



**University
Hospitals Sussex**
NHS Foundation Trust

Graves disease

Department of Endocrinology

Patient information

What is the thyroid?

The thyroid is a gland in the front of the neck which makes thyroid hormone. Hormones are chemical messengers produced by your glands and carried in the blood. Thyroid hormone controls the body's metabolism (use of energy).

What is Graves' disease?

Graves' disease is an over activity of the thyroid gland, named after a Dr Graves. It is an 'autoimmune' disease, caused by antibodies which stimulate the thyroid gland to produce too much thyroid hormone. Antibodies are produced by the body's immune system to help fight infections. In patients with 'autoimmune diseases', antibodies react with the body's own tissues.

You may also hear the words 'thyrotoxicosis' or 'hyperthyroidism': these both mean an overactive thyroid gland. Your thyroid gland may become large and swollen ('a goitre').

Graves' disease is most common in young women and is more common in women than men. Other family members may also be affected with thyroid disease: either Graves' disease, or a thyroid swelling alone (goitre), or an under active gland.

What symptoms does it cause?

When the thyroid is overactive many of the body's processes operate too quickly causing symptoms such as:

- Irritability and 'swings' in emotion; nervousness or anxiety.
- Weight loss in spite of a good appetite.
- Palpitations (fast or irregular heart beat).
- Sweating and feeling hot.
- Shaking or tremor.

- Poor sleep.
- Muscle weakness, with difficulty getting out of a chair or climbing stairs.
- Frequent bowel movements.
- In women who are having periods, these may become light and scanty or stop altogether.

Many of these symptoms are similar to those that occur as a result of stress or worry and it is often difficult to tell the difference between an overactive thyroid gland and the effects of stress without a blood test. The thyroid gland itself which is in the middle of the neck just below the Adams apple, may become enlarged and very easy to see (a goitre). Family and friends or your doctor may notice it. All these symptoms may have been going on for several months before your Graves' disease is recognised.

What is thyroid eye disease?

In about 20% of people with Graves' disease their eyes become more prominent and staring ('Thyroid Eye Disease' or 'TED'). In some cases they may become inflamed, and feel sore or gritty. If you develop double vision or blurred vision, or your eyes or eyelids are very red and swollen, contact your doctor for urgent advice as you may need referral to an eye specialist. The risk of thyroid eye disease is greater in smokers: quitting smoking is helpful.

What causes it?

In Graves' disease the body mistakenly thinks the thyroid is a foreign tissue and produces an antibody against it ('autoimmunity'). This antibody stimulates the thyroid gland causing it to produce too much thyroid hormone. Why the antibody is produced is not known. Thyroid disease may run in your family. Sometimes stress seems to trigger the disease. In most cases the cause is not known.

How is it diagnosed?

Measuring the level of thyroid hormones in the blood confirms that the thyroid is over active. Measurement of thyroid antibodies, together with the findings when you are examined by the doctor, may be used to confirm that the over activity is due to Graves' disease. Sometimes scans of the thyroid gland are necessary.

How is it treated?

There are three treatment options: tablets, radioiodine or surgery.

What tablets are used?

Beta blockers

Beta blocking tablets such as propranolol may be used to help control some of the symptoms while the thyroid over activity is being brought under control. These tablets do not stop the over production of thyroid hormone.

Carbimazole and propylthiouracil (PTU)

Carbimazole is the drug most commonly used in the UK to treat Graves' disease. Carbimazole is usually given at a high dose to begin with (20mg daily) until your thyroid blood tests are normal. This usually takes 4-6 weeks. You should begin to feel the benefit from the carbimazole after 2-4 weeks.

After 6 weeks the dose is reduced depending on the results of your blood tests. Alternatively your doctor may continue high dose carbimazole and add thyroxine (the 'block-replace' regimen). You will remain on carbimazole for about 12-18 months.

In around 30-40% of people when the tablets are stopped normal thyroid function will persist, but in the other 60-70% their thyroid will become overactive again. If this is going to happen it usually happens in the first year after stopping carbimazole. It is often difficult to predict in advance which group you will fall into. If your thyroid becomes overactive again you may notice that your symptoms have come back or your doctor may notice it in your blood tests.

Carbimazole is the most commonly used anti-thyroid medication. Carbimazole can cause a rash, which will often settle if you take an antihistamine tablet. Propylthiouracil (PTU) is another anti-thyroid tablet, which is also used to treat women with Graves' disease who are in the first three months of pregnancy or breast feeding. It is very important that you inform your GP and any other doctors looking after you if you are being treated for hyperthyroidism and are pregnant or trying for a baby, as your medication needs careful monitoring and may need adjusting (see separate Pregnancy and Hyperthyroidism leaflet). Both carbimazole and PTU may rarely cause jaundice or joint pains.

A very rare but serious side effect of carbimazole or PTU treatment is a sudden loss of white cells ('neutrophils') in the blood. This means you are more vulnerable to infection. You should be given specific instructions in relation to this from your doctor (see separate Carbimazole / PTU warning leaflet). The first sign of this happening is a very sore mouth or throat without any reason.

If this happens you must stop taking the tablets immediately and see a doctor the same day for a blood test.

What is radioiodine therapy?

Radioiodine is a small dose of radioactivity given as an iodine tablet. It takes several weeks to months to have its full effects (see separate Radioiodine leaflet). It is often used to treat patients who have not been successfully cured by tablets. It is also used in many patients once their thyroid blood tests are controlled, without trying a full course of tablets first. In most people only one treatment will be necessary and the thyroid over activity will not come back again. There is a risk of the thyroid becoming under active following treatment and therefore all patients need to have regular checks. The treatment is safe except in pregnant or breast-feeding women. Further information on radioiodine is available in another leaflet.

Can I have an operation?

An operation to remove part of the thyroid gland is another alternative. This is not used very frequently unless the enlarged thyroid is pressing on the windpipe or the gullet, or tablets or radioiodine are unsuccessful or unsuitable. Surgery is only performed after the thyroid activity has initially been controlled by tablets.

Patient support organisations:

British Thyroid Foundation www.btf-thyroid.org

Thyroid Eye Disease Charitable Trust www.tedct.org.uk

There is a link to short videos about thyroid treatment options and thyroid eye disease on our website.

www.bsuh.nhs.uk/services/diabetes-and-endocrinology

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