

British Thyroid Association Patient Information Leaflet 1: The thyroid gland and thyroid cancer – tests and treatment

What is the thyroid gland?

The thyroid gland is an endocrine gland and makes hormones, which are released into the bloodstream. These hormones affect cells and tissues in other parts of the body and help them to function normally.

Where is the thyroid gland?

The thyroid gland is at the base of the neck. It is made up of two lobes (each about half the size of a plum). The two lobes lie on either side of your windpipe, with the gland as a whole lying just below your Adam's apple.

What does the thyroid gland do?

The thyroid gland produces three hormones that are released into the bloodstream:

- thyroxine (T4);
- triiodothyronine (T3); and
- calcitonin, which has no known action in healthy people. Raised levels of calcitonin may indicate the presence of medullary thyroid cancer (MTC).

(For more information see the British Thyroid Association Patient Leaflet – Medullary Thyroid Cancer.)

T4 and T3 can both be replaced by medication, and the body can function perfectly well with little or no calcitonin.

What do the thyroid hormones do?

Thyroid hormones (T3 and T4) help to control the speed of body processes – your metabolic rate. In the body, T4 is converted into T3 which is the active hormone which influences the way cells and tissues work. If too much thyroid hormone is released, your body works faster than normal and you have 'hyperthyroidism'. This would make you feel overactive and anxious, hungrier than usual, and you would lose weight. However, if too little of the thyroid hormones is produced, your body works slower than normal and you have 'hypothyroidism'. In that case, you would feel tired and sluggish, and put on weight easily.

How is the thyroid gland controlled?

The thyroid is controlled by the pituitary gland, which lies underneath your brain in your skull and senses the levels of thyroid hormones in your bloodstream. If the levels drop below normal,

the pituitary reacts by releasing a hormone called thyroid stimulating hormone (TSH). TSH stimulates the thyroid gland to produce more T3 and T4. If the thyroid hormone levels rise above normal levels, the pituitary senses this and stops releasing TSH and so the thyroid gland will produce less T3 and T4.

How is thyroid activity measured?

Your doctor will start by taking a history of your symptoms and by a physical examination. You will also be asked to give a small sample of blood, which will be analysed in the laboratory to show how much T4, T3 and TSH are being produced. These tests are sometimes called thyroid function tests or TFTs.

What are the parathyroid glands and how do they affect calcium levels?

Near your thyroid gland are four tiny parathyroid glands, each the size of a pea. They are not related to the thyroid except by name – 'para' comes from the Greek for 'near'.

Parathyroid glands release a hormone called parathyroid hormone (PTH) which helps to regulate calcium, phosphate and magnesium levels. Calcium levels need regulating because they fluctuate constantly in response to a number of factors such as food, drink, exercise, stress, infection, and other medications.

Calcium is an important mineral because it is in every cell of the body. It affects bones, nerves, muscles, heart rhythm and cell function as well as your emotions. Levels must therefore be kept stable to make sure your body functions correctly.

The parathyroid glands regulate calcium levels by means of a feedback mechanism. They continually monitor the amount of calcium in your blood as it passes through them and they make constant adjustments by releasing just enough PTH to keep your levels stable.

Sometimes the parathyroid glands may be temporarily affected by surgery and stop producing enough PTH. In some cases this may be permanent. Without enough parathyroid hormone calcium levels become too low. This condition is called hypoparathyroidism. Low calcium (hypocalcaemia) causes a range of symptoms, so if the parathyroids are permanently damaged, you will need to take medication for life and to have regular blood tests.

Thyroid cancer

Most cancers of the thyroid gland are very slow growing and it may be many years before the symptoms become obvious.

There are several different types:

- Papillary thyroid cancer – this is the most common thyroid cancer. It is more common in younger people, particularly women.
- Follicular thyroid cancer – this is less common, and tends to occur in slightly older people than those with papillary cancer.
- Medullary thyroid cancer – this is a rare type of thyroid cancer, which is sometimes hereditary (i.e., it is passed down through a family from one generation to the next).
- Anaplastic thyroid cancer – a rare and aggressive form of thyroid cancer which occurs most often in people over 60.

Thyroid cancer can be ‘differentiated’ or ‘undifferentiated’. ‘Differentiated’ means the cancer cells still look like normal thyroid cells in appearance. They do not spread as rapidly as the undifferentiated type of cancer cells. ‘Undifferentiated’ cells look very different from normal thyroid cells. Papillary and follicular thyroid cancers are both differentiated. Anaplastic thyroid cancer is undifferentiated. There are several less common variants of differentiated thyroid cancer, such as Hurthle cell, tall cell, insular, and columnar.

Most thyroid cancers are very treatable and curable, but it is possible that they will recur. This can occur at any stage, but recurrences can be treated successfully. Life-long follow-up is usually recommended except for some very small cancers treated with surgery alone.

What is the cause of thyroid cancer?

Exposure to radiation either in the environment or due to radiation in childhood is known to increase the risk of getting thyroid cancer. For example, after the Chernobyl accident, many more children in the area got thyroid cancer. It has also been found in people who had external radiotherapy (X-ray treatment) to the neck 10 or 20 years earlier and in people who have had radiation treatment for cancer earlier in life.

In most cases the cause of thyroid cancer is unknown. Medullary thyroid cancer is sometimes hereditary (i.e. it is passed down through a family from one generation to the next). Very occasionally papillary cancer is hereditary.

What are the symptoms of thyroid cancer?

- a painless lump in the neck which gradually increases in size;
- difficulty in swallowing due to pressure of the enlarged thyroid gland on the oesophagus (gullet);
- difficulty in breathing due to pressure of the enlarged thyroid gland on the trachea (windpipe); or
- hoarseness of the voice.

Patients suspected of having medullary thyroid cancer may have some of these symptoms but they may also have diarrhoea caused by higher than normal calcitonin levels. Some patients with medullary thyroid cancer are identified through a DNA blood test.

Cancer cells do not generally affect hormone production from the thyroid, so symptoms of an over- or underactive thyroid are rare.

Often there are no symptoms, however, and it is found by chance.

What tests will I need?

If you have one of the above symptoms, you should discuss these with your GP who will usually examine your neck and arrange a blood test. If your GP thinks the lump in your neck is suspicious they will refer you either to a specialist (usually an endocrinologist or surgeon) or to a Multi-Disciplinary Team (MDT) with a special interest and expertise in thyroid cancer.

Fine needle aspiration (FNA). This is done in an outpatient hospital clinic. A very thin needle is inserted into any swelling you may have in your neck and a sample of cells is taken out. These cells are then analysed under a microscope. This may confirm that thyroid cancer is present but it cannot diagnose follicular thyroid cancer.

Blood tests. Some additional blood tests may be done to re-check the function of your thyroid and your thyroid antibody levels.

Thyroid ultrasound scan. A picture of the thyroid gland is obtained by using sound waves which will show any solid lumps or cysts. This cannot diagnose cancer on its own but it can help with the overall diagnosis and in planning treatment. A thyroid ultrasound scan can often rule out thyroid cancer.

What treatment will I be offered?

You will usually be offered surgery (thyroidectomy).

Surgery is usually the first line of treatment for thyroid cancer. Some people will have a ‘hemithyroidectomy’ or ‘lobectomy’ (half the thyroid is removed). Some people will have a total thyroidectomy (whole thyroid gland is removed). Sometimes the operation is done in two stages, a hemithyroidectomy followed by a ‘completion thyroidectomy’. The type of operation depends on various factors such as the type of thyroid cancer, your age, the size of the lump and results of the tests mentioned above. If the FNA has been inconclusive you will be offered a lobectomy so that the lump can be analysed in the laboratory. If this shows that cancer is present you may be offered completion surgery to remove the other lobe in a second operation.

In some cases some of the lymph nodes in your neck will be removed at the same time.

After a thyroidectomy, you will need to take levothyroxine tablets (also known as synthetic thyroxine or T4) as prescribed for the rest of your life. You will need to have regular blood tests to check that your thyroid hormone levels are within normal limits, and that the TSH level is suppressed. Eventually you should only need a blood test once or twice a year.

(For more information see the BTA Patient Leaflet – thyroid surgery.)

Following your discharge you will need to be reviewed in the outpatient clinic to check how your wound is settling down, your hormone levels and how you are feeling. When you are at home after your surgery, please contact your treatment centre or your GP if:

- you feel extremely tired;
- you have feelings of pins and needles in your hands, feet or face;
- you have palpitations;
- you feel shaky;
- you become very overactive; or
- you generally feel very unwell.

This may mean you need to have your thyroid or calcium levels checked and your medication dose may need to be increased or decreased.

Unless you have medullary thyroid cancer, or anaplastic thyroid cancer, you may need to have radioactive iodine (RAI) treatment after surgery. The purpose of RAI is to destroy any remaining thyroid cells. Your specialist will tell you if you need RAI treatment. RAI treatment is painless. It means taking either one or two capsules or as a liquid, in a single dose. For the safety of others, you need to stay in hospital for the first 2–4 days and to reduce your social contact. If you need this treatment you will be given detailed information by your specialist consultant. (*See also the BTA Patient Leaflet on radioactive iodine.*)

In the early years following RAI you will need to keep your TSH 'suppressed' (i.e. turned off). Your thyroid cancer specialist will advise on the dose and it is important that no-one else changes the dose without discussion with your specialist.

It will be particularly important to have your thyroid hormones checked as soon as it has been confirmed that you are pregnant, as you may need to increase your dose of levothyroxine by about 30%. More frequent checks on your thyroid hormone levels will be required during pregnancy.

Currently, patients in Scotland, Wales and Northern Ireland do not have to pay for their prescriptions. Patients in England taking lifelong levothyroxine or who are diagnosed with hypoparathyroidism are currently entitled to free prescriptions for all medicines. You should obtain the appropriate leaflet from your doctor who will sign it and send it on. You will then receive an exemption certificate, which you must show to your pharmacist when collecting medicines.

Most thyroid cancers are very treatable and curable. There are, however, some more aggressive forms of thyroid cancer that will need a different treatment regimen.

Please contact your specialist treatment centre staff or your GP if you have any questions or concerns after reading this information. Together we can help you through your investigations, treatment and recovery.

Patient support organisations

Being diagnosed with a rare cancer can make you feel isolated. Talking to others who have been through it can help. Support and information are available through the patient-led organisa-

tions mentioned below who have collaborated in writing this leaflet. Together we can give you informational and emotional support to help you through your investigations, treatment and recovery.

Association for Multiple Endocrine Neoplasia Disorders – AMEND. AMEND provides information and support to families with multiple endocrine neoplasia (MEN) and associated endocrine tumours, including medullary thyroid cancer.

Address: The Warehouse, Draper Street, Tunbridge Wells, Kent TN4 0PG

Tel: 01892 516076

Website: www.amend.org.uk

Email: info@amend.org.se.uk

British Thyroid Foundation. The British Thyroid Foundation is a charity dedicated to supporting people with all thyroid disorders and helping their families and people around them to understand the condition.

Address: 2nd Floor, 3 Devonshire Place, Harrogate, West Yorkshire GH1 4AA

Tel: 01423 709707/709448

Website: www.btf-thyroid.org

Email: info@btf-thyroid.org

Butterfly Thyroid Cancer Trust. Butterfly Thyroid Cancer Trust is the first registered charity in the UK dedicated solely to the support of people affected by thyroid cancer.

Address: PO Box 205, Rowlands Gill, Tyne & Wear NE39 2WX

Tel: 01207 545469

Website: www.butterfly.org.uk

Email: enquiries@butterfly.org.uk

Hypopara UK. Hypopara UK is the national patient organisation for people with parathyroid conditions, including post-surgical calcium issues and permanent hypoparathyroidism.

Address: 6 The Meads, East Grinstead, West Sussex RH19 4DF

Tel: 01342 316315

Website: www.hypopara.org.uk

Email: info@hypopara.org.uk

Thyroid Cancer Support Group – Wales. Supporting thyroid cancer patients and families not only in Wales but nationally and occasionally internationally. The group is funding the first national tissue bank specifically for research into anaplastic thyroid cancer.

Address: 'Morcote', Sunlea Crescent, New Inn, Pontypool, Gwent, South Wales NP4 8AD

Tel: 0845 009 2737

Website: www.thyroidsupportwales.co.uk

Email: thyroidgroup@tiscali.co.uk