can be enlarged, this can be seen or felt at the front of the neck this is known as a goitre.
- Your eyes may become 'staring' and can sometimes feel gritty and irritated.
- Double vision, especially when looking upwards can happen.
- Sleep disturbance.

How will this be diagnosed?

Your family doctor (GP) will take some blood tests to check the level of your thyroid hormone. They will then refer you to a Consultant Endocrinologist for assessment. The combination of blood tests and examination by the doctors along with your account of your symptoms will give the diagnosis.

What treatment will I be given?

The usual first line treatment given is tablets. Radio-iodine may be given but usually after a trial of tablets. Surgery may be performed if these treatments do not work, your symptoms return after these treatments have been given or if you have a goitre (an enlarged thyroid gland) that causes problems with swallowing or breathing.

What do the tablets do?

There are two tablets that can be given, Carbimazole or Propylthiouracil. Both stop your thyroid gland from producing thyroxine.

There are two ways the tablets can be used:

1. On their own to stop your thyroxine output 'titration regime'. Either tablet can be given in high doses to begin with. Regular blood tests will be needed to assess the level of thyroxine in your blood. When this level begins to fall the dose of the tablets will be reduced. This allows your thyroid gland to still produce some thyroxine but not too much.
2. As part of a "block and replace" regime. For this you will be given either of the above tablets at a steady dose. Blood tests will be taken to check when your thyroxine level starts to fall, and then replacement thyroxine tablets will be added. Both anti thyroid tablets and thyroxine tablets need to be taken each day with this regime.

You may also be given a tablet called Propanolol to help with palpitations, sweating and anxiety.

What is 'block and replace'?

The 'block' is achieved by taking Carbimazole or Propylthiouracil to 'turn off' your thyroid gland. Approximately six weeks after starting the tablets the store of thyroxine in your thyroid gland will be used up. This will be checked with blood tests.

You will then be given Thyroxine tablets to take and this is the 'replace' part of your treatment. This is to stop you developing the symptoms of an under active thyroid such as tiredness, weight gain and constipation. You would then need to continue taking Carbimazole or Propylthiouracil as well as Thyroxine as prescribed. This treatment would continue for twelve to eighteen months.

What is the 'titration regime'?

Carbimazole or Propylthiouracil is taken to 'turn off' your thyroid gland. Approximately six weeks after starting the tablets the store of thyroxine in your thyroid gland will be used up. This will be checked with blood tests.

The dose of carbimazole or Propylthiouracil is then gradually reduced to the lowest dose that keeps your thyroid function tests within the usual reference ranges; this means your blood tests are checked every 6-8 weeks. This treatment will continue until you either have definitive treatment or until your blood tests show you are starting to become underactive.

What are the side effects?

Both Carbimazole and Propylthiouracil will stop your thyroid gland from producing any thyroxine hormone so you could develop hypothyroidism, an under active thyroid gland. Both tablets can cause rashes and itching but this is usually only temporary. Nausea (feeling sick) with mild stomach upsets and headaches have also been reported. Rarely, you can get a serious reduction in the white blood cells in your body. These cells help to fight infection in your body.

If you develop signs or symptoms of infection, especially a sore throat, or unexplained bruising or bleeding, you should seek medical advice straight away so that your full blood count can be measured to check your white blood cell count. Do not stop your medication unless told to do so by the Endocrine team.

How long will I have to take the tablets for?

The usual treatment course is twelve to eighteen months. The exact time is decided by assessing your response to the treatment. You will need to take the tablets every day. During the treatment course you will be reviewed by the nurse specialists at regular intervals to have your blood checked. You will also continue to attend the doctor's clinic. This will also give you an opportunity to discuss any problems or concerns you may have.

What will happen if I don't take the tablets?

- You would get increased problems with symptoms such as sweating and anxiety.
- Palpitations would get worse and your heart develops an irregular beat.
- If left without treatment, hyperthyroidism can cause very high body temperatures and sometimes unconsciousness.
- Thinning of your bones can also happen if hyperthyroidism is left untreated for many years. If your bones become thin they can break more easily.
- If you are pregnant, you are at increased risk of developing some pregnancy complications such as premature labour, miscarriage and foetal development abnormalities.

What happens after the treatment course is completed?

Your specialist will review you in the clinic and advise you when to stop taking your anti thyroid tablets. This is usually after twelve to eighteen months of treatment.

You will continue to be reviewed by a specialist nurse or doctor approximately every three months for a total of twelve months after stopping your treatment. If your level of thyroxine remains normal after this time, you will be discharged to the care of your GP.

If your hyperthyroidism recurs after completing the treatment you may have a return of some or all your initial symptoms. If this happens further treatment options will be discussed. A blood sample will be taken to check the level of your thyroxine.

What other treatments are there?

Radio-iodine

This reduces the over activity of the thyroid gland by destroying some of the cells and preventing repair of others. You can be given the treatment as an outpatient and it takes the form of a capsule or tasteless drink.

This is usually given after a course of tablets to reduce the activity of the thyroid gland (block and replace regime).

It is performed in the Nuclear Medicine department and on your first visit there your suitability for this treatment will be assessed. This will be by a thyroid scan. The staff in the department will discuss the treatment in detail with you and advise when you would need to stop taking your medications.

How long does the treatment take to work?

The full effects of this treatment can take up to eight weeks to happen. During this time you may need to restart your anti-thyroid medication, Carbimazole or Propylthiouracil; or restart Propranolol to help control your symptoms. Your thyroid hormone level will be checked regularly following the Radio-iodine treatment to monitor its effectiveness. Sometimes a second dose of radio-iodine may be needed to reduce the thyroid activity fully.

What else do I need to know about this treatment?

The main result of this treatment is hypothyroidism which is an under active thyroid gland. The doctors looking after you will check for this. If you develop hypothyroidism you may feel tired and sluggish, have constipation, gain weight and have dry skin and hair. This condition is easily treated with thyroxine tablets taken each day. If you do become hypothyroid following radio-iodine treatment you would be on Thyroxine for life.

Following radio-iodine you will need to avoid close contact with family and friends, especially children and pregnant women. You will be advised about this by the nuclear medicine department following your treatment.

If you were pregnant or planning a pregnancy within six months of the treatment alternative treatments would be considered.

Men should avoid fathering a child for six to twelve months after radio-iodine treatment.

There is a separate leaflet giving details of Radio-iodine treatment (available from nuclear medicine PIF 1506).

Surgery

If you had a return of your symptoms after the medical treatments described above you may be offered surgery to remove all or part of your thyroid gland.

Surgery may also be offered if your thyroid gland became enlarged causing problems with breathing and swallowing due to extra pressure around your windpipe and gullet. There is a separate leaflet, available from your surgeon, giving full details of thyroid surgery.

Why are my eyes affected?

This is thought to be due to an auto immune response, damaging the tissues behind the eye. This causes the eye to be pushed forward and 'bulge'.

Your doctors may call this proptosis. As this condition worsens the muscles which move the eye can become swollen and stiff. This can cause double vision as the eyes can no longer move in line with each other. The exact cause is unclear but it is closely linked to autoimmune thyroid disease.

Smokers are eight times more likely to develop thyroid eye disease and it will be more difficult to treat successfully if you continue to smoke.

What problems will I have with my eyes?

Commonly reported problems are:

- Soreness or grittiness of the eyes, often with one eye more affected than the other.
- Increased watering of the eyes and continual blinking with 'blurry' vision.
- Dislike of bright lights or sunny weather.
- Discomfort behind the eyes, especially on looking up or to the side. Double vision may also occur.
- Puffiness or 'bags' around the eyes, which are worse in the mornings.
- 'Staring' eyes or 'pop' eyes caused by increased pressure behind the eye. This pushes the eye forward and makes it prone to irritation from wind, sun, dust and grit.

What can be done to help problems with my eyes?

This will usually settle down after a period of one to two years.

During that time the following actions may prove helpful:

- If you smoke, stop completely.
- Artificial tear drops can be given to help irritation and watering of eyes.
- Puffiness around the eyes is often worse in the mornings, sleeping propped up may reduce this. Wear sunglasses in bright or sunny weather and try to avoid facing into wind.
- 'Staring' or 'pop' eyes generally get better with time.

- If severe or present for a long time and provided the condition is stable, surgery can be performed to your eyelid to help improve appearance.
- Double vision - if mild and only when you look out of the corner of your eye, then treatment is not usually necessary.

If double vision is frequent and interferes with daily life then specialist help will be needed from an ophthalmologist (eye doctor). This may be in the form of glasses with special lenses fitted.

If very severe or getting worse then you may need medicines to treat the double vision. These are known as immunosuppressive treatments and are steroid tablets taken at high doses. As these tablets can cause other problems such as weight gain, sleeplessness and diabetes they are only used in very severe cases and under specialist supervision.

Will my eyes return to normal?

This depends on how badly affected they were. If the problems were only mild then within two years your eyes may return to how they were before the onset of the disease.

If you had severe problems or the problems were longstanding then the effects are less likely to reduce. If you are very troubled by the appearance of your eyes then specialist surgery can help.

Is my sight at risk?

It is very rare for vision to be severely affected. If you find you are developing problems with your eyesight then you should contact your specialist immediately.

The problems can be treated with immunosuppressive treatments or surgery.

Feedback

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

Further Information

Please feel free to contact the Endocrine Specialist Nurses with any questions you may have. There is an answer machine where you can leave your name and contact details. We will return all calls.

The Endocrinology Specialist Nurses:

Tel: 0151 706 2417

Textphone number: 18001 0151 706 2417

Related Patient information leaflets:

Anti-thyroid medications (PIF 1577)

Radioactive iodine treatment for hypothyroidism your questions answered (PIF 1506)

There are also two very good patient support groups, which offer excellent advice through letters and telephone contact. They also hold local area group meetings. They are:

**British Thyroid Foundation
Suite 12, One Sceptre House
Hornbeam Square North
Hornbeam Park
Harrogate
HG2 8BP
Tel: 01423 810093**

**www.btf-thyroid.org
Email: info@btf-thyroid.org**

**Thyroid Eye Disease Charitable trust (T.E.Dct)
PO Box 1928
Bristol
BS37 0AX
Tel: 07469921782
www.tedct.org.uk
Email: helpline@tedct.org.uk**

**There is also advice available from the RNIB:
RNIB Helpline
Tel: 0303 123 9999
www.rnib.org.uk**

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All Trust approved information is available on request in alternative formats, including other languages, easy read, large print, audio, Braille, moon and electronically.

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