

Cancer of the thyroid gland is rare, but it is increasing in incidence. Any cancer diagnosis is alarming, but thyroid cancer has a very high cure rate, and fortunately, most patients go on to live a full and normal life.

What are the main types of thyroid cancer?

The types of thyroid cancer that doctors see most are **papillary thyroid cancer** and **follicular thyroid cancer** (together referred to as '**differentiated**' thyroid cancer but other less common forms of thyroid cancer are also seen. This Guide will concentrate on the differentiated thyroid cancers as these are by far the most common. Other forms of thyroid cancer may need different ways to treat them. 'Differentiated' means the cancer cells have similar features to normal thyroid cells.

How is thyroid cancer diagnosed?

If you notice a lump in your neck or have any other symptoms such as rapid growth of a goitre, or symptoms of a hoarse voice, or difficulty in swallowing, you should see your family doctor (GP). **Not all lumps, nodules or swellings in the thyroid gland are cancerous** – in fact most lumps and swellings in the thyroid gland are benign (not-cancer). It is most important, though, that any lump or swelling discovered should be investigated. Likewise, an increase in size of an existing thyroid lump needs to be investigated. Your GP will examine you, carry out thyroid blood tests and may refer you to the hospital to see a specialist for further tests.

In some people, a thyroid nodule that you are not aware of may be identified during medical scanning for another condition. Depending on the size and appearance of it, this nodule may also require further testing.

The specialist will usually arrange an ultrasound examination, in some cases you may also have a fine needle biopsy (or fine needle aspiration cytology – (FNAC)) to remove cells from the lump or swelling so they can be examined under a microscope. About 19 out of 20 thyroid lumps are benign (not cancer). In some cases the biopsy will show there is thyroid cancer present. Unfortunately, sometimes the biopsy does not give a clear answer. In such cases the biopsy may have to be repeated or additional tests may be requested. In some cases the only way of knowing whether a thyroid lump contains cancer cells is to remove part of the thyroid gland by an operation.

What is the treatment for thyroid cancer?

That depends on the type of cancer and the stage at the time of treatment.

Surgery

Papillary and follicular cancers are usually treated by removing the whole thyroid gland (total thyroidectomy). In some cases, however, only the affected side of the thyroid is removed (hemithyroidectomy). The surgeon may also remove some of the lymph nodes in the neck to check whether any cancer cells have spread. There is a small risk that surgery may damage your parathyroid glands (which control the calcium in your body) or your voice. Usually the damage is temporary but in some cases the change may be permanent. Ask your surgeon to explain the risks to you beforehand. National guidelines recommend that your surgery is performed by an experienced **endocrine or head-and-neck surgeon** who frequently does thyroid and parathyroid surgery working as part of a Multi-Disciplinary Team (MDT).

Radioactive iodine

After surgery you may be treated with radioactive iodine, known as radioactive iodine ablation (RAI ablation). You will not be treated with RAI ablation if you still have half your thyroid in your neck, or if the risk of your cancer returning is very small. Normal thyroid cells and thyroid cancer cells are unique because they are the only cells in the body to store radioactive iodine. This means RAI

ablation can be used to treat thyroid cancer without damaging other tissues. The radiation in the iodine destroys the thyroid cells. There are small risks of dry mouth and altered taste and a minimal risk of other cancers which you should discuss with your specialist before you consent to treatment. After RAI ablation, patients can usually be monitored simply by an examination of the neck, blood tests and/or scans to see if the cancer is cured.

Before RAI ablation, it is necessary to stimulate any remaining thyroid cells, whether they are normal cells or cancer cells, in order to increase the uptake of radioactive iodine. This is done by raising the level of thyroid stimulating hormone (TSH). There are currently two ways to do this:

- to have an injection of a man-made TSH called recombinant TSH
- to stop taking your thyroid hormone tablets a few weeks before treatment (thyroid hormone withdrawal)

Both approaches raise the level of TSH, which encourages the remaining thyroid cells to take up the radioactive iodine very effectively.

Recombinant TSH: after removal of your thyroid gland you will be prescribed levothyroxine (**L-T4**). Before RAI ablation you will receive two injections of **recombinant human TSH (rhTSH)**, which is also known as Thyrogen®. Thyrogen® injections will be given into the buttock on the two consecutive days before your RAI ablation. On the third day you will go into hospital for the RAI ablation. You will remain on (L-T4) throughout and therefore you will avoid the symptoms of hypothyroidism.

Thyroid hormone withdrawal: after removal of your thyroid gland you will be prescribed thyroid hormone replacement. If you are due to receive RAI ablation relatively soon after your surgery, you will probably be prescribed Liothyronine (L-T3). L-T3 will be stopped two weeks before the RAI ablation. If there is a longer gap between surgery and RAI ablation, then you may receive L-T4. L-T4 is usually stopped six weeks before RAI ablation and is replaced with L-T3 for four weeks before that also stopped. The withdrawal of thyroid hormones may cause your metabolism to slow down. As a result you may experience symptoms of hypothyroidism, such as feeling cold, having dry hair and skin, constipation, tiredness, and sometimes concentration problems and mood changes. You should be careful if you are using machinery and should avoid driving. Remember that this will pass and you will feel a lot better when you are back on your thyroid medication.

You can also help your treatment by following a low-iodine diet beforehand. Your doctor or specialist nurse will provide guidelines for you to follow, and there are further details about a low-iodine diet on our website.

Radioactive iodine is taken usually as a capsule. You may well need to stay in hospital for a few days in a single room as the treatment will make you radioactive. During this time, and for a short time after you return home, you will need to take precautions to prevent exposing other people to radioactivity, such as restricting the number of visitors and the length of their stay. Your doctor or specialist nurse will provide you with further details about the restrictions you should follow.

If you are pregnant you must not have radioactive iodine. After RAI ablation treatment, women should avoid conceiving for six months and men should avoid fathering children for four months.

In a few cases RAI ablation does not remove all of the thyroid cancer cells and you may need to have a further course of treatment.

Thyroxine (levothyroxine)

Levothyroxine (synthetic thyroxine or L-T4) replaces the thyroid hormone that your body would naturally produce and prevents you from being hypothyroid. You will need to take this for life. The amount of levothyroxine prescribed may be slightly higher than that normally used to treat hypothyroidism (an underactive thyroid gland). This is in order to suppress the blood TSH level, as a high TSH can cause any remaining thyroid cells to grow. For patients who have had an excellent response to treatment, TSH suppression may only be necessary a short time (less than 12 months) after your treatment. You should not alter your dose without discussion with your consultant.

What kind of follow-up will I receive?

The kind of follow-up you receive will be decided by your consultant. People with very small cancers that have been removed surgically may not require follow-up. If you have received surgery and RAI ablation, you will generally get regular blood tests to check your thyroid hormone levels (TSH, T4) and to check whether there is a thyroid protein called 'thyroglobulin' (Tg) in your blood. Tg is only made by normal or thyroid cancer cells, so it acts as a sensitive marker for any remaining thyroid cancer cells in your body. You may also have an ultrasound scan and occasionally other scans may be required. If you have any unexplained symptoms between check-ups you should discuss them with your doctor.

Should you need a radioactive iodine scan, it may be possible to use Thyrogen® instead of stopping the levothyroxine medication.

What about other types of thyroid cancer?

Medullary thyroid cancer (MTC)

MTC is rare and arises in the C cells of the thyroid, which produce a hormone called calcitonin. Some types of medullary thyroid cancer are associated with other endocrine abnormalities and may run in families. In genetic cases there is a 50% chance of each child of an affected parent inheriting the faulty gene. Families with a history of MTC should be referred to one of the UK's genetic counselling centres.

MTC usually requires the whole thyroid gland to be removed (total thyroidectomy). Most people also need some of the lymph nodes in the neck removed at the time of thyroidectomy.. Follow-up is very similar to that with differentiated thyroid cancer with ultrasound scans and blood tests, but measuring calcitonin rather than thyroglobulin.

Neither radioactive iodine nor suppression of TSH to low levels help people with MTC, so you will not need these treatments.

For further information about MTC go to:

The Association of Multiple Endocrine Neoplasia Disorders (AMEND): www.amend.org.uk

Anaplastic cancer

This is another rare and unfortunately aggressive form of thyroid cancer. It usually affects older people. Treatment may involve surgery, chemotherapy and radiotherapy.

Thyroid Lymphoma

There is also a rare condition known as a **thyroid lymphoma** or non-Hodgkin's lymphoma of the thyroid, which occurs mainly in older people.

How will I cope?

Hearing that you might have cancer is a devastating experience. You may feel a whole range of emotions: shock, denial, anger, fear and uncertainty. Waiting for the test results can be very stressful. All these feelings are normal. If you find it hard to talk about it with family and friends, you may find it helpful to talk to someone independent or to other patients who have gone through what you may be experiencing now. Ask your doctor or specialist nurse about support groups or contact the British Thyroid Foundation.

What is the outlook?

The majority of thyroid cancers are treatable. The outlook for differentiated (papillary and follicular) cancer is particularly good and most patients are cured with a combination of surgery and RAI ablation, even if the cancer has spread to the lymph nodes. In a few cases, the cancer does not

respond well to RAI ablation. New targeted treatments, such as tyrosine kinase inhibitors may be available and appropriate to treat these cancers and for advanced MTC when surgery is not possible.

Some important points....

- If you discover a lump you should see your doctor. Benign thyroid nodules and swellings are extremely common but it is important to investigate any new lump or swelling.
- Differentiated Thyroid cancer can usually be treated very successfully and most patients are cured
- After RAI ablation women should avoid conceiving for six months and men should avoid fathering a child for four months

Thyroid problems often run in families and if family members are unwell, they should be encouraged to discuss with their own GP whether thyroid testing is warranted.

If you have questions or concerns about your thyroid disorder, you should talk to your doctor or specialist as they will be best placed to advise you. You may also contact the British Thyroid Foundation for further information and support, or if you have any comments about the information contained in this leaflet.

The British Thyroid Foundation

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The British Thyroid Foundation is a registered charity: England and Wales No 1006391, Scotland SC046037

Endorsed by:

The British Thyroid Association - medical professionals encouraging the highest standards in patient care and research

www.british-thyroid-association.org

The British Association of Endocrine and Thyroid Surgeons - the representative body of British surgeons who have a specialist interest in surgery of the endocrine glands (thyroid, parathyroid and adrenal)

www.baets.org.uk



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