

British Thyroid Association Patient Information Leaflet 6: Advanced or higher risk differentiated (papillary and follicular) thyroid cancer

Many patient information leaflets focus on the diagnosis and treatment of early stage differentiated thyroid cancer. This can be frustrating when you are facing something more complex.

This leaflet aims to explain some investigations and treatments that patients with more advanced or high risk thyroid cancer may need to undergo. It is not possible to mention every situation but the most common ones are explained below.

Hearing that your thyroid cancer is more complex is daunting. Unlike many more common cancers, however, it is often possible to live for longer with advanced or higher risk thyroid cancer and enjoy a good quality of life.

What does advanced or higher risk thyroid cancer mean?

This term is used when referring to patients who need more than neck surgery and one dose of radioactive iodine (RAI) treatment in order to eliminate all traces of thyroid cancer.

This still covers a wide range of situations ranging from someone who may be given a series of RAI treatments to get rid of their cancer completely to someone who may have thyroid cancer that has spread to other parts of the body and who no longer benefits from RAI treatment.

What makes my cancer advanced or high risk?

The risk category that you fall into will depend on factors such as your age, gender, and features related to your particular thyroid cancer. These include tumour size, whether the cancer has extended beyond the thyroid gland; whether the cancer has spread to other parts of the body; whether it is possible to remove the bulk of the cancer by thyroid surgery; and whether the initial RAI treatment has been successful.

The following sections cover a number of different situations that can arise. Not all of them may be relevant to you.

I have had a thyroidectomy and RAI and have been told my follow up thyroglobulin (Tg) blood test has not returned to normal. What does this mean?

If you still have thyroglobulin detectable in your blood this means there are still thyroid cells (either normal or cancer cells) present somewhere in your body. Sometimes in this situation a neck or body scan will not show where the thyroid cells are in the body. This is more likely when the level of thyroglobulin is not very high.

What happens next will depend on your particular circumstances. Your doctor will take into account how close to normal your thyroglobulin result is and the features of your particular thyroid cancer when deciding what to do.

If your thyroglobulin test result is close to normal, you may be advised to have a repeat thyroglobulin blood test after perhaps 6–12 months. Alternatively you may be advised to undergo another RAI treatment. It is not uncommon for patients to need more than one RAI treatment to remove all traces of thyroid tissue (whether that is normal or cancer containing thyroid tissue).

I have had a thyroidectomy and RAI treatment and been told my follow up scan is not normal, what does this mean?

If your follow-up ultrasound scan of the neck has shown enlarged or odd looking lymph glands you may need to have more tests including a biopsy, and you may be referred back to your thyroid surgeon to consider whether the lymph glands can and should be removed. This will depend on where the glands are in your neck, how big they are, how well you are and obviously your wishes.

If surgery is not performed then you will be advised on whether you need RAI treatment or possibly radiotherapy (x ray) treatment instead (described in more detail below).

I have been told that I need radiotherapy to my neck. What does this involve?

Radiotherapy involves using powerful x-ray beams to try and kill cancer cells whilst allowing the normal cells around the same area to survive.

The treatment is given in a radiotherapy department and the machines are called linear accelerators or Linacs.

Treatment is usually given over a period of several weeks on a Monday to Friday basis (no treatment at the weekends usually). You may be in the treatment room for a total of about 20 min each day.

It is important to keep the position of your head and neck as still as possible during treatment so a special plastic mask is usually made that fits snugly around the shape of your face and neck. There are different types of mask. You only wear the mask whilst you are on the treatment bed.

You are treated lying on your back. You do not feel anything whilst the x ray beam is switched on but you can usually hear the machine working.

The treatment is likely to cause some side effects. The commonest ones are:

- painful swallowing
- dry mouth
- dry, red, painful or blistered skin in the region of the treatment
- altered sense of taste
- tiredness
- (feeling sick/nausea and hair loss are not likely to occur)

The side effects will vary depending on exactly what part of the body needs treating and your doctor will explain in detail the likely effects that you might experience and whether they are likely to be temporary or longer lasting.

I am on follow-up and have been told my thyroglobulin blood test result is higher than normal and rising. What does this mean?

Thyroglobulin is only made by normal thyroid cells and differentiated thyroid cancer cells. If you have had your thyroid gland removed and you have received RAI you shouldn't have any normal thyroid cells left, so a raised thyroglobulin level is likely to be due to some remaining thyroid cancer cells. If your thyroglobulin was previously normal, your doctor will discuss with you how best to investigate what is going on.

How is a raised thyroglobulin blood test result investigated?

There are a number of different tests. Not all of them may be relevant to your situation and your doctor will explain what is needed.

Tests include:

- Neck ultrasound scan: this can assess where your thyroid gland used to sit (called the thyroid bed) as well as the lymph gland areas of the neck. It may be combined with a needle biopsy if the scan shows something abnormal
- Computerised tomography (CT) scan of chest: this assesses the lymph nodes in the central area in the chest (called the mediastinum) as well as the lungs
- CT or Magnetic Resonance Imaging (MRI) scan of other parts of the body depending on symptoms and results of other tests
- Isotope bone scan: this involves an injection of a small amount of a radioactive chemical into the bloodstream followed by a scan of the entire skeleton. The radioactive chemical can show areas of bone that are either more active or less active than normal. The results are sometimes difficult to interpret however as arthritis or old fractures can also show up. In these cases your doctor may recommend another type of scan to gather some more information
- Positron Emission Tomography (PET)-CT scan: this is used less often and is another form of radioactive scan

that involves an injection along with a scan of the whole body

I have a raised thyroglobulin blood test but my scans have not shown where my cancer is

This may seem a bit confusing or worrying for you but is a fairly common situation. Your thyroid cancer doctor will have come across this situation a lot of times.

The usual reason for this situation to arise is that very small lesions cannot be seen or may be hidden.

It is common for the thyroglobulin level to rise first before anything can be seen on a scan. Thyroglobulin tests are very sensitive and can detect signs of remaining thyroid cells (normal or cancer containing) or recurring thyroid cancer cells before they become visible on scans.

In this situation your specialist may consider a trial of RAI treatment to see if the whole body RAI scan after treatment shows where the disease is and to see if your thyroglobulin result improves afterwards. This is sometimes called 'empiric' RAI treatment.

Your doctor will discuss the available options with you. This may include simply monitoring the thyroglobulin.

I have a raised thyroglobulin blood test result and scans have shown my cancer has spread to my lungs

Usually there are lots of small areas of thyroid cancer in both lungs rather than one larger lump and because of this surgery and radiotherapy are not usually the right options.

The most likely treatment option to be discussed with you in this situation is RAI treatment. The final decision will however take into account any other medical conditions you may have, how well you feel, and any previous treatments you have received. The possible benefits of treatments along with any side effects will be discussed so that you are able to make a decision that suits you.

I have a raised thyroglobulin blood test result and scans have shown my cancer has spread to my bones

If your scans have shown just one area of bone affected by thyroid cancer your doctor may suggest asking an orthopaedic or spinal surgeon to review your scans to see if surgery may be helpful. Surgery is not always possible however. It will depend on which bone(s) is affected, what the surgery would entail and any other medical conditions you may have.

Radiotherapy (x-ray) treatment is sometimes recommended after surgery or instead of surgery. The number of radiotherapy treatments you are offered depends on a number of factors. One or five daily outpatient treatments are commonly used.

Your doctor will want to know if the bone disease is causing you any problems with pain or with your daily activities and will discuss pain medication and possibly bone strengthening medicine (e.g. bisphosphonates) with you.

I have a raised thyroglobulin blood test result and scans have shown my cancer has spread to lots of different places in my body

Your doctor will need to find out if you are experiencing any symptoms from the areas of cancer shown up on the scans and advise you on how these are best treated. The symptoms will depend on where the areas of cancer are in the body and may include shortness of breath or bone pain.

Thyroid cancer that has spread from the thyroid gland to other parts of the body is called metastatic cancer. These areas are often called 'secondaries'.

It is not always possible to get rid of thyroid cancer once it has spread in this way so the treatment is aimed at trying to reduce the amount of cancer that is present, to improve symptoms, to try and keep people as independent as possible, and to maintain quality of life. It is often possible to live for longer with thyroid cancer secondaries with a good quality of life compared with other cancers you may have heard of.

The first treatment type that is considered in this situation is RAI. This will depend on a number of factors including whether you have had benefit from any previous RAI treatments as well as taking into consideration any other medical conditions you may have and how well you feel. RAI treatment isn't always appropriate.

Chemotherapy (drug treatment) is used in the treatment of many types of cancer but isn't commonly used for thyroid cancer patients. If your doctor feels you might benefit however, they will talk to you about what this would involve and what potential benefits you may gain. The drugs most commonly used in this situation include doxorubicin or epirubicin or a combination of doxorubicin and cisplatin.

I have been told that RAI treatment is no longer working for me

This is a relatively common situation and is often called non RAI avid disease or RAI refractory disease. This occurs when thyroid cancer cells lose their ability to take up RAI and therefore the radiation energy cannot kill off the cancer cells. If this has happened you won't get any benefit from further RAI treatment.

There are new anticancer drugs called 'tyrosine kinase inhibitors' (TKIs) which are becoming available for the targeted treatment of various types of cancers. There are currently no licensed targeted therapies for use in thyroid cancer but this is expected to change. Examples include sorafenib and lenvatinib.

Your doctor will talk to you about any available clinical trials that may be suitable for your situation. These aren't always available in every cancer hospital so if there is a trial available it may involve referring you to another hospital for further discussion.

Patient support

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 organisations 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.

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

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

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

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

The following websites provide additional information:

- Types of scan:
 - www.goingfora.com.
- Radiotherapy:
 - <http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Radiotherapy/Radiotherapy.aspx>.
 - www.goingfora.com/oncology/radiotherapy_room.html.
 - <http://www.cancerresearchuk.org/cancer-help/about-cancer/treatment/radiotherapy/external/plan/radiotherapy-moulds#masks>.

- Drug treatment:
 - <http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Chemotherapy/Individualdrugs/Individualdrugs.aspx>.
- Clinical Trials:
 - <http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Clinicaltrials/Clinicaltrials.aspx>.

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