Thyroid Cancer
For Patients. By Patients.
Third Revised Edition
Living Positively
Racehorse trainer and author Jenny Pitman OBE and BTF Patron, writes:

‘When I was diagnosed with thyroid cancer nineteen years ago I didn’t know which way to turn and quite honestly some of the literature I read was quite frightening. Having studied this new information booklet I am very happy to recommend it and I am sure it will help you to understand the disease and your treatment. Hopefully it will also help you avoid one of the mistakes I made: not discussing my thyroid cancer with my family. I thought if I didn’t mention it they would forget it ever existed. One night at around 1am when I eventually broached the subject with my husband we talked for well over an hour before I went and made us both a mug of tea: I then slept soundly for the first time in many months.’

TV presenter and sports journalist Clare Balding OBE and BTF Patron writes:

‘If you’ve ever been diagnosed with thyroid cancer or suspect that you may have it, this booklet is a must-read. There is valuable information on every page and I would particularly echo the advice to take someone with you when you go to see the specialist. After you hear the word “cancer” you do not really hear much more that is said and you need someone else to ask the appropriate questions.

I had two lots of surgery and radioactive iodine treatment and I barely missed a beat as far as work and life in general were concerned. I decided to attack the disease full on, never to use it as an excuse, and never to get negative about the outcome. It not only helped me to be positive but I do think it helps those around you, who can often worry more than you would.

Having read the booklet again, I now realise that I have been drinking milky tea too close to taking my pills in the morning, which may have been affecting their efficiency. I can therefore recommend reading it more than once, and perhaps getting those you love to read it too.’
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THYROID CANCER has a very high cure rate, of around 96% of cases, and after treatment most patients go on to live a full and normal life. There are people alive now who were diagnosed more than fifty years ago. But if you are worried you may have thyroid cancer, have just been diagnosed, or are going through treatment, you may be feeling bewildered and confused, and you and your family and friends may want to know what is involved and what treatment and support is available to you.

The British Thyroid Foundation (BTF) has produced this booklet in order to provide information about the different types of thyroid cancer, available tests and treatment, and sources of further help. What makes this booklet special is that most of it has been written or reviewed by thyroid cancer survivors who have themselves been through diagnosis and treatment.

This third revised edition has been expanded and updated. We have revised it in line with the British Thyroid Association (BTA) Guidelines for the Management of Thyroid Cancer (third edition, 2014) and Patient Information Leaflets. These documents emphasise personalised decision making, especially if there is uncertainty as to which treatment options are best for an individual patient. We have also included new information in response to patients’ comments.

The information about the low iodine diet has been revised in line with the findings of the UK Low Iodine Diet Working Group 2016. There is also additional guidance about the treatments which may be used for patients with advanced thyroid cancer.

At the back of the booklet there is a helpful glossary which defines all of the words in bold italics. We have also provided checklists of questions to ask your doctors at different stages of your treatment which we hope you will find useful. Do contact us if you have suggestions to add to these.

Please let us know what you think of this booklet. Your comments will help us when we next revise it. Please email us at: books@btf-thyroid.org or write to the address on the back cover and mark your envelope: ‘BTF Cancer Booklet: Comments’.

We are particularly grateful to Dr Kristien Boelaert, Dr Carla Moran, Mr Mark Lansdown, Dr Petros Perros, Prof Mark Strachan, Jackie Kehoe, Peter Esslemont, Dr Fiona Riley and Judith Taylor for their comments and helpful suggestions; to Ingrid Haupt-Schott for help with the LiD; to Leeds Cancer Centre for kindly providing photographs to use in this booklet; and to all of the patients and medical professionals who have reviewed this booklet and made helpful contributions along the way.
Last but not least, we are very grateful to our BTF thyroid cancer telephone contacts, who are all volunteers with personal experience of thyroid cancer. They are always ready to listen and give you information and emotional support if you are facing a diagnosis of thyroid cancer or have questions about treatment, or if you simply want to talk. Their contact details can be found on the BTF website.

Janis Hickey
BTF Founder and Director

Julia Priestley
BTF Development Officer

Acknowledgments

We would like to dedicate this third edition of the Thyroid Cancer Booklet to Carole Ingham who played a key role in producing the first edition. Carole was a tireless and enthusiastic supporter of the BTF and made an important difference to the lives of thyroid patients in her role as local coordinator, telephone contact and BTF trustee.
ALTHOUGH thyroid cancer is considered to be a rare cancer, the number of cases is increasing each year. According to statistics from Cancer Research UK (CRUK), over 3,200 people (including more than 2,400 women) were diagnosed with thyroid cancer in the UK during 2013, and it is now the 19th most common cancer which affects women. The CRUK statistics team estimates that the lifetime risk of developing thyroid cancer in the UK is now one in 842 for men and one in 324 for women.

Thyroid cancer starts in the thyroid gland, one of the endocrine glands in the body. It has been estimated that 15-20% of the UK population have an enlarged thyroid gland known as a goitre. It can be diffuse, involving the whole gland; or nodular, consisting of one (solitary) or more (multi-nodular) lumps (also known as nodules). Most nodules are harmless. The cause of most thyroid nodules is unknown but some are due to autoimmune conditions such as Hashimoto’s thyroiditis or Graves’ disease. It is best to have them checked promptly in case they are among the few that are cancerous.

If you have a longstanding goitre and notice any change, such as a new nodule or increase in size of a previously stable nodule, you should ask your GP to refer you to an appropriate specialist.

CHAPTER 1: What is thyroid cancer?

This is a diagram of a normal thyroid gland. The thyroid sits in the neck below the Adam’s apple, is butterfly-shaped and has two lobes joined by a narrow strip called the isthmus. It makes, stores, and releases three thyroid hormones: thyroxine (T4) and triiodothyronine (T3), which are both vital for the body to function normally; and another hormone called calcitonin which influences calcium levels but is not crucial for well-being. The parathyroid glands, of which there are usually four, are situated behind (or sometimes in) the thyroid gland. The parathyroid glands are important in regulating calcium levels in the blood.
What are the main types of thyroid cancer?

Thyroid cancer can be differentiated, undifferentiated or medullary. ‘Differentiated’ means the cancer cells still look like normal thyroid cells in appearance and do not spread as rapidly as the undifferentiated type of cancer cells. ‘Undifferentiated’ cells look very different from normal thyroid cells. There are four main types of thyroid cancer:

Papillary cancer – this is the most common type of differentiated thyroid cancer. It is more usually seen in younger people, in particular women of child-bearing age. About 80% of differentiated thyroid cancers are papillary.

Follicular cancer – this is a less common type of differentiated thyroid cancer which tends to occur in slightly older people. About 20% of all differentiated thyroid cancers are follicular. The cells often look very similar to normal thyroid cells but can be a different shape. There is also a mixed or follicular variant of papillary thyroid cancer.

There are several less common variants of papillary and follicular thyroid cancer, such as Hurthle cell, tall cell, insular and columnar cancers.

Medullary cancer – this is an uncommon form of thyroid cancer. It arises in the parafollicular C cells of the thyroid, which produce calcitonin. It can occur in association with other endocrine disorders. Some types of medullary thyroid cancer run in families.

Anaplastic cancer – a very rare and aggressive form of thyroid cancer which occurs most often in people over 60. It is an undifferentiated thyroid cancer.

There is also a rare condition known as a thyroid lymphoma, or non-Hodgkin’s lymphoma of the thyroid, which occurs mainly in the elderly.

What is the outlook?

Any diagnosis of cancer is alarming, but thyroid cancers have a very high cure rate, and most patients go on to live a full and normal life. It is possible that they will recur, especially in the very young and very old. This can occur at any stage but recurrences can be treated successfully so life-long follow-up is most important.

The outlook for differentiated (papillary and follicular) cancer is particularly good, and most patients are cured with a combination of surgery and radioactive iodine ablation.

Differentiated thyroid cancer is usually slow-growing and even if it has spread to the lymph nodes in the neck, the outlook is still good. Distant spread, or
metastases, to other parts of the body is far less common, and is mainly in the bones and lungs. If it spreads, there is usually treatment available to control the cancer for a long time.

**What causes thyroid cancer?**

There are some known causes of thyroid cancer, although in most cases, the cause is not known.

Thyroid cancer can be caused by excessive radiation exposure either in the environment or due to radiotherapy treatment during childhood. It has been linked to radiation to the head and neck area given to some children in the 1950s and 1960s for common disorders such as acne and tonsillitis. Fortunately these treatments have long since been discontinued.

It is now known that some forms of thyroid cancer are hereditary. Medullary cancer has been the most extensively investigated to date. Approximately 25-30% of medullary thyroid cancer cases are hereditary, either arising alone within a family (familial medullary thyroid cancer) or as part of a syndrome called *Multiple Endocrine Neoplasia Type 2* (MEN2 or Type 3 (MEN3, previously MEN2B)), which causes more than one gland of the body’s endocrine system to develop tumours. Approximately 80% of cases of medullary thyroid cancer are sporadic, i.e. arising as an isolated case, and the cause is not known. In hereditary cases of medullary thyroid cancer there is a 50% chance of each child of an affected parent inheriting the faulty gene. Families with a history of medullary thyroid cancer should ask their doctor to refer them to one of the UK’s genetic counselling centres to discuss the possibility of genetic testing.

There has recently been some research into hereditary forms of differentiated, i.e. papillary and follicular thyroid cancer. The collective name for these forms is *hereditary non-medullary thyroid carcinoma*, or HNMTC. It has been estimated that someone who has a first-degree relative with thyroid cancer has a risk of developing thyroid cancer that is five to ten times higher than the general population. The general recommendation is that when three or more members of a family are affected by thyroid cancer, these cases should be considered to be HNMTC. Families with three or more members with thyroid cancer should, therefore, ask to be referred to a genetic counselling centre.

People identified by their GP as having familial thyroid cancer, neck irradiation in childhood and/or family history of MEN2 or MEN3, should be screened for thyroid cancer.

People with a statistically increased risk of thyroid cancer but who are not required to be screened include those with endemic goitre, Hashimoto’s thyroiditis (risk of lymphoma), *Cowden’s syndrome* (PTEN mutation), obesity, and a family or personal history of thyroid adenoma or adenomatous polyposis.
What are the symptoms of thyroid cancer?

Thyroid cancer is normally found when a lump appears on the thyroid or in the lower neck. Sometimes there are more subtle symptoms or no obvious symptoms at all and thyroid cancer is found by chance. Symptoms can include one or more of the following:

- A painless swelling or lump (nodule) in the thyroid or lower neck
- Hoarse voice
- Difficulty in swallowing and awareness of pressure when swallowing
- Difficulty in breathing, especially when sleeping

If you discover a lump, however small, you should immediately see your doctor. Not all lumps, nodules or swellings in the thyroid gland are cancerous – in fact, benign thyroid nodules and swellings are extremely common. It is most important, though, that any lump or swelling is investigated straightaway.

Sometimes the raised calcitonin level that may occur with medullary thyroid cancer may cause diarrhoea, and it may not be immediately apparent that this is associated with a problem with the neck. Medullary cancer is diagnosed with blood tests, biopsy and scans.

How would I know I have thyroid cancer?

If you have any of the symptoms listed above you should discuss these with your GP who will usually examine your neck and arrange a blood test. GPs should always make an urgent referral to a specialist for any lump in the neck that they consider to be suspicious (see below).

If your GP does not think the lump is suspicious you may simply be asked to monitor yourself and to return if there is no improvement. If you continue to be concerned, you should ask to be referred to a specialist.

When further investigations are needed your GP 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. According to the Department of Health document Cancer Waiting Times: A Guide, all patients with possible cancer should be seen within two weeks. However, the BTA Guidelines for the Management of Thyroid Cancer 2014 do not recommend that all nodules are referred under the two week rule but only those with suspicious clinical features. It is proposed that optimum care can be provided by adopting a target of four weeks from first referral to initial assessment. You do not need to have a thyroid scan before referral; this can be organised quickly by the hospital team if required.
If you have **stridor** (an abnormal high-pitched wheezing caused by a blockage) as well as a lump your GP may request an emergency referral the same day.

**Patients write:**

I had gone to the doctor with constant sore throats and then a small painless lump appeared on the right side of my neck.

I had a goitre that was drained twice but continued to grow and press on my windpipe.

After my third daughter was born I never felt quite myself. Then after a year my mother noticed a swelling on my neck.

I noticed a swelling on my neck but no other signs or symptoms.

I first noticed a painless lump about the size of an almond in the middle of my neck at the front. I contacted the doctor who told me it was just a cyst and it would go down in a few days. I wasn’t happy with this and asked her to refer me, I think I just knew it wasn’t right.

### Checklist

- [ ] Do I have a lump, swelling or any other symptoms?
- [ ] Should I see my GP?
- [ ] Do I want a family member/friend to accompany me to the appointment?
- [ ] If I am asked to monitor myself what should I look for, and when should I return to see my GP?
- [ ] If I need further investigations who will I be referred to and are they a thyroid specialist?
- [ ] Will an appointment be made for me?
CHAPTER 2: Getting a diagnosis

IF YOU ARE referred to a specialist it is a good idea to write down your questions before your appointment. This will help you concentrate on what is being discussed with you during your appointment and to remember the questions you want to ask. There is a checklist of questions you might want to ask at the end of chapters 1, 2, 4 and 5 (and a complete set of checklists in Appendix 2) and of course you can add your own questions to the list. Some people find it helpful to take a friend or family member along with them to appointments.

What tests am I likely to have?

Your specialist will ask some questions about your medical history and do a physical examination. You will need to have some tests depending on your symptoms. These tests may include:

**Fine needle aspiration cytology (FNAC)** – this is a biopsy to obtain cells and/or fluid from the lump for examination. A very fine needle is inserted into the thyroid and sucks some cells out. The sample is sent to the laboratory for analysis. This test can confirm that there is thyroid cancer present, but cannot always effectively rule it out. Some centres offer a core biopsy that takes a little more tissue;

**Blood tests** – to check thyroid hormone concentrations and general health;

**Thyroid ultrasound scan** – this locates any solid lumps or cysts. Often the thyroid ultrasound can indicate if a lump is benign or not. If the nodule looks suspicious on ultrasound a fine needle aspiration biopsy is usually performed. Sometimes it is unclear if the lump is suspicious or not and a fine needle aspiration biopsy is usually undertaken in that instance;

**CT or MRI scan** – sometimes a computed tomography (CT) or magnetic resonance imaging (MRI) scan is done to help the diagnosis and plan surgery. If you have a CT scan it is important for this to be done without iodinated contrast medium as this could affect the uptake of iodine should you need radioactive iodine treatment after surgery;

**Isotope bone scans and Positron Emission Tomography (PET)** – these scans may be used to gather more information on the entire skeleton or whole body.

More detailed information about all of these tests will be available from the hospital. You should ask your specialist or the hospital staff if you have any questions.
When and how will I hear the results?

Reaching a diagnosis can take time. It takes one to two weeks for the laboratory to examine a biopsy and issue a report. Your specialist needs to gather all the information first and often a multi-disciplinary discussion looking at all the results is undertaken. Some tests may need to be repeated to confirm your diagnosis and to decide on the right treatment.

Some people feel they can cope better alone, but you may find it helps to take a family member or close friend with you for support when you go for your results. You may be told straightaway whether you have thyroid cancer or not. There are, however, times when the results are inconclusive and cancer cannot be either confirmed or ruled out until after surgery. The tissue that is removed will be examined and a diagnosis given. If a diagnosis of cancer is given after surgery you may need a second operation to remove the rest of the thyroid.

The specialist will provide you with full information about your diagnosis during your meeting together and/or give you a contact name and number to call at a later date.

It can be hard to take in all the information at once so it is a good idea to take a pen and paper to make some notes. Don’t be afraid to contact the hospital later if you still have questions.

Some teams have a nurse specialist who will spend time talking with you about the diagnosis, helping you to plan your future treatment, and ensuring you are at ease before leaving the hospital. The nurse may give you some contact details so that you can get answers to questions you think of later. Some hospitals have a dedicated room in which this conversation can take place.

The emotional impact of the diagnosis

Waiting for results and details of any future treatment can be an anxious time for you and your family. If you hear the words ‘You (may) have cancer’ your world turns upside down, your stomach churns, and you wonder if you will ever lead a normal life again. You may feel a whole range of emotions: shock, denial, anger, fear and uncertainty. All of these feelings are normal.

Each person deals differently with this and there is no right or wrong way for you to handle the news. Those around you may be finding it difficult to cope too.

If you find it hard to talk about your feelings with family and friends, you may find it helpful to talk to someone independent, or someone who has already been through it. Some hospitals have their own support groups and can put you in touch with patients, or you can contact the British Thyroid Foundation (BTF) who will have a list of telephone contacts that you can speak to. (See Appendix 3: Useful contacts.)
Patients write:

I was just 18 when I was diagnosed and my life turned upside down.

I handled the diagnosis very well; I have always been a carefree sort of person. I think my partner was affected emotionally by the diagnosis a lot more than me but because I was so positive that helped her to cope.

When I heard the words ‘you may have cancer’ my first reaction was to look at my watch. I wanted to get away ... I felt like something - or someone - had suddenly taken over control of my life.

It was like hitting a brick wall.

All I could see was the consultant’s chin going up and down, but I could hear no words, so the moral to this is always have someone accompany you on every visit to the hospital.

When I was first told it was cancer, my husband was with me and I remember telling the doctor just to stop talking and let me get my head sorted. He was very kind and let me calm down before he carried on. I just remember hearing it was the best cancer to get, and I just had a faulty gene. It doesn't feel like a good cancer when you hear that word !!!

I felt relaxed when I was diagnosed, it was a relief to know what was wrong with me. I didn't feel scared. The time not knowing was scarier, once I knew what was wrong with me I knew what I had to fight.

When I was first diagnosed my first feeling was disbelief, as there had not been any mention of cancer before then. My feelings when I saw my children were pain and anguish, would I see them grow up?

When I was first diagnosed I was shocked and didn't want to know anything about thyroid cancer but after a couple of weeks I started to search online for information. I found some websites gave odd and misleading information. At my next appointment I told my surgeon and he gave me details of a good and factual website, so I would advise anyone else to be cautious about online information. The last thing you want at this point is to scare yourself unnecessarily!
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<td>□ Is there a special/private room where I can receive the diagnosis?</td>
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<td>□ How am I feeling? Would it help me to talk to medical support staff, family, friends, or someone who has had treatment after a similar diagnosis?</td>
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<td>□ Is support available for my family member(s)?</td>
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CHAPTER 3: Treatment

TREATMENT DEPENDS on the type of cancer and the stage at the time of diagnosis and typically occurs within 30 days of diagnosis. In most cases of thyroid cancer a **total thyroidectomy** will be performed but sometimes removing just one side (**hemithyroidectomy** or **lobectomy**) is sufficient. Sometimes some lymph nodes are also removed.

You should be treated by a regular member of a Thyroid Cancer **Multi-Disciplinary Team (MDT)**. The MDT will normally consist of an endocrinologist, a surgeon, an oncologist (or nuclear medicine specialist), with support from a pathologist, medical physicist, biochemist, radiologist and specialist nurse, all with a special interest in thyroid cancer. You may not always be seen by the same doctor on every visit so the treatment may seem less ‘personal’, but we think this is far outweighed by having expert care and advice.

Papillary and follicular thyroid cancers, including Hurthle cell cancers, are treated by surgery which is sometimes followed by **radioactive iodine ablation**. You will only have surgery (and not follow-up radioactive iodine ablation) if the pathology report is favourable, the tumour is less than four centimetres, and the tumour has not extended beyond the thyroid capsule. (British Thyroid Association **Guidelines for the Management of Thyroid Cancer 2014**.)

Medullary thyroid cancer has varying levels of aggressiveness but tends to be slow-growing and a cure is possible if surgery is performed early. Even if this is not the case it is possible to use surgery and other treatments to control the cancer for a long time. The Association for Multiple Endocrine Neoplasia (AMEND) can provide you with more detailed information about medullary thyroid cancer. (See Appendix 3: Useful contacts.)

Anaplastic thyroid cancer is more difficult to treat. It does not respond to radioactive iodine ablation. **External beam radiation** and **chemotherapy** are often used, and there are treatments available to alleviate symptoms. There are clinical trials currently taking place so there is hope for better treatment in the future.

Thyroid lymphoma is treated with radiotherapy or chemotherapy or a combination of both and most patients respond well to this. The diagnosis can often be made from a core biopsy and surgery is seldom needed.

Surgery for all types of thyroid cancer is followed by **levothyroxine** treatment unless only a hemithyroidectomy or lobectomy was required. Even then, if the remaining lobe does not produce sufficient thyroxine then levothyroxine will be required. Levothyroxine is a synthetic form of the thyroid hormone thyroxine (T4)
and provides you with the hormones your body is no longer able to produce. You will need to take tablets every day for the rest of your life, but it is simple to take, free of charge, and quickly becomes routine, like brushing your teeth. (See Chapter 7: Thyroid medication.)

Sometimes thyroid cancer is diagnosed during pregnancy. Depending on when it is diagnosed, the surgery may take place either during the pregnancy itself or after the pregnancy. Your doctor will discuss the options for treatment with you.

If you live alone and do not have family or friends who can help you when you come out of hospital, talk with your doctor and the medical team at the hospital beforehand about what support is available.

A patient writes:

My diagnosis was at 32 weeks of pregnancy and my surgeon advised me to have surgery two weeks later as the pregnancy hormones were making the tumour grow fast. Because the surgery is not abdominal, I was told that being under anaesthetic would pose no threat to my baby, but to reassure me I was on a baby monitor and had a midwife present throughout. I had steroid injections beforehand to help with the baby’s lung development. My baby woke up as soon as I did. I gave birth normally with no pain relief at 40 weeks. Baby was 7 lb 3 oz and no intensive care was required. I breastfed for 12 weeks and stopped completely three days before RAI.
CHAPTER 4: Surgery

Preparation for surgery

YOU WILL NORMALLY be given an appointment to see the surgeon and to have a pre-operation check a few days before the operation.

Thyroid surgery has been traditionally performed by general surgeons but there is an increasing trend towards specialisation. Department of Health Cancer Standards require that surgeons who operate on patients with thyroid cancer should perform a minimum of 20 thyroidectomies each year. We recommend that your surgery is performed by an experienced endocrine or head-and-neck surgeon who regularly does thyroid surgery, and works as part of a Multi-Disciplinary Team (MDT). Don’t hesitate to check your surgeon’s experience and ask any questions, such as the number of thyroid operations your surgeon performs each year and their rate of complications, before you decide (see the checklist at the end of this chapter). Thyroid surgeons are now required to make public their results as part of a national audit project. Before the operation you will be asked to sign an informed consent form and you should be given written information about the proposed surgery, and the possible risks, such as bleeding, scarring, infection or voice changes.

If you do not understand any of the information you are given, please ask. It is important for you to make the choice that you are comfortable with.

Your surgeon should also perform a vocal cord check before the operation, to check their current state. If you are in any doubt, ask beforehand.

If you depend on your voice in your work, or if you are a singer (or both) discuss this with your surgeon and make sure they are aware of how important this is to you. There is a small risk that the nerves that control the voice box can be damaged during surgery, resulting in temporary and sometimes permanent voice change. This could make it difficult for you to project your voice in a classroom, for example. There is always some risk, even in very experienced hands, depending on the size of the tumour and the extent of nerve involvement, but this risk is smallest in experienced hands. Some surgeons use intra-operative recurrent laryngeal nerve monitoring during the operation to reduce the risk of damaging these nerves. Sadly even when the nerves remain intact the voice can still change subtly which can be a problem for singers especially.

The parathyroid glands, which control the level of calcium in your body, are at more risk of accidentally being damaged during surgery for thyroid cancer than during other types of thyroid surgery. As part of the routine pre-operative check before surgery you should have a blood test for calcium and for vitamin D, if you think you are at risk of low levels. Even in the best hands, there is a small chance
of temporary, or in a few cases, permanent, parathyroid damage. Most people
have four (or sometimes more) parathyroid glands, about the size of a grain of
rice, which are usually next to or sometimes embedded in the thyroid gland.
These glands control the amount of calcium in your body. Bruising or,
occasionally, removal of one or more parathyroid glands, or disruption of the
blood flow to these glands, is sometimes unavoidable, and can result in low blood
calcium, or **hypocalcaemia**. (See the section on *Possible complications of
surgery* in this chapter.)

The operation will involve you having a **general anaesthetic**. If you know that
you are prone to nausea after an operation, it is a good idea to mention this to the
**anaesthetist** and discuss if you can have an anti-sickness tablet. (As a general
rule, people who are travel-sick tend to be more prone to sickness after an
operation.)

If you would like to speak to former patients who have been through surgery for
thyroid cancer, ask the hospital whether they are able to arrange this, or contact
the BTF to get in touch with one of the volunteer telephone contacts.

**During surgery**

If thyroid cancer has already been diagnosed, the surgeon will discuss with you
whether to remove one side of the thyroid (this is called a **lobectomy** or
**hemithyroidectomy**) or the entire thyroid gland (this is called a **total
thyroidectomy**).

If thyroid cancer is suspected but not confirmed before surgery, it is more usual to
remove only the half that contains the lump. Depending on the pathology results,
the surgeon may remove the other half in a second operation a few weeks later.

Sometimes cancer is detected in one or more lymph nodes, which will involve
more extensive neck surgery such as a **selective neck dissection**. Be sure to
discuss the options thoroughly with your surgeon before the operation so that
you feel confident that you understand what it involves.

**After surgery**

You will be propped up in bed to help reduce swelling and may be given extra
oxygen. Most patients are up and walking after the first day. A member of staff will
help you to the toilet at first.

There will be a tube – known as a **cannula** – in the back of your hand in case you
need a drip, or you may already be on one. There may also be one or more tubes
near the wound to drain away excess blood and fluid that will be regularly emptied.
and cleaned by a member of the nursing staff. They will usually be removed a day or two after your operation when there is very little fluid coming through.

There are many ways of closing the wound including clips, staples, stitches or a special type of glue. Before the operation you can ask the surgeon what they will use. You might have some bruising beyond the site of the thyroid area (for example, on your face and chest) which could be a bit of a shock to you and your visitors, but any bruising will disappear quickly over the next few days.

For a short period after your operation you may find it painful to swallow but you should be able to eat and drink without too much difficulty a few hours after the operation. You may feel some discomfort, soreness and stiffness around your neck. If you do feel uncomfortable at any time you can ask for a painkiller.

You can expect to spend up to a few days in hospital depending on how quickly you recover. Depending on the length of your stay, the clips, staples or stitches may be removed while you are in hospital or you may be given an appointment to have them removed after you return home. The scar may be thick or thin depending on skin type, pigment and age.

You will need to take it easy while your neck wound is healing and you will be given painkillers to take home to relieve any discomfort. Any swelling, discomfort or numbness will gradually ease as healing takes place.

After a few weeks your neck and shoulder movements should be back to normal. If you had more extensive neck surgery to remove lymph nodes you may be referred to a physiotherapist.

**Taking care of the wound**

You will be told how to clean the wound when you leave the hospital. It must be kept clean around the edges by using warm water and patting dry. Avoid using cotton wool as this sticks to the wound, use gauze instead. Keep the wound as dry as possible after cleansing. It will start to feel tight as the healing process begins – creams such as calendula, Nivea, aloe vera, E45 or any non-perfumed moisturiser regularly applied keeps the area supple. Arnica cream is excellent for bruised areas but must not be used on broken skin. The pressure of rubbing the cream in will also help soften the scar.

The scar will be in a natural crease line. Most scars will eventually become very faint. People with fair skin are often pleasantly surprised to see that their scar is barely noticeable after six months (see picture). You should always protect a new scar from the sun for the first few months, however, otherwise it may tan a different shade from the rest of your skin and this will make the scar more noticeable.
In a few cases the scar can be disfiguring. Examples include *widened scars*; *hypertrophic scars* which are usually raised, red and itchy, but tend to flatten over time; and *keloid scars* which tend to remain raised, red and itchy. People from darker skinned groups tend to be more susceptible to keloids. The possible treatments for raised or widened scars include vitamin E oil, topical steroid creams, and silicon gel sheeting. If these treatments fail, steroid injections or scar revision by a cosmetic surgeon may be worth considering.

**Possible complications of thyroid surgery**

**Voice**  – Your voice may be noticeably weaker or more hoarse than normal. This will be monitored by your consultant. Generally your voice recovers completely within a few months, but if not, further treatment may be required. This usually involves speech therapy but if one or both of the *recurrent laryngeal nerves* have been damaged, *phonosurgery* (surgery to the voice box) may improve matters.

**Parathyroid damage**  – If your whole thyroid has been removed blood will be taken after surgery to check your calcium levels. However if you experience a tingling sensation in your hands/fingers or around your mouth, you should immediately alert a member of the medical team, as this can mean that your calcium levels have dropped. Should this happen, you may need to take calcium and/or vitamin D supplements (Alfacalcidol or Calcitriol) to correct this. Untreated, low blood calcium can lead to severe muscular spasms, known as *tetany*. Fortunately you do not need all four parathyroid glands, and even if one or more is bruised or removed, in most cases the remaining parathyroids will begin to work properly again, usually within a few days or weeks, although sometimes it can take several months.

As long as your body is producing at least some *parathyroid hormone* (PTH) you may be able to be weaned off supplements. Any attempts to withdraw the
medication should be done under medical supervision. The BTA Guidelines for the Management of Thyroid Cancer (2014) set out information that covers this topic. A few people, however, need to take calcium and vitamin D permanently. The likelihood of this will depend to some extent on the type of operation you need. If this happens it is important your calcium levels, bones and kidneys are monitored long term and sometimes adjustment of your medication is needed. A temporary or permanent deficiency of parathyroid hormone is called hypoparathyroidism. A patient leaflet has been produced by Hypopara UK in conjunction with the Society for Endocrinology is available from Hypopara UK. (See Appendix 3: Useful contacts.)

Patients write:

I felt very lonely after the surgery, very tired and low as I had two drains attached. Once they were taken away I started to feel a bit brighter. As I hadn’t told my kids about the cancer I felt very isolated as I didn’t want them to visit but I realise now it was a daft thing to do even though I was only trying to spare their feelings. I would advise other patients to tell their family and friends and have as much support as they can get.

I had a total thyroidectomy and modified radical neck dissection (removal of lymph nodes in the neck) and it was a four-hour operation so I was given calcium and monitored very closely for the next few days in case there was any parathyroid damage. My calcium levels returned to normal after 24 hours.

The aftercare I received from all of the hospital staff was fantastic.

Half the clips were removed and surprisingly I didn’t feel a thing.

I was devastated to hear after my first surgery that the surgeon had ‘touched’ one of the recurrent laryngeal nerves and he thought I might never sing again. I was so happy to prove him wrong! Luckily I was able to continue singing in a choir, although I have had to transfer to the alto line. My speaking voice, though, has suffered and I still find it hard to raise my voice in a noisy restaurant or bar.

I had numbness and pins and needles in my mouth, hands and feet the day after surgery. Fortunately I knew to call for help. I was put on calcium and alfacalcidol and was in hospital for two weeks. I’m now two years post-op and still have fluctuating calcium levels. I have regular appointments at my GP and endocrinologist, I can have a calcium blood test when I feel like I need one and I am getting good support. I take levothyroxine, calcitriol (vitamin D supplement) and sandocal (calcium supplement). I do think the effect all this has on the rest of the family is under-estimated.
### Checklist

#### Before surgery
- Do I want a family member/friend to accompany me to the appointment?
- How many thyroid surgeries has my surgeon performed? How many this year?
- Which tests will be carried out before the operation?
- What are the risks of voice and/or parathyroid damage?
- Is intra-operative laryngeal nerve monitoring available during the operation?
- Will I have a vocal cord check?
- Will I have a parathyroid function test?
- Will some of my parathyroid tissue be transplanted?
- How much of my thyroid will be removed?
- Will any lymph nodes be removed?
- How will the wound be closed?
- Where will the scar be?
- Can I get an anti-sickness tablet if I need one?
- How many days will I be in hospital?

#### After surgery
- When will my stitches be removed?
- Have I been shown how to clean the wound?
- What treatment will I have after surgery, and where?
- Will I be on thyroid medication (levothyroxine) after surgery? If so do I have a prescription?
- Have I requested a prescription charge exemption form from my GP’s surgery?
- Have I got a follow-up appointment or have I been told that one will be sent to me?
- Have I got the contact details of a nurse or doctor if I have any follow-up questions?
- How am I feeling? Do I need to talk to medical support staff, family, friends, or someone who has been through similar surgery?
IF YOU HAVE BEEN diagnosed with papillary or follicular thyroid cancer you may have radioactive iodine ablation (*RAI ablation*) within a few weeks of surgery, depending on the size of the tumour, type of cancer, and risk of residual diseased thyroid cells. The thyroid gland is the main organ in the body that takes up iodine, and therefore the purpose of RAI ablation is to take up radioactive iodine into the remaining thyroid cells, whether normal or cancerous, and destroy them. RAI ablation has been used since the early 1940s and is considered extremely safe for patients.

This treatment is not given to people with medullary thyroid cancer as this type of cancer arises from the C cells which do not take up iodine.

RAI ablation is also avoided if you are currently taking anti-arrhythmic medication, such as amiodarone, or have taken it in the last 12 months, due to its high iodine content. It is given either as a capsule or as a drink and it looks and tastes like water. Before giving the treatment some centres perform a scan to determine how much normal tissue remains after surgery.

It is very important that you do not have RAI ablation if you are pregnant, or think there is a chance that you may be. If you are a woman of child-bearing age, your hospital may ask you to take a pregnancy test before giving you the RAI ablation.
If in doubt, ask. (For further advice on fertility and pregnancy after RAI ablation, see Chapter 10: Life after thyroid cancer.) If you are breastfeeding you should stop this at least six and preferably eight weeks before RAI ablation and you should not begin breastfeeding again until after a future pregnancy.

**The countdown to RAI ablation**

If you are already taking thyroid medication, you will need to stop this a few weeks before having RAI ablation. This is to ensure your body has a high *thyroid stimulating hormone (TSH)* concentration as this allows any cancer cells to absorb the radioactive iodine better.

If you were prescribed *liothyronine* (T3) tablets after the operation you will be asked to stop taking these about two weeks before the ablation. If you are taking levothyroxine tablets (T4) you will be asked to stop these about four weeks before the RAI ablation; some doctors may change your tablets to liothyronine (T3) for two weeks followed by two weeks with no medication.

One less pleasant effect of thyroid medication withdrawal in the preparation for RAI ablation is that your metabolism will slow down. Your body will need to work harder than usual, and you may experience some of the symptoms of *hypothyroidism* (an under-active thyroid), such as, feeling cold, dry hair and skin, constipation, tiredness, and sometimes concentration problems and mood changes. You should exercise care in using machinery and should preferably avoid driving. You may be required to inform your car insurance company and the Driver and Vehicle Licencing Agency (DVLA) about your medical condition. You may also wish to let your work colleagues know how you feel.

As you slow down down, especially in the last one or two weeks, you may find it more of a challenge to do things in the way that you are used to doing them. It may help to plan ahead and stock up your store cupboard, and you may find it more convenient to shop online. It is also a good idea to prepare some (low iodine) meals beforehand and store these in the freezer. Don’t hesitate to ask family and friends to help, for example, with doing the shopping or housework or picking your children up from school.

Not everyone experiences thyroid hormone (levothyroxine or liothyronine) withdrawal in the same way; some will have very few symptoms, while for others it can be fairly severe. Remember, this too will pass, and you should feel a lot better once you are on thyroid medication again.

**An alternative to levothyroxine withdrawal**

Nowadays there is an alternative to stopping levothyroxine treatment. It is possible to be injected with *recombinant human TSH (rhTSH)* which is also
known as Thyrogen®. Recombinant human TSH raises the body’s TSH levels while remaining on levothyroxine. The use of rhTSH means that you do not have to stop taking levothyroxine and therefore you avoid the symptoms of hypothyroidism.

Thyrogen® is licensed in the UK both for post-surgical RAI ablation and for follow-up (for whole-body scans and measuring thyroglobulin) in differentiated thyroid cancer. There may be a few side effects such as nausea or headaches, but these symptoms are not usually severe and do not last long.

You should talk to your specialist about whether you can use Thyrogen® and about the pros and cons. Your doctor may recommend thyroid hormone (levothyroxine or liothyronine) withdrawal if Thyrogen® is not in your best interests.

If you are having Thyrogen® for RAI ablation you will be given an injection on two consecutive days and will go to the hospital for the radioactive iodine dose on the third day. You will probably go to your GP for the injections, which are given in your buttock.

**Patients write:**

*Having to stop taking levothyroxine for four weeks prior to having a whole-body scan made me feel so ill from the effects of hypothyroidism that I was off work for a further four months until my thyroxine levels were stabilised and I felt able to cope both emotionally and physically with work.*

*The only part of the treatment I found hard was having to come off levothyroxine; that was hell, not only for me and how it made me feel but also for everyone around me. Now I understand that there is a medication that could be used to avoid this period which wasn’t available at the time. I only wish it had been available then as this was in my opinion the worst part of the treatment.*

*Until you are on the correct dose of levothyroxine after RAI ablation you don’t realise just how you struggled, it affects every aspect of your life.*

*After surgery for thyroid cancer I had to withdraw from taking levothyroxine four times for radioiodine treatment. Whilst this period of withdrawal lasted for two weeks on each occasion, this two-week period can be divided into two separate periods in my experience. The first 8-10 days were reasonably comfortable but towards the end I experienced mild headaches/woolliness, greasy skin, some lack of energy and sleep. The last four days included more intense experiences of the earlier unpleasantness and constipation. Whilst all of this was unpleasant the problems were not intolerable. I used painkillers, and senna to help with the constipation. Psychologically I did not allow the withdrawal symptoms to upset me and used the power of positive thought that I was on the road to recovery and that*
withdrawal was a means to an end. I was able to ignore most of the unpleasant feeling as I was convinced the feeling was temporary and this gave me the incentive of having something to look forward to. A half-full glass. Not a half-empty one. Now life is good.

The Low Iodine Diet (LID)

You can help your RAI treatment by following a low iodine diet for about two weeks before ablation and avoiding all foods, vitamins and food supplements containing high levels of iodine. There is good evidence that the low iodine diet helps. This is because thyroid cells take up iodine from food, so by emptying the thyroid cells of iodine beforehand the radioactive iodine can be better absorbed by any thyroid cells. It is not possible or necessary to follow a no iodine diet.

For more details about the diet including a meal plan and recipes see Appendix 1: LID diet and meal plan.

A patient writes:

As a non-meat eater (I eat fish though) I found the low-iodine diet very difficult initially. Having said that, once I got my head round it, I ate a varied vegan, extremely healthy diet, and I have to say this counteracted the levothyroxine withdrawal leaving me feeling healthy and still able to go on bike rides two days before treatment. I’m convinced this helped with my recovery too. Not only that, but I suffered no weight gain.

The RAI room

RAI treatment is carried out at specialist centres because of radioactivity. For safety reasons i.e. to stop the radioactivity adversely affecting others who have a healthy thyroid, you will be in a room of your own, away from the main ward, for a few (usually two to four) days.

If you have accessibility issues such as mobility, sight or hearing, or if you are anxious about being isolated, ask if you can visit the room beforehand and if there is a counsellor either at the hospital or recommended by your GP who you can talk to about any concerns. Being able to visualise the room beforehand and talking with someone about it can often help. Some people find relaxation exercises or hypnosis useful, or there could be a role for medication if you are anxious. If you are already on medication we recommend you review this with your doctors – especially if you are not sleeping well.

The radioactivity - which eliminates any remaining thyroid cells in your body – including cancerous ones - is expelled through your normal bodily fluids: urine,
perspiration, blood, and especially saliva, which can be many times more concentrated with iodine than either blood or perspiration.

Each hospital has a slightly different set-up and will usually have its own information leaflet. It is advisable to find out beforehand about any regulations, what you can take in with you and what you can take home afterwards, and what facilities there are in the room. Having the opportunity to visit the room before your treatment will give you the chance to ask any questions you have and should help put your mind at rest.

Typical regulations might cover:

- Restriction on visitors, especially those under 18, pregnant women, and those breastfeeding
- Disposal of bodily fluids
- Physical contact with staff and others
- What you should bring with you and whether you will be able to take your possessions home with you or they will need to be disposed of
- Temporary restrictions on your return home

Photos of the RAI treatment rooms at Leeds Cancer Centre, The Leeds Teaching Hospitals NHS Trust.
Patients write:

The RAI involved having to go off my medication, so I developed hypothyroidism during that time - my skin was dry, I was super tired and it was a bit rubbish! But once I was back on my medication it went away. Aside from that, I’ve had no real complications.

There was a big window in the room so it really didn’t feel too claustrophobic.

I underestimated how dull it’d be and how cut off I’d feel. I don’t feel like I was given any warning on that and it was a bit of a culture shock. What I probably learned from it is to keep occupied, I took my laptop with me but I’d have taken books and other things next time to really keep me busy while I was in there.

I took an exercise sheet in with me so I felt I was doing something constructive.

This period of isolation can be a difficult time, but it does not last forever. You could use the time to enjoy a favourite pastime, and there may be games and activities provided in your room. Don’t, however, take in anything you are very attached to, or a hobby on which you have spent many hours, such as embroidery or a sketch, without checking beforehand. Due to contamination risks you might not be able to take it home with you!

After the ablation dose you may experience some temporary side effects, such as sickness or nausea, which is treatable; and some foods may taste different. Sometimes there may be a little discomfort around the thyroid gland for a few days, and you may have a sore throat. If you notice or feel any swelling in the neck area you must tell the staff immediately.

Precautions against salivary gland damage

Radioactive iodine ablation can damage the salivary glands, especially the parotid glands just below and in front of your ears. This is because the salivary glands, like the thyroid gland, have the ability to concentrate iodine. You may notice a swelling, tenderness, dry mouth, or a change or loss of taste. It is quite common for people to complain about a salty or metallic taste in the mouth. Often this is temporary, but it can persist for a year or more. Sometimes the symptoms only appear some months, or occasionally years, after RAI ablation. Foods that make your mouth water such as sour sweets, fruit, spicy foods or drinking diluted lemon juice while you are in isolation may help increase the flow of saliva and therefore help protect your salivary glands. Some doctors recommend waiting 24 hours before doing so.

It is important to drink enough when you are in isolation. Drinking more than usual will help remove the radioactivity from your body more quickly and may help protect your salivary glands. Anything will do, water, tea, coffee, squash or canned drinks. However, it is important NOT to drink to excess.
As you should be drinking more than usual you will use the toilet frequently. As all your body fluids are radioactive you should flush the toilet twice after use, be sure to wash your hands well, and if possible take two showers a day.

Things to take to hospital for RAI

Your hospital should provide you with a list of what you will need, which will give you an idea, but this list is made up from suggestions by other patients.

Check beforehand what’s in the room you will be using – some have a kettle, fridge, hairdryer, phone, TV, DVD etc. but some do not. Also check before you stay what arrangements your hospital has for the use of phones, TV, etc. You may need to buy phone and TV cards beforehand.

Anything you take in might be retained by the hospital if it has become contaminated during your stay however hospital regulations vary.

Volunteers from the Thyroid Cancer Support Group Wales (TCSGW) created these gardens to transform the view from the two rooms where patients receive RAI ablation at the Velindre Cancer Centre in Cardiff.
Photograph courtesy of the Thyroid Cancer Support Group Wales.
Sometimes the hospital bags these items up so that you can collect them a few weeks later and some let you take them home and wash them. Others prefer you to take in only those items you are prepared to dispose of. The most likely things to be retained are your clothes and your toothbrush. Check what your hospital does if you’re not sure.

**Clothes**

Your clothes are the most likely things to be retained so try to take in old clothes that you can either wash once on their own in your washing machine, or ones that you can just throw away, or clothes that you won’t miss for a few weeks while they decontaminate as the radioactivity naturally decays.

Also make sure you take in enough warm clothes as you may feel colder than normal.

- [ ] pyjamas / nightdress
- [ ] dressing gown
- [ ] slippers / flip-flops (some units won’t let you have bare feet in the room)
- [ ] shoes – you may prefer real shoes to slippers
- [ ] a couple of changes of clothes
- [ ] underwear
- [ ] warm socks
- [ ] towels (your hospital may provide some)
- [ ] fresh clothes to be worn on discharge: these can be kept in a suitcase in your room to avoid them becoming radioactive

**Toiletries**

- [ ] toothbrush (leave this behind when you leave hospital)
- [ ] toothpaste
- [ ] shampoo, conditioner
- [ ] shaving kits (preferably disposable)
- [ ] shower gel
- [ ] face / hand / body cream
- [ ] body spray
- [ ] soap
- [ ] hairbrush
After RAI ablation

Before going home, or a few days after discharge, you will have a whole-body scan to check that the RAI ablation uptake has been active in the thyroid and to

- sanitary towels/tampons
- medication (if you are on any)
- hairdryer

**Food**

You should check whether you are required to maintain the LID whilst you are in hospital. If so you could take some low iodine snacks in case your hospital isn’t able to provide them.

- sour sweets – to flush out salivary glands
- drinks, fruit juice, cordial
- snacks (see Appendix 1)
- fruit

**Things to do**

If you handle something a lot, maybe a book or sewing, it may be retained, so make sure you finish the book before you leave!

- laptop, mobile phone, MP3 or similar (if allowed) – use disposable earplugs for your MP3
- books (not library books)
- games, puzzles and puzzle books
- sewing, knitting or other craft
- journal, notepad
- pens
- magazines and newspaper
- phone numbers of friends and family
- money/card for phone (hopefully you will have one in your room) or mobile phone if permitted
- small amount of money
- CDs, DVDs or videos if there are the relevant players in the room
check whether there is uptake elsewhere in the body, which may indicate that further treatment is required.

You will be given a prescription for levothyroxine (T4) tablets. Sometimes a short course of liothyronine (T3) tablets is prescribed as well as levothyroxine since it acts faster. You may find that the centre where you are being treated puts you on liothyronine tablets until you have been given the ‘all clear’.

Another important aspect of thyroid cancer treatment is TSH suppression. Your specialist will want to keep your thyroid hormone levels slightly higher than normal to turn your TSH production off. Depending on the risk posed by your cancer and the response to treatment this may be required for at least the first five years following diagnosis and sometimes for longer. It is important that your GP is aware and they should be asked to contact your specialist and your thyroid team before making any changes in your medication. Some centres give out TSH alert cards for patients to carry. You will also be given a follow-up appointment to see the hospital specialist.

You should receive written advice from the medical physics team about any restrictions you may need to follow at home such as separate beds, separate utensils, avoidance of crowded areas and of public transport, and keeping some distance from babies, young children, and pregnant women. This last restriction may be difficult especially if you have young children. Some people prefer to arrange for their children to stay with other family members for a few days. You should also avoid close contact with any pets when you first leave hospital. The restrictions may need to be in place for one to three weeks, depending on how much radioactive iodine is still in your body. Remember though that they are only temporary.

If you have recently had radioactive iodine ablation you may trigger radiation detectors used for security purposes, for example at airports and seaports. This can occur for up to 95 days after treatment. If you are travelling within this time period you should carry a letter from your hospital explaining the treatment you have had.

It may take several weeks before you feel you are back to normal. Remember that information and support is available from the hospital and support groups, and family and friends may be able to help and encourage you too.

A patient writes:

I was given good verbal and written information about the radioactive iodine treatment which made me lose quite a lot of my anxieties.
### Checklist

#### Before RAI

- Check what are the hospital’s isolation room and decontamination regulations?
- Check can I visit the room beforehand?
- Check is there someone I can speak to who has had this treatment?
- Check will I be given anti-nausea medication?
- Check I suffer from claustrophobia. Is there a counsellor I can talk to? Are there exercises or medication that may help me?
- Check can I have Thyrogen® instead of stopping my levothyroxine tablets? (If so) do I have a prescription for Thyrogen® or how will I receive this?
- Check do I understand the LID?
- Check what is available in the room and what should I bring myself?
- Check what are the hospital’s visiting regulations while I am in isolation?
- Check have I notified my employer about my treatment and sent in a sick note if necessary?
- Check have I found out about sick pay and benefits?
- Check do I need to notify my health insurer?

#### After RAI

- Check what restrictions should I observe when I return home?
- Check when should I be able to return to work?
- Check have I been given documentation explaining the RAI ablation, to carry with me if I’m travelling through airports and seaports?
- Check do I need to inform my car insurance company and the Driver and Vehicle Licencing Agency (DVLA) about my treatment?
CHAPTER 6: Follow-up

Follow-up tests after radioactive iodine ablation

Dynamic Risk Stratification

FOLLOWING SUCCESSFUL surgery (total thyroidectomy) and radioactive iodine ablation (RAI ablation), many (but not all) patients will undergo Dynamic Risk Stratification. This involves measuring Thyroglobulin (Tg) after stimulation with Thyrogen® (recombinant TSH injection) and performing a neck ultrasound with or without a whole body radioactive iodine scan at 9-12 months after initial RAI ablation. This allows doctors to determine the risk of thyroid cancer recurrence, the duration of follow up and frequency and types of later tests. It also allows the doctors to decide on the appropriate levothyroxine dose. (British Thyroid Association Guidelines for the Management of Thyroid Cancer 2014.)

Thyroglobulin test

Your Tg should be measured within 9-12 months after RAI ablation, and regularly thereafter.

Thyroglobulin (Tg) is produced by thyroid cells: both benign (non-cancerous) cells and cancerous cells. After successful thyroid surgery and radioactive iodine ablation, thyroglobulin is usually not detectable in the blood. High Tg levels after cancer surgery and RAI ablation suggest that thyroid cancer cells may be present in the body.

There are two ways to measure Tg. It can be measured when the TSH is high (this is called a stimulated Tg level). The TSH can be raised by either (a) stopping levothyroxine/liothyronine (T4 four weeks/T3 two weeks) before the test or (b) administering Thyrogen® (recombinant TSH) injections to raise the TSH artificially while you continue to take your thyroid medication as normal. A stimulated Tg is a more sensitive way to measure Tg.

Alternatively Tg can be measured without raising the TSH; this is called an unstimulated (or suppressed) Tg level. For this test you would continue to take your levothyroxine/liothyronine as usual and would not require injections. This is the most common way in which doctors measure Tg when following up people who have had thyroid cancer.

If the initial stimulated Tg is undetectable, subsequent tests may be done when the TSH is suppressed (or unstimulated). You do not need to follow a low iodine diet before the blood test.
Occasionally people can have *anti-thyroglobulin antibodies (TgAB)* present in the bloodstream. It is important to note if these are present since they can interfere with the Tg measurement and make it less reliable.

**Ultrasound scan**

A neck ultrasound is used increasingly as part of follow up of patients with thyroid cancer. It is used to visualise the thyroid ‘bed’ (the site within the neck where the thyroid gland used to sit before surgery) and the neck lymph nodes. It is a very sensitive test and can detect very small areas of thyroid cancer recurrence.

If an earlier Tg test showed raised amounts of Tg, then a **whole-body scan** may show where the remaining cancer cells are. They may remain in the neck area, or they may (although this is rare) have spread to other parts of the body.

A whole-body scan is sometimes used to check for possible recurrence later on if other tests indicate that a recurrence is likely.

**Procedure for using Thyrogen® for follow-up**

For a follow-up whole-body scan and thyroglobulin (Tg) measurement, the British Thyroid Association *Guidelines for the Management of Thyroid Cancer* (2014) recommend that Thyrogen® is given by injection on two consecutive days, followed by radioactive iodine administration on the third day. You will be able to return home but you should ask the nuclear medicine team for advice on whether there are any restrictions.

You may be advised to keep some distance from small children and pregnant or nursing women for 24 hours. You will be asked to go back to the hospital two days later (on day five) for a whole-body scan and for a blood test to measure your Tg level. You should follow a low iodine diet for two weeks beforehand.

For a follow-up Tg measurement only, Thyrogen® is given by injection on two consecutive days, followed by a blood test at the hospital on the fifth day. You do not need to follow a low iodine diet.

You will probably go to your GP for the injections, which are given in your buttock.

**If the tests are positive...**

Sometimes these tests show that the first RAI ablation was not completely successful. If that is the case, you may be referred either for further surgery or RAI ablation. It is estimated that about a third of patients may need further surgery and/or RAI ablation.

Thyroid cancer can return many years later, although this is rare. Later recurrences of thyroid cancer are usually very treatable with surgery or RAI ablation.

Additional tests that are sometimes used in follow-up:

**Radioactive iodine scan (sometimes called a whole-body scan)**

Occasionally, a follow-up whole-body radioactive iodine scan will be performed. Since the thyroglobulin (Tg) test is a very sensitive way of knowing whether there
is any cancer present within the body, a whole-body scan is not often requested during follow-up. It is sometimes performed on people who have anti-thyroglobulin antibodies (as these interfere with the reliability of the Tg result, see above) or for people who had evidence of thyroid cancer outside the neck on the initial radioactive iodine scan after radioactive iodine ablation.

For this scan you will need either to stop taking your levothyroxine/liothyronine (T4 four weeks/T3 two weeks) before the scan or you may be offered Thyrogen®. In either case you should follow a low iodine diet for two weeks beforehand.

**SPECT-CT Scan**

This is a combination of two types of scan; a CT scan and a SPECT scan, both carried out on the same day in hospital. SPECT scan images are obtained following an injection of radioactive iodine; this is carried to any thyroid cancer cells (and some other cells too) in the body and is detected by a nuclear medicine camera. CT images are obtained by a large ring-shaped X-ray machine. The images from the two scans are then merged and interpreted together. If any areas suspicious for residual or recurrent thyroid cancer are detected by the SPECT scan, the CT allows doctors to accurately locate this tissue.

**Advanced thyroid cancer**

A small number of patients with papillary or follicular thyroid cancer have cancers that continue to grow and spread *after* surgery and repeated RAI ablation, or have a recurrence many years later. The most common sites of spread are the neck lymph nodes, bones and lungs. In some cases the cancer is described as ‘radio-iodine resistant’.

In the first instance the doctors will decide whether further surgery or RAI ablation would be beneficial. If not, or if the cancer is resistant to regular treatment, there are still treatments that can help symptoms. There are also several lines of ongoing research that may result in improved treatment in the future.

**Options for treatment of advanced thyroid cancer**

**Tyrosine kinase inhibitors**

These are medications (tablets) that are occasionally used for advanced thyroid cancer. Tyrosine kinases are proteins that act as chemical messengers (enzymes which can encourage cancer cells to grow. Medications called *tyrosine kinase inhibitors (TKIs)* stop these proteins from working. They do not provide a cure but can stabilise the growth of the thyroid cancer. They have many side effects so the risks and benefits of the medication need to be discussed carefully before starting this treatment.
There are two licensed drugs in this class: sorafenib and lenvatinib. The availability of these drugs is different across the United Kingdom.

**External Beam Radiotherapy**

External Beam Radiotherapy (EBRT) is a high dose x-ray treatment which is given in hospital. It can be used for patients with residual cancer in the neck following surgery or for cancer that has spread to the bone and the brain.

**Medications to control symptoms**

If the thyroid cancer has spread to the bone and is causing pain, medications such as biphosphonates can be used to help control the pain. Painkillers can also be used of course.

**Research**

A number of potential new treatments are still under investigation. If you are told that your cancer is radioactive iodine resistant you could discuss with the specialist team looking after you whether there is suitable clinical trial in your area.

**Palliative care**

Although thyroid cancer is highly treatable, and cured in about 96% of cases, a small proportion of patients will have recurrent end-stage disease (or anaplastic thyroid cancer). If you are in this situation, you might want to seek referral to your local specialist palliative care team. Your GP or oncologist can arrange this for you. A palliative care nurse can visit you in your own home if you wish. She/he can help with controlling any symptoms you might have, provide emotional support for you and your family, and can access a range of specialist palliative care health and social care professionals depending on your needs.

The aim of palliative care is to relieve symptoms and to provide patients with the best possible quality of life. It can also help with communication and support for families. Options for management of symptoms include medication (including adequate painkillers), high-dose palliative external beam radiation, or surgery.

Some symptoms can be very distressing and it may help to talk with a counsellor and your specialist nurse if you have one.
YOU WILL NEED TO take thyroid medication for life. You may be started on levothyroxine tablets immediately after surgery, especially if you have had a total thyroidectomy, but if you are going to have RAI ablation, depending on the timing, this might be delayed until after ablation.

Levothyroxine tablets replace the thyroid hormone that your body would naturally produce and prevent you from experiencing symptoms of hypothyroidism. At least initially, the amount of levothyroxine prescribed will usually be higher than that typically used to treat hypothyroidism. This is in order to suppress the thyroid stimulating hormone (TSH) level since there is a concern that having a high TSH level can encourage thyroid cancer cells present to grow if present. Depending on how high risk your initial cancer was and how you respond to initial treatment, the doctors will decide on the most appropriate levothyroxine dose for you. The doctors will then advise you and your GP on your target TSH level. For example this might be a target TSH of <0.1mU/L if you require a high dose of levothyroxine or a target TSH level of 0.3-2.0mU/L if you are deemed to have a very low risk of the cancer returning.

Your levothyroxine dose will be adjusted based on regular blood tests. Try to be patient – achieving the correct dose of levothyroxine and getting the right dose for you can take a few adjustments.

Taking levothyroxine means you currently qualify for exemption from prescription fees for all prescription drugs. Ask your GP for a prescription exemption application form.

Once your treatment has finished, after any temporary side effects of your treatment have been dealt with, and you are on the correct dose of levothyroxine, you should start to feel as though you are getting back to normal. If you do not feel well soon after starting levothyroxine, ask to see your specialist.

Your levothyroxine tablets are a vital part of the treatment for thyroid cancer. Not all GPs are familiar with thyroid cancer – remember that it is an uncommon condition and that they may see very few cases. If you have your bloods checked by your GP they may find the free thyroxine (fT4) level is higher than the laboratory reference range and that the TSH is lower than the reference range. This is usually appropriate for people with thyroid cancer. **If your GP wants to change your dose always speak to your specialist first**, and ask your specialist to write a letter to your GP to explain the need for a higher dose.
How to take and how to store levothyroxine

Levothyroxine is the generic name for synthetic thyroxine. You should take it exactly as your specialist has prescribed. It is best taken in the morning, with water, on an empty stomach, at least half an hour before eating and drinking anything else, as food can affect the absorption. It is also best taken four hours apart from calcium, iron, certain cholesterol-lowering drugs (bile sequestrants such as cholestyramine, colestipol), and multivitamin tablets, as these too can decrease absorption. Grapefruit on the other hand is known to increase the absorption of levothyroxine due to increased acid in the stomach.

There are a number of other drugs that interact with levothyroxine. Always check with your doctor or pharmacist if you are on any other prescription or over-the-counter medication.

Levothyroxine loses its potency over time and should be stored at room temperature away from moisture and heat.

If you are travelling by sea or air, it is advisable to take your tablets – along with any other prescription medication – in your hand baggage, and in the original container.

A patient writes:

*I feel fine about taking my levothyroxine each day. I try to take it first thing and then not eat or drink for 30 mins which can sometimes be quite difficult. The thyroid nurse said to have it by my bed and take it as soon as I wake up.*
CHAPTER 8: Long-term follow-up

THE BRITISH THYROID ASSOCIATION Guidelines for the Management of Thyroid Cancer 2014 recommend that you have regular check-ups for life but for some patients this can safely be done by your GP. If, however, you have any unexplained symptoms in the meantime, you should see your GP straightaway and they can refer you back to the specialist team.

A few centres have introduced nurse-led clinics and/or telephone follow-up of patients who are on life-long thyroxine replacement.

A check-up will usually consist of a blood test to check your thyroid hormone levels in order to confirm that you are taking the correct dose of levothyroxine to achieve your target TSH levels; your thyroglobulin will be measured to check that the cancer has not returned; and you will have your neck examined. Your calcium levels may also be checked, and you may also have a neck ultrasound.

If your thyroid medication needs adjusting you will be advised regarding this and will be asked to have another blood test in approximately two to three months to check that the new dose is correct.

If your thyroglobulin level is rising, you may need to have further tests such as an ultrasound, a whole-body scan a SPECT-CT scan, or a Positron Emission Tomography (PET) scan, to see whether the cancer has returned and whether you need further surgery or RAI ablation.

Patients write:

Now I’m starting to settle down on levothyroxine I realise it has been easier to dwell on how bad I’ve felt than to pick myself up and get on with enjoying life.

I now just have an annual check-up with my oncologist and my surgeon.

I am very confident that any changes in my condition will be picked up straight away. This has actually been the case and the changes were dealt with immediately.

With regular blood tests and scans the disease is closely monitored by two very good specialists.

I am monitored every six months and I now feel fantastic.
I go to the hospital once a year to have blood tests and a neck check. Other than that I feel fine now, I sometimes get very tired when I have overdone things, but mostly I’m fine.

I felt quite vulnerable when the treatment had finished but just wanted to get back to normal life as soon as possible. Now, I sometimes forget about it completely until just before my annual check-up.
Thyroid cancer in children and young people is rare. The incidence is one per two million children per year, which is the equivalent of just five new cases every year.

Any childhood cancer is shocking. However, the outcome for thyroid cancer is very favourable, even though it is sometimes more aggressive in children than in adults, and patients might need more repeat treatments. In one UK study of people who had been treated for thyroid cancer in childhood the average survival was 53 years, and these children were treated at a time when the understanding of thyroid cancer was far less sophisticated than it is now.

If your child is diagnosed with thyroid cancer, their treatment and management will be basically the same as for adults, except that the managing team should include a paediatric endocrinologist, a paediatric oncologist, and a nurse specialist or counsellor. (BTA Guidelines for the Management of Thyroid Cancer 2014.)

Your child may need both surgery and radioactive iodine ablation. For more information about what this may involve, see Chapters 4 and 5.

There are several hospitals in the UK with special experience of treating children with RAI ablation. As parents, you may be able to share in their care and to be with them during the day so that they are not so isolated.

After treatment your child will need to take levothyroxine tablets for the rest of their life. After starting treatment you should ensure that your child takes the medication regularly and has regular check-ups. Giving levothyroxine to very young children can be a challenge, but if the tablet is crushed it can be given in liquid form. For babies however, you should not add the crushed tablet to your baby’s feeding bottle as this may result in the baby not receiving the whole dose. In this instance it is better to use the liquid form of levothyroxine.

Your child will also need annual check-ups with thyroglobulin monitoring for life. The most common form of thyroid cancer seen in children is papillary.

Children in families with familial medullary thyroid cancer are often advised to have prophylactic surgery within the first few years of life.
Patients write:

I was only 14 when I first noticed two lumps in my neck and I had surgery a year later. This was in 1965! I always suspected that it was cancer, but my parents would only say it was ‘something nasty’, so I couldn’t talk about it to anyone. Thankfully, people are much more open now.

I first knew there was a problem when we found a lump on my three-year-old son’s neck. I knew it was serious but it took four months of testing to get the diagnosis of papillary thyroid carcinoma. The doctor was brilliant and tried to explain it to me, wrote down his number and who my son was being referred to but I had just switched off. The shock set in a couple of days later and for three days I cried. You hear cancer and, no matter what, you fear the worst. All the talk of this being the ‘good cancer’ doesn’t matter when it is your three-year-old child. I had prepared myself for his diagnosis, always fearing cancer, but when they say the words you think of death. My son has had his thyroid removed and was treated with RAI ablation. He’ll be on levothyroxine for the rest of his life but that is a small price to pay for your child’s health.

I was just 11 years old when I had a lump biopsied. Doctors told me that my thyroid was like a sunflower that was shedding seeds that were bad for me so it needed to be removed. I also understood the conversation that they had with my parents about me having cancer in my thyroid gland and was sent for major surgery. When I woke I could hardly speak and couldn't look at my neck. I then had four rounds of RAI ablation. As I was so young at the time they were unsure of how to treat me with, what doses I could have and how it would affect me long term.

It was hard as I missed nearly all of my first year of high school, which put me behind, but I caught up and my scar healed to a very faint line. When I got closer to 16 I had depression and did a lot of silly things as I had started to understand how serious my illness had been but I saw a therapist who helped me come to terms with it all.

I am happy to say I have now been in remission for 25 years. I'm a fully qualified senior hair stylist and am married with 2 lovely daughters aged 3 and 6 that I'm very proud of. I will always need to have yearly check ups at the hospital as they are still so unsure as to how I may be affected long term but so far my life has been brilliant and I wouldn’t change it for the world. You can have a normal, happy and fulfilling life after cancer. Beat it, don’t let it beat you!
MOST THYROID cancers have a high cure rate. Regular check-ups and annual blood tests allow for the early detection of any recurrence, so be sure to attend check-ups regularly and talk to the medical staff if you have any questions. Apart from attending annual check-ups there is no reason why you should not be able to live a full and active life.

**Psychological effects**

It is not unusual to have an emotional reaction once the treatment is finished. Once the routine of hospital visits and doctor appointments is behind you, you may feel inexplicably low, tired, and even depressed. Do talk with your doctor to check that your thyroid medication is properly balanced and to rule out a physical cause, and to discuss possible treatments. Sometimes it helps to talk with other people, family, friends, or other cancer patients. Regular exercise may help. But if you are severely depressed, you may find that you need to see a counsellor or to take antidepressants.

**Getting back to work**

If you were working at the time of your diagnosis, you may feel well enough to return to work a few weeks after treatment, but some people may take longer to get back. There is no ‘one size fits all’, and it will also depend on the type of work you do. You should discuss your return to work with your doctor. If you are waiting for a scan or RAI ablation you may find it a challenge to work up to the time of the scan if you are told to stop taking your thyroid medication for a few weeks beforehand.

Information about benefits may be available from your employer and the medical team. The Department for Works & Pensions will also have information about benefit entitlement. They will be able to provide you with information on statutory sick pay, carer’s allowance and most state benefits including special arrangements for those with advanced cancer.

Many employers are able to support their employees if they are diagnosed with cancer and will make special arrangements to keep you working during your treatment, or help you to return to work in stages.

It helps to build a good relationship with your employer, and if you can, to talk openly about what you are going through, so that you can make good arrangements that suit you both.
Cancer is covered by the Equality Act 2010. If you feel you are being discriminated against in the workplace because of your cancer, it may be worth seeking advice, for example from your local Citizens Advice Bureau in the first instance. Organisations such as the Advisory, Conciliation and Arbitration Service (ACAS) or the Equality and Human Rights Commission are worth consulting in difficult cases.

Having a family

If you are a woman who has been treated successfully for thyroid cancer, any subsequent pregnancy will not be affected and you can expect to have a normal baby. You should, however, let your specialist know that you are trying for a baby, and contact your GP as soon as you know you are pregnant, as you are likely to need to increase your levothyroxine dose in early pregnancy and to have your TSH measured regularly during the pregnancy.

Our medical advisors recommend that you immediately increase your levothyroxine dose by 25mcg per day as soon as you have a positive pregnancy test. You should then make an appointment with your GP for follow-up blood tests.

There is no reason why you cannot successfully breast-feed. The suppressed TSH does not interfere with your body’s ability to produce milk. From the baby’s perspective there are no concerns about the safety or quality of breast-milk. Pregnancy should be avoided for six months after RAI ablation. Men who have had RAI likewise should avoid fathering a child for at least four months after treatment. (BTA Guidelines for the Management of Thyroid Cancer 2014)

Patients write:

I feel very privileged and happy to be able to enjoy life to its full and now have a wonderful baby daughter.

When I was pregnant with my oldest son I was diagnosed with a possible recurrence. I had surgery and RAI treatment some months after he was born. He is now 28 years old, and I also have a daughter of 19. They are both healthy!

Thyroid cancer and insurance

You should always give clear, correct and precise information to the insurance companies. Unfortunately some patients have been asked to pay a higher premium for life insurance or travel health insurance, sometimes many years or even decades since being declared free from cancer. Some travel insurance companies even charge a higher premium if the person is on levothyroxine. Often
this happens because insurance companies are applying a ‘one size fits all’ approach to cancer regardless of the type of cancer involved.

If you are refused cover by one company it definitely pays to shop around. This is a situation where it is up to each individual company and underwriter to decide. Insurance brokers are usually able to provide details of companies which have policies for people with cancer.

If travelling in Europe you should apply for European Health Insurance Card (EHIC) which replaced the E111. EHIC does not replace travel insurance but enhances it by entitling the bearer to reduced cost or sometimes free treatment in Europe. EHIC covers treatment for existing medical conditions. You can apply for it online on the NHS website.

Macmillan Cancer Support has a guide to travel insurance that is updated annually and includes a list of travel insurance companies that cover certain types of cancer. This may be especially useful for people who are currently having treatment or have recently completed treatment. No guarantees of cover are given.

**Late effects of thyroid cancer**

Having a suppressed TSH level (<0.1mU/L) over many years can increase the risk of osteoporosis and/or can aggravate or lead to heart problems. For this reason it is important to have a blood test to check your thyroid hormone levels each year so that the correct amount of levothyroxine is prescribed.

Osteoporosis - literally ‘porous bones’ - is a medical condition in which your bones become thinner, fragile and more likely to break. It is more common in the wrist, spine and hip. All men and women are at some risk of getting osteoporosis, but it is more common in older women after the menopause as they produce less oestrogen.

It will also depend on other factors such as your family history, diet, and exercise. If you have been on suppressive doses of levothyroxine for years, speak to your specialist or GP about a bone density scan and ask for advice on how to prevent or manage osteoporosis. Osteoporosis is a treatable condition.

**Patients write:**

*Life after thyroid cancer, most definitely yes!! When I recovered from my operations and the radioactive iodine treatment, I decided I would make the most of every day, enjoying the little things as well as big ones. I wasn’t unhappy in my job but having thyroid cancer motivated me to change it and I now have one I absolutely love. I returned to horse riding and while I will never be a top eventer or show jumper, I am so happy when I am riding. I still have my check-ups, now*
annually and apart from taking my levothyroxine every morning, sometimes I forget I actually had cancer.

The moral of this story is to warn men not to be macho. Go to your GP and have it checked out. I am alive today because I did just that.

Being a young doctor, I thought I was safe with my medical knowledge and protected within the false assumption it could not happen to me because I would know what to look out for. It took someone else to open my eyes to the cancerous lump in my neck. Now being on the other side of the operating table and clinics, I am learning to prioritise life and appreciate every day as it comes.

Although I would not call thyroid cancer a ‘good’ cancer, I have been very fortunate that these side effects have never been more than a nuisance and have not stopped me having a full life, raising a family, pursuing a fulfilling career and singing!

On the whole though it has been a very positive experience. It brought our family closer together. It made me evaluate my life and embrace life. I focus on the bigger picture and less on trivial matters, although I do slip and have trivial moments. I have been lucky to be given the time to be able to reflect and realise I have more to offer, that I can be more than I was.

I did find it hard when I finished the treatment. I developed mild depression and struggled for a while as it was hard to step out of that bubble and get used to things again. Cancer was massively intense, it was trips to hospital, operations, treatment - then suddenly, it was all gone and I was free of it. But I couldn’t just step straight back into the status quo, I essentially had to start from scratch and it really wasn’t easy. But now, I’m doing a lot better. I’ve got a better outlook on life, I’ve got goals I’m determined to follow and dreams I want to achieve - that’s what I’m fighting for now.

Never be afraid to ask questions and be positive - there is light at the end of the tunnel !!!!!
Introduction to the low iodine diet

The purpose of following the low iodine diet (LID) is to significantly reduce the amount of iodine in the rest of your body before the radioactive iodine ablation (RAI). This will help the RAI to be absorbed better by any remaining thyroid tissue. The diet is only for a short period before the treatment; doctors usually recommend following the diet for one to two weeks before patients go into hospital for the RAI.

The diet is a low iodine diet and not an iodine free diet or a low- or no-salt diet. Salt in the UK is not iodised, unlike the USA, Canada and countries in Europe where the salt is generally iodised. Hence the LIDs in the USA, Canada and parts of Europe are much stricter, as iodised salt is used in the manufacture of food products such as bread, meat products and some dairy products. Patients are advised therefore not to follow the LIDs used in other countries. Sea salt, so long as it is processed in the UK, is also safe to consume as it has a low iodine content.

Following a LID can be helpful and may support the success of the RAI ablation, but please remember that if you have a slip it will not cause the treatment to fail. We are aware that a minority of hospitals do not recommend that patients follow the LID as they feel it does not make a difference to the uptake of iodine. You should always follow the guidance of your medical advisers.

Key Points

- Use fresh meat, vegetables and fruit and make home cooked food
- Avoid restaurant foods, fast foods and takeaways, since there is no reliable way to determine what is in these foods
- Read the ingredient lists on labels of packaged and processed foods
- Check with your doctor about medications you are taking
- Prepare meals in advance to freeze before you stop taking your levothyroxine tablets and start your LID.

Low iodine diet directions for food and ingredients

Allowed

- Any fresh fruit
- Any fresh vegetables (canned or frozen might be processed with iodised salt according to the rules in the country of origin)
• Whites of eggs
• Fresh meat or poultry up to 6 ounces/180g a day. Please note that pies, sausages and canned or frozen meats might be processed with iodised salt according to the rules in the country of origin
• Grain, cereal and bakery products up to four servings per day, provided they have no high-iodine ingredients
• Pasta (but not egg pasta)
• Sugar, jelly, jam, honey, maple syrup
• Black pepper, fresh or dried herbs and spices and non-iodised salt
• Oils - all vegetable oils including soya oil
• Coffee, tea, herbal and green tea (two to three mugs of tea and/or coffee made with two tablespoons of milk per day)
• Beer, wine, other alcoholic drinks, fruit juices, canned drinks and colas
• Milk substitutes such as rice, coconut, almond or soya milk (please check ingredients labels and avoid brands that contain carrageenan which is a seaweed derivative)
• Non-dairy spreads
• Dark or plain chocolate with a minimum of 70% cocoa solids
• Crisps

_Not allowed_

• Seafood (fresh and salt-water fish, smoked fish, shellfish, seaweed, kelp)
• Dairy products (milk, cheese, cream, yoghurt, ice cream, butter)
• Egg yolks, and foods that contain egg yolks (eg custard, mayonnaise, fresh egg pasta, egg fried rice)
• Dried fruit
• Milk chocolate and white chocolate
• Foods that contain certain additives (carrageenan, agar-agar, algin, alginates – additives extracted from seaweed); margarine/vegetable oil spreads can contain alginites
• Cured and processed foods (ham, sausages, pies, burgers, nuggets, cold meats or chicken that has been injected with broth that might contain iodine)
• Bread, rolls and bakery products, laverbread (which contains seaweed
• Iodised salt, and sea salt which has been processed outside the UK and pink Himalayan salt if imported from or bought outside the UK (non-iodised salt may be used)
• Food supplements e.g. Complan
• Vitamin and mineral supplements, nutritional supplements, and some cough mixtures (unless prescribed by your medical team)
• Health foods that contain iodised sea salt, seaweed, kelp and cod liver oil
• Foods from Europe, America and elsewhere that contain iodised salt, such as foreign bread, meat products and some dairy products

_Easy snacks for home, work or travel_

• Fresh fruit or juice, fruit smoothies
• Fresh raw vegetables
- Popcorn
- Nuts and seeds, granola bars or cereal bars
- Peanut butter or other nut butters (with apple slices, carrot sticks and crackers)
- Breadsticks and crackers (if produced in the UK with non-iodised salt)

## Sample seven-day menu plan

<table>
<thead>
<tr>
<th></th>
<th>Breakfast</th>
<th>Lunch</th>
<th>Dinner</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Day One</strong></td>
<td>Fruit smoothie</td>
<td>Chicken salsa wrap Fruit</td>
<td>Beef curry with basmati rice</td>
</tr>
<tr>
<td><strong>Day Two</strong></td>
<td>Quaker oats made with water, add sugar, jam, syrup or fresh fruit and nuts to taste</td>
<td>Basil pesto pasta Fruit smoothie</td>
<td>Grilled chicken salad with new potatoes (no butter)</td>
</tr>
<tr>
<td><strong>Day Three</strong></td>
<td>Toast with honey or jam (no butter)</td>
<td>Minestrone soup with bread roll Fruit</td>
<td>Baked vegetable pasta (no white sauce)</td>
</tr>
<tr>
<td><strong>Day Four</strong></td>
<td>Fruit kebab</td>
<td>Baked potato with chicken salsa Fruit</td>
<td>Chicken chasseur with sauté potatoes</td>
</tr>
<tr>
<td><strong>Day Five</strong></td>
<td>Scotch pancakes with jam, honey or maple syrup</td>
<td>Pasta salad Fruit</td>
<td>Grilled pork chops with roasted vegetables and oven chips</td>
</tr>
<tr>
<td><strong>Day Six</strong></td>
<td>Fried mushrooms on toast</td>
<td>Moroccan soup with bread roll Fruit</td>
<td>Chicken vegetable kebab with basmati rice or couscous</td>
</tr>
<tr>
<td><strong>Day Seven</strong></td>
<td>Blueberry muffins</td>
<td>Roast chicken, beef, lamb or pork with roast potatoes, vegetables, and homemade gravy Crushed meringue with berry fruit coulis</td>
<td>Roasted vegetable soup with bread roll</td>
</tr>
</tbody>
</table>
Breakfast

Fruit smoothie

Can use supermarket bought smoothies which consist solely of fruit.

Blueberry muffins

4 fl oz/125ml/¼ cup vegetable oil
4 oz/125g/½ cup sugar
3 egg whites, whisked
8 oz/500g/2 cups white flour
3 teaspoons baking powder
1 teaspoon non-iodised salt
4 oz/125g blueberries – canned or fresh

Beat the sugar and oil, fold in the whisked egg whites. Stir in the rest very lightly. Add the blueberries last by folding them into the mixture. Line a muffin tin with paper cups, or grease lightly. Bake at 200 degrees Celsius for around 15 minutes or until spongy and firm to the touch. Makes 12 muffins

Scotch pancakes

2 egg whites
2 tablespoons sugar
1 teaspoon vanilla essence
8 oz/250g flour (plain or whole wheat)
2 teaspoons baking powder
1 teaspoon salt
1 teaspoon cinnamon
1 teaspoon vegetable oil
4 fl oz/125ml water

Beat the two egg whites with the sugar, then add the vanilla and stir in the rest of the ingredients. Lastly add the water to get the desired batter consistency for your pancakes. Spoon about one tablespoon of batter onto greased non-stick frying pan. The batter should make about 8-10 scotch pancakes. Any left can be frozen and cooked in the toaster. Serve hot with jam, honey or maple syrup.
Lunch

Chicken salsa
2 oz/60g of diced chicken
1 medium chopped tomato
Half a red onion chopped
Diced avocado
Chopped green peppers
½ teaspoon olive oil
Pepper and chilli (optional) to taste

Mix all the ingredients together in a bowl. Serve in a baked potato or in a tortilla wrap.

Dinner

Beef curry
2 lbs/1 kg cubed stewing meat
3 medium potatoes, quartered
1 red pepper chopped
1 large onion, chopped finely
1 teaspoon garlic, chopped finely
2 tablespoons garam masala (Indian spice)
2 tablespoons curry powder
1 cup water
Non-iodised salt to taste

Fry onion and garlic for one minute in 1 tablespoon of cooking oil. Add the cubed meat and potatoes and fry until meat is browned, mixing well. Sprinkle the garam masala over the meat mixture. Stir well and fry for about 2 minutes. Add the curry powder and keep stirring until mixture starts sticking to bottom of pan; then add about 1 cup of water. Add salt to taste, cover, and cook until meat is done and mixture thickens a little for around 20 minutes. Serve with basmati rice.

This recipe can also be made with cubed chicken breasts.

Basil pesto pasta
4 cloves garlic
6 tablespoons pine nuts
Salt
Pepper
1 large handful fresh basil
6 tablespoons extra virgin olive oil

Throw ingredients into blender, blend them, and then toss them into fresh pasta.

**Baked vegetable pasta**

3 oz/80g penne pasta
1 teaspoon olive oil
Half a medium red onion chopped
Chopped red and green peppers, half a cup
Half a courgette, chopped
6 button mushrooms, sliced
½ teaspoon balsamic vinegar
Pasta sauce (not white sauce)

Fry the onions in a large pan until soft, then add the rest of the vegetable ingredients. Fry for about 4 minutes then add the pasta sauce and cook for a further 5 minutes. Finally add the chopped basil and the cooked pasta. Put in a baking dish and cook in the oven at 180 degrees Celsius for 20 minutes.

**Roasted vegetables**

Cherry tomatoes
Sliced green, red and yellow peppers
Medium red onion chopped into quarters
2 large mushrooms cut in half
Olive oil
Splash of balsamic vinegar
¼ cup chopped fresh basil or 1 tablespoon dried basil

Put all the ingredients into a baking dish, drizzle with the olive and add the balsamic vinegar. Roast in oven at 200 degrees Celsius for 30 minutes.

**Chicken chasseur**

3 tablespoons vegetable oil
6 chicken breast halves without skin
2 shallots - finely chopped
8 oz/250g mushrooms – quartered
1 clove garlic – crushed
2 large tomatoes - peeled, seeded, chopped
½ teaspoon tarragon
1/2 teaspoon salt
1/4 teaspoon black pepper
1/2 cup dry white wine
1/2 cup chicken stock – homemade
1 tablespoon cornflour dissolved in 2 tablespoons water

In a large frying pan, heat oil over medium heat. Add chicken and cook, turning until brown all over – about 10 minutes. Remove and set aside. Add shallots to pan drippings. Cook for 1 minute to soften. Add mushrooms; cook until lightly browned – about 3 minutes. Add garlic, tomatoes, tarragon, salt and pepper. Simmer for 5 minutes. Add white wine and stock. Return chicken to pan, cover and cook over low heat until tender – about 20 minutes. Remove chicken. Stir dissolved cornflour into sauce. Bring to the boil and cook, stirring until thickened – about 1-2 minutes. Return chicken to pan and coat with sauce. Serve with sauté potatoes and green vegetables.

Soups

Moroccan soup
2-3 cups cooked kidney beans
1 cup brown lentils, washed and picked over
1/2 to 1 cup long grain rice (eg basmati) washed
2-4 tablespoons olive oil
1-2 large onions, chopped – save some for the garnish
2 carrots, sliced
3 cloves garlic, minced
2 teaspoon turmeric
2 teaspoon cumin
2 teaspoon cinnamon
2-3 shakes cayenne
1/2 teaspoon salt
2x16 oz tins of salt-free tomatoes, drained
2 heaped tablespoons salt-free tomato purée
handful of flat leaf parsley, chopped
4-6 cups vegetable or chicken stock (or 2-3 cups dry white wine plus 2-3 cups water)

Sauté the onions in the olive oil over a medium heat until soft, about 5 minutes. Add the carrots and garlic. Stir well and add more oil if needed. Add dry spices, turn down heat, and stir constantly to be sure not to burn the spices. Cook for 3 or 4 more minutes until spices lose their raw aroma. Add kidney beans and stock or wine/water to cover. Bring to the boil, cover and simmer for 30 minutes. Add
lentils, rice, tomatoes and tomato purée. Check liquid level to be sure to have an inch of liquid over the beans. Return to the boil and simmer for a further 30 minutes. Add parsley and check for seasoning, salt and cayenne. You might want to add some sweet red pepper if you would like to boost the vegetables. Garnish with onion.

**Roasted vegetable soup**

6 beefsteak tomatoes, halved and cored  
2 leeks, white and green parts sliced  
2 carrots, sliced  
4 garlic cloves  
2 tablespoons olive oil  
salt and pepper to taste  
3 cups chicken stock  
handful of fresh basil, chopped or 1 teaspoon dried basil

Toss all vegetables and seasonings in a roasting pan. Drizzle with olive oil. Bake in a single layer at 200 degrees Celsius until cooked (about an hour). Using tongs peel the tomatoes and discard the skins. In a saucepan heat the stock and vegetables. Simmer for 10 minutes. Puree in batches in the blender. Stir in the basil.

**Minestrone Soup**

3 tablespoons olive oil  
3 garlic cloves, chopped  
2 onions, chopped  
2 cups celery, chopped  
5 carrots, sliced  
4 cups water  
4 cups passata  
1 cup white beans (cooked)  
15 oz/375g green beans (fresh or frozen beans, cooked)  
1 teaspoon dried oregano  
2 teaspoons dried basil  
½ teaspoon non-iodised salt and pepper  
Half cup of small pasta

Sauté garlic and onion in a large saucepan for about 8 minutes. Add celery and carrots and cook for a further 4 minutes. Add water and passata and bring to boil, stirring frequently. Reduce heat and add white beans, green beans and spices. Simmer 30-40 minutes. Cook pasta and drain. Add to soup. Freeze into smaller portions for easy reheating.
APPENDIX 2: Checklists

A list of questions to ask at different stages of treatment

**Diagnosis – seeing your GP**
- Do I have a lump, swelling or any other symptoms?
- Should I see my GP?
- Do I want a family member/friend to accompany me to the appointment?
- If I am asked to monitor myself what should I look for, and when should I return to see my GP?
- If I need further investigations who will I be referred to and are they a thyroid specialist?
- Will an appointment be made for me?

**Diagnosis – seeing your specialist**
- Do I want a family member/friend to accompany me to the appointment?
- Have I written down my questions beforehand?
- Do I know which tests will be carried out?
- Do I understand the test procedures?
- Is there a special/private room where I can receive the diagnosis?
- Does the hospital have a Multi-Disciplinary Team?
- Does the department have a nurse specialist?
- Have I got the contact details of the nurse specialist or doctor to contact if I have any follow up questions?
- Do I have any follow-up questions?
- Have I got a follow-up appointment or will one be sent to me?
- Do I need advice about getting other family members tested?
- How am I feeling? Would it help me to talk to medical support staff, family, friends, or someone who has had treatment after a similar diagnosis?
- Is support available for my family member(s)?

**Questions before surgery**
- Do I want a family member/friend to accompany me to the appointment?
- How many thyroid surgeries has my surgeon performed? How many this year?
- Which tests will be carried out before the operation?
- What are the risks of voice and/or parathyroid damage?
Is intra-operative laryngeal nerve monitoring available during the operation? 
Will I have a vocal cord check? 
Will I have a parathyroid function test? 
Will some of my parathyroid tissue be transplanted? 
How much of my thyroid will be removed? 
Will any lymph nodes be removed? 
Where will the scar be? 
Can I get an anti-sickness tablet if I need one? 
How many days will I be in hospital?

Questions after surgery

When will my stitches be removed? 
Have I been shown how to clean the wound? 
What treatment will I have after surgery, and where? 
Will I be on thyroid medication (levothyroxine) after surgery? If so do I have a prescription, if needed? 
Have I requested a prescription charge exemption form from my GP’s surgery? 
Have I got a follow-up appointment or have I been told that one will be sent to me? 
Have I got the contact details of a nurse or doctor if I have any follow up questions? 
Do I have any follow-up questions? 
How am I feeling? Do I need to talk to medical support staff, family, friends, or someone who has been through similar surgery? 
Is there any support or counselling available after my treatment which will help me deal with what I’ve been through and get back to normal life?

Questions before RAI

What are the hospital’s isolation room and decontamination regulations? 
Can I visit the room beforehand? 
Is there someone I can speak to who has been through this treatment? 
Will I be given anti-nausea medication? 
I suffer from claustrophobia. Is there a counsellor I can talk to about this? Are there any exercises or medication that may help me? 
Can I have Thyrogen® instead of stopping my levothyroxine tablets? 
If so, do I have a prescription for Thyrogen® or how will I receive this? 
Do I understand the low Iodine diet?
What is available in the room and what should I bring myself?
What are the hospital’s visiting regulations while I am in isolation?
Have I notified my employer about my treatment and sent in a sick note if necessary?
Have I found out about sick pay and benefits that are available?
Do I need to notify my health insurer?

Questions after RAI

What restrictions should I observe when I return home?
When should I be able to return to work?
Have I been given documentation explaining the RAI ablation to carry with me if I’m travelling through airports and seaports?
Do I need to inform my car insurance company and the Driver and Vehicle Licencing Agency (DVLA) about my treatment?

Questions about follow-up

How often will I need to be checked up?
For how long will I need to be checked up?
Who will be responsible for my care?

Add your own questions here
Patient Support Organisations

The British Thyroid Foundation
Suite 12, One Sceptre House
Hornbeam Square North
Hornbeam Park
Harrogate HG2 8PB
tel: 01423 810093
dom: info@btf-thyroid.org
www.btf-thyroid.org

Action Cancer Northern Ireland
1 Marlborough Park
Belfast BT9 6XS
Northern Ireland
tel: 028 9080 3344
dom: info@actioncancer.org
www.actioncancer.org

Association for Multiple Neoplasia Disorders – AMEND
Information on medullary thyroid cancer
AMEND Administrative Office
The Warehouse
No 1 Draper Street
Southborough, Tunbridge Wells
Kent TN4 0PG
tel: 01892 516076
dom: info@amend.org.uk
www.amend.org.uk

Butterfly Thyroid Cancer Trust
P.O. Box 205
Rowlands Gill, Tyne & Wear
NE39 2WX
tel: 01207 545469
dom: enquiries@butterfly.org.uk
www.butterfly.org.uk

Cancer Research UK
PO Box 1561
Oxford OX4 9GZ
tel: 0300 123 1022
www.cancerresearchuk.org

Cancer Support Scotland
75 Shelley Road
Gartnavel Campus,
Glasgow G12 0ZE
tel: 0141 337 8199
dom: info@cancersupportscotland.org
www.cancersupportscotland.org

Children’s Leukaemia and Cancer Group (CLACS)
A leading children’s cancer charity and the UK and Ireland’s professional association for those involved in the treatment and care of children with cancer
University of Leicester
Clinical Sciences Building
Leicester Royal Infirmary
LE2 7LX
tel: 0116 252 5858
dom: info@cclg.org.uk
www.cclg.org.uk

CLIC Sargent
Information and support for children and young people with cancer and their families
tel: 0300 330 0830
www.clicsargent.org.uk

Contact a Family
For families with disabled children
209-211 City Road
London EC1V 1JN
tel: 0808 808 3555
dom: helpline@cafamily.org.uk
www.cafamily.org.uk
Force Cancer Support Centre
For people in Exeter and surrounding area
Force Cancer Support Centre
Corner House
Barrack Road
Exeter EX2 5DW
tel: 01392 406151
e-mail: support@forcecancercharity.co.uk
www.forcecancercharity.co.uk

The Get A-Head Charitable Trust
Support for head and neck cancers
The Get A-Head Charitable Trust
Head and Neck Office
Room 23F, 4th Floor
Nuffield House
Queen Elizabeth Hospital
Birmingham B15 2TH
tel: 0121 371 5046
e-mail: getaheadcharity@uhb.nhs.uk
www.getahead.org.uk

Hyppopara UK
Patient organisation for adults and children living with a parathyroid condition.
6 The Meads
East Grinstead
West Sussex RH19 4DF
tel: 01342 316315
e-mail: lizglenister@hypopara.org.uk
www.hypopara.org.uk

Childhood Cancer International
The world’s largest organisation for childhood cancer
www.childhoodcancerinternational.org

The Irish Cancer Society
43/45 Northumberland Road
Dublin 4
Ireland
tel: 1 800 200 700
e-mail: cancernurseline@irishcancer.ie
www.cancer.ie

Light of Life Foundation
American organisation for people with thyroid cancer
www.checkyourneck.com

Macmillan Cancer Support
Support and information for patients and their families. They also facilitate an online forum for thyroid cancer patients
89 Albert Embankment
London SE1 7UQ
tel: 0808 808 0000
www.macmillan.org.uk

New Approaches to Cancer
Promotes complementary therapies and holistic treatment through positive self-help
PO Box 194
Chertsey
Surrey KT16 0WJ
tel: 0800 389 2662
e-mail: help@anac.org.uk
www.anac.org.uk

The Patients Association
PO Box 935
Harrow
Middlesex
HA1 3YJ
tel: 020 8423 8999
www.patients-association.org.uk

Penny Brohn UK
Helping people live well with cancer
Chapel Pill Lane
Pill
Bristol BS20 0HH
tel: 0303 3000 118
www.pennybrohn.org.uk
Rare Disease UK
*The national alliance for people with rare diseases and all who support them*
Level 3, Barclay House
37 Queen Square
London
WC1N 3BH
tel: 020 7831 0883
eemail: info@raredisease.org.uk
www.raredisease.org.uk

Teenage Cancer Trust
Third Floor
93 Newman Street
London W1T 3EZ
tel: 020 7612 0370
eemail: hello@teenagecancertrust.org
www.teenagecancertrust.org

Tenovus
*Cancer support in Wales*
Gleider House
Ty Glas Road
Cardiff CF14 5BD
tel: 0808 808 1010
eemail: post@tenovus.org.uk
www.tenovuscancercare.org.uk

Thyroid Cancer Alliance
*International network of national thyroid cancer support organisations*
eemail: info@thyroidcanceralliance.org
www.thyroidcanceralliance.org

Thyroid Cancer Support Group – Wales & Beyond
Velindre Cancer Centre
Velindre Road
Whitchurch,
Cardiff CF14 2TL
tel: 0845 009 2737
eemail: thyroidgroup@tiscali.co.uk
www.thyroidsupportwales.co.uk

Thyroid Cancer Survivors’ Association – USA
eemail: thyca@thyca.org
www.thyca.org

Cancer Focus Northern Ireland
40-44 Eglantine Avenue
Belfast BT9 6DX
tel: 028 9066 3281
eemail: hello@cancerfocusni.org
www.cancerfocusni.org

Further sources of information

Advisory, Conciliation and Arbitration Service (ACAS)
tel: 0300 123 1100
www.acas.org.uk

Cancer Index
*A guide to internet resources for cancer*
www.cancerindex.org

Citizens Advice
www.citizensadvice.org.uk

Driver and Vehicle Licensing Agency (DVLA)
*How to inform the DVLA about your medical condition*
www.gov.uk/driving-medical-conditions/

Equality and Human Rights Commission
*Information about the Equality Act 2010*
www.equalityhumanrights.com

NHS
www.nhs.uk

Northern Ireland Cancer Network
www.cancerni.net
Patient UK
Comprehensive health information
www.patient.info

UK Self Help Groups and Support Organisations
An online guide to patient support and self-help
www.self-help.org.uk

Professional Organisations

British Association of Dermatologists
Information on keloids
tel: 0207 383 0266
www.bad.org.uk

British Association of Endocrine and Thyroid Surgeons
www.baets.org.uk

British Society for Genetic Medicine
Information on UK genetic centres
www.bsgm.org.uk

British Thyroid Association
A non-profit making learned society of professional clinical specialist doctors and scientists in the UK who manage patients with thyroid disease and/or are researching into the thyroid and its diseases in humans
www.british-thyroid-association.org

Cancer52
Cancer52 represents 90 predominantly small cancer charities united by their vision of seeing a better future for everyone affected by the rare and less common cancers
www.cancer52.org.uk

National Cancer Intelligence Network (NCIN)
NCIN is part of the National Cancer Research Institute, and promotes efficient and effective data collection throughout the cancer journey
NCIN
www.ncin.org.uk

Thyroid Cancer Forum UK
A national organisation that facilitates communication between doctors and scientists working in the thyroid cancer field
www.thyroid-cancer-forum-uk.org

Books

Explains the course of thyroid cancer and all aspects of its treatment. Written by a thyroid cancer patient
Available at www.amazon.com

by Mark Vanderpump and Michael Tunbridge
A comprehensive guide for people with thyroid disorders and their families

Understanding Thyroid Disorders (Family Doctor Publications, 3rd edition, 2008) by Dr Anthony Toft
In clear non-technical language, Dr Toft explains the working of the thyroid, what can go wrong, and how the problems are treated

Disclaimer: Whilst every care is taken in compiling this list the British Thyroid Foundation is not responsible for the information provided by the organisations listed here or for the content of third party websites.
A list of terms you may come across in your treatment, and what they mean.

ABLATION: Literally means destruction. Radioactive iodine ablation destroys any remaining thyroid cells in the body after surgery.

ANAESTHETIST: a specialist doctor who gives anaesthesia to a patient and monitors them before, during and after surgery.

ANAESTHETIC: a drug that is used to reduce or take away sensation so that surgery can be performed painlessly. A GENERAL ANAESTHETIC is a drug or combination of drugs/gases that brings about a reversible loss of consciousness.

ANAPLASTIC THYROID CANCER: a rare and aggressive form of thyroid cancer that occurs most often in people over 60. It is an undifferentiated thyroid cancer.

ANTI-ANGIOGENIC DRUGS: a class of anti-cancer drugs that inhibit the growth of new blood vessels.

ANTI-THYROGLOBULIN ANTIBODIES (TgAB): some individuals have antibodies to thyroglobulin. If there are thyroglobulin antibodies in the blood, the thyroglobulin measurement is less reliable and other tests may be needed to check for the presence of cancer cells. These TgAB usually disappear after successful treatment for thyroid cancer.

BENIGN: not cancerous.

BIOPSY: the removal of a small piece of tissue for examination under a microscope.

C CELL: also called parafollicular cell, a type of cell in the thyroid gland which produces calcitonin.

CALCITONIN: a hormone produced by the thyroid gland. It is used as a marker for monitoring medullary thyroid cancer.

CANNULA: a tube used to drain or insert fluids.

CARCINOMA: a malignant tumour derived from epithelial cells (ie cells that cover the organs of the body).

CT SCAN: see COMPUTER-ASSISTED TOMOGRAPHY.

CHEMOTHERAPY: chemical agents used to treat or control disease.

COLUMNAR CELL: an epithelial cell that is shaped like a column. There is a rare columnar cell variant of papillary thyroid cancer.

COMPUTER-ASSISTED TOMOGRAPHY (CAT) also known as COMPUTED TOMOGRAPHY (CT): a medical imaging method used in diagnosing cancer, which generates a
three-dimensional image from a series of two-dimensional x-ray images, in order to show various bodily structures based on their ability to block the x-rays. During a CT scan you will need to lie still on a table which passes through the centre of a large x-ray machine. You may be asked to hold your breath at times. Sometimes a contrast dye is injected or given by mouth in order to highlight specific areas and give a clearer picture.

**CORE BIOPSY:** a biopsy in which a cylindrical sample of tissue is obtained by a hollow needle.

**COWDEN SYNDROME:** a rare inherited disorder characterised by multiple non-cancerous, tumour-like growths called 'hamartomas' and an increased risk of developing certain cancers, including thyroid cancer.

**DIFFERENTIATED CANCER:** the cancer cells look similar to normal thyroid cells and tend to grow slowly. Papillary and follicular cancers are the most common types and are usually treated by surgery and radioactive iodine ablation. Differentiated cancers are associated with a better outlook than other forms of cancer.

**DYNAMIC RISK STRATIFICATION:** a test to help doctors determine the risk of thyroid cancer recurrence, the duration of follow-up and frequency and types of later tests.

**EBR:** see EXTERNAL BEAM RADIATION.

**ENDEMIC GOITRE:** a type of goitre that is associated with dietary iodine deficiency.

**ENDOCRINE GLANDS:** glands that produce hormones.

**ENDOCRINE DISORDERS:** disorders affecting one or more organs of the endocrine system such as the thyroid, parathyroids, adrenal, pituitary, pineal and thymus glands, the pancreas, and the male and female sex organs.

**ENDOCRINE SURGEON:** a surgeon who specialises in surgery of the endocrine (thyroid, parathyroid, adrenal) glands.

**ENDOCRINOLOGIST:** a doctor specialising in diseases of the endocrine (hormone) glands including the thyroid, pituitary, adrenals, gonads and others.

**EXTERNAL BEAM RADIATION (also known as EXTERNAL BEAM RADIOTHERAPY):** uses a linear accelerator, a high-energy x-ray machine, to direct radiation to a tumour.

**FINE NEEDLE ASPIRATION CYTOLOGY (FNAC):** a test using a small needle that is passed into the thyroid gland to remove a small sample of tissue for examination.

**FIRST-DEGREE RELATIVE:** someone who shares 50% of their genes, i.e., a parent, child, brother or sister.

**FOLLICULAR THYROID CANCER:** a less common type of differentiated thyroid cancer. About 20% of all differentiated thyroid cancers are follicular. The cells often look very similar to normal thyroid cells but are arranged differently.
**GENE:** the basic unit of heredity in a human organism. Genes pass genetic traits on to offspring.

**GENETIC COUNSELLING:** the process by which families at risk of an inherited disorder can get advice about the probability of developing or transmitting it, and the available options for family planning and treatment.

**GOITRE:** a swelling of the thyroid gland.

**GRAVES’ DISEASE:** an autoimmune condition which is the most common cause of an overactive thyroid in the UK. It is much more common in women than in men. It got its name from Robert Graves, an Irish physician who described patients with this condition in the 19th century.

**HASHIMOTO’S THYROIDITIS:** the most common form of autoimmune thyroiditis, a disorder in which the body’s immune system attacks the thyroid cells as though they were foreign cells, leading to thyroid failure (hypothyroidism).

**HEAD-AND-NECK SURGEON:** a surgeon specialising in surgery of the head and neck, including thyroid surgery. Other terms used are ear, nose and throat (ENT) surgeon and otorhinolaryngologist.

**HEMITHYROIDECTOMY:** surgical removal of one side of the thyroid gland, also known as a **LOBECTOMY**.

**HEREDITARY NON-MEDULLARY THYROID CANCER (HNMTC):** the collective name for hereditary forms of differentiated, i.e. papillary and follicular, thyroid cancer.

**HORMONE:** a substance produced by one gland or organ that travels through the blood stream to affect another gland or organ. Hormones are sometimes described as the body’s ‘chemical messengers’.

**HURTHLE CELL:** an enlarged follicular thyroid cell. Hurthle cell thyroid cancer is an uncommon and sometimes aggressive form of differentiated thyroid cancer where the tumour takes up less iodine.

**HYPERTHYROIDISM:** the condition resulting from an overactive thyroid gland, or from excessive thyroid medication.

**HYPERTROPHIC SCAR:** a scar that is raised, red, and itchy. Hypertrophic scars tend to flatten in time.

**HYPOPARATHYROIDISM:** a deficiency of parathyroid hormone, which may be characterised by low blood calcium (hypocalcaemia). Post-operative hypoparathyroidism occurs sometimes after thyroid surgery when the parathyroid glands are damaged or removed.

**HYPOTHYROIDISM:** the condition resulting from an underactive thyroid gland, or from too little thyroid medication.

**IODINE:** an essential element, found in seafood and dairy, needed for the normal metabolism of cells. The thyroid gland takes up iodine in order to make the thyroid hormones thyroxine and triiodothyronine.
INSULAR: a rare and aggressive form of thyroid cancer with an island-like growth pattern.

INTENSITY MODULATED RADIOTHERAPY (IMRT): an advanced type of high-precision radiation therapy that delivers radiation to the tumour more precisely at high doses and with less damage to surrounding tissue.

INTRA-OPERATIVE RECURRENT LARYNGEAL NERVE MONITORING: a technique used by some surgeons during thyroid surgery to monitor the recurrent laryngeal nerves, especially during complex surgery.

ISTHMUS: the bridge of tissue connecting the two lobes of the thyroid gland.

ISTHMUSECTOMY: surgical removal of the central part of the thyroid gland.

KELOID: a hard, smooth, pinkish, raised growth of scar tissue at the site of a wound, tending to occur more frequently in dark-skinned people.

LEVOTHYROXINE: a synthetic form of the thyroid hormone thyroxine (T4) contained in tablets.

LIOTHYRONINE: a synthetic form of the thyroid hormone triiodothyronine (T3) contained in tablets.

LOBE: the thyroid gland consists of two lobes, the right and left lobe.

LOBECTOMY: surgical removal of one side of the thyroid gland.

LYMPH NODE: a small, bean-shaped organ, also called a lymph gland.

There are 500-600 lymph nodes throughout the human body, linked by lymphatic vessels. They contain white blood cells and are important to the functioning of the immune system. They may become inflamed due to an infection or to cancer.

LYMPHOMA: cancer arising from the lymphatic system. A thyroid lymphoma is a rare form of lymphoma arising from the thyroid gland. See also NON-HODGKINS LYMPHOMA OF THE THYROID.

MEDULLARY THYROID CANCER: a type of cancer arising from the C cells, which produce calcitonin.

MAGNETIC RESONANCE IMAGING (MRI): imaging technique using magnetic resonance imaging rather than x-rays, used to visualise the internal structure of the body. It provides much greater contrast between the different soft tissues than computed tomography (CT), making it especially useful to help in diagnosing cancer.

METASTASES: secondary cancer cells found elsewhere in the body away from the site of the original cancer.

MRI SCAN: see MAGNETIC RESONANCE IMAGING (MRI).

MULTI-DISCIPLINARY TEAM (MDT): the team of medical staff supervising your treatment which may include a surgeon, endocrinologist, oncologist, nuclear medicine physician, specialist nurse, pathologist, biochemist.
MULTIPLE ENDOCRINE NEOPLASIA TYPE 2 (also known as MEN2): a group of medical disorders of the endocrine system. MEN2 typically includes medullary thyroid cancer, pheochromocytoma and/or primary hyperparathyroidism. It is also known as ‘Sipple Syndrome’.

NECK DISSECTION: removal of lymph nodes and surrounding tissue from the neck. The different types of neck dissection are: selective neck dissection, modified radical neck dissection, and radical neck dissection. It is sometimes done either during or following thyroid surgery to remove cancerous lymph nodes.

NERVE PALSY: dysfunction of nerve(s), for example, palsy of the recurrent laryngeal nerve, which can result in one or both vocal cords failing to open or close properly.

NODULE: a lump (on the thyroid or in the neck area.

NON-HODGKINS LYMPHOMA OF THE THYROID: a rare cancer of the thyroid arising from lymphocytes.

OSTEOPOROSIS: thinning of the bones which causes an increase in the risk and incidence of fracture. It is most common in post-menopausal women but also affects men and younger people.

PAEDIATRIC ENDOCRINOLOGIST: a doctor who specialises in the diagnosis and treatment of endocrine disorders such as diabetes and thyroid disorders in children.


PALLIATIVE CARE: a branch of medicine that aims to relieve symptoms and to provide patients with the best possible quality of life.

PAPILLARY THYROID CANCER: the most common type of differentiated thyroid cancer. About 80% of differentiated thyroid cancers are papillary.

PARATHYROID: four very small glands about the size of a grain of rice lying very close to, and sometimes embedded in, the thyroid gland. They are responsible for controlling the level of calcium in your blood.

PARATHYROID HORMONE (PTH): a substance secreted by the parathyroid glands to increase the concentration of calcium in the blood.

PARATHYROID AUTOTRANSPLANTATION: a technique by which one parathyroid gland is removed during thyroid or parathyroid surgery and transplanted elsewhere in the same individual (usually in a muscle in the arm) to preserve parathyroid function.

PET SCAN: see POSITRON EMISSION TOMOGRAPHY (PET).

PHONOSURGERY: surgery to the voice box.

POSITRON EMISSION TOMOGRAPHY (PET): a medical imaging technique that produces a
three dimensional picture of functional processes in the body after injecting a tracer liquid (usually glucose). A PET scan is used to evaluate some cancers, including thyroid cancer, usually alongside a CT or MRI scan.

**RADIOACTIVE IODINE (RAI):** radioactive isotope of iodine used in tests and treatment for thyroid cancer.

**RADIOACTIVE IODINE ABLATION (or RAI ABLATION):** Radioactive iodine treatment which destroys any remaining thyroid cells in the body after surgery.

**RADIOACTIVE IODINE SCAN:** a medical imaging test that uses a small amount of radioactive iodine (1-131) to help evaluate thyroid nodules before surgery, or to determine if there is spread outside the thyroid gland.

**RECOMBINANT HUMAN THYROID-STIMULATING HORMONE (rhTSH):** a chemical hormone similar to the body’s own naturally-produced TSH. The commercial name is Thyrogen®.

**RECURRENT LARYNGEAL NERVE:** a nerve that controls the voice box.

**SALIVARY GLANDS:** produce saliva to aid in digestion. There are three main types of salivary glands in the head and neck: the parotid glands, the submandibular glands, and the sublingual glands.

**SELECTIVE NECK DISSECTION:** removal of the lymph nodes in the central (front) compartment and sometimes the lateral (side) compartment of the neck.

**SPECT-CT SCAN:** a combination of two types of scan, a CT scan and a SPECT scan, both carried out on the same day in hospital. The images from the two scans are merged and interpreted together.

**SPECT SCAN:** a scan detected by a nuclear medicine camera. It is carried out following an injection of radioactive iodine which is carried to any thyroid cancer cells (and some other cells too) in the body.

**SUPPRESSED:** literally, reduced by force, inhibited. For example, as in suppressing TSH by giving a high dose of levothyroxine.

**STRIDOR:** an abnormal high-pitched wheezing caused by a blockage of the large airways.

**TALL CELL:** an uncommon variant of papillary thyroid cancer that is aggressive and has a higher chance of recurrence.

**TETANY:** muscle spasms caused by low levels of calcium in the body, due to removal of, or damage to, the parathyroid glands during surgery.

**THYROID ADENOMA:** a benign tumour of the thyroid gland.

**THYROGLOBULIN (Tg):** a protein produced by thyroid cells, also found in blood that is monitored to detect any thyroid cancer recurrence; also known as a tumour marker.
THYROIDECTOMY - COMPLETION: surgical removal of the remaining thyroid gland, for example, if lobectomy shows there is a malignancy.

THYROIDECTOMY - PARTIAL: surgical removal of part of the thyroid gland (also known as subtotal thyroidectomy).

THYROIDECTOMY - SUBTOTAL: surgical removal of part of the thyroid gland.

THYROIDECTOMY - TOTAL: surgical removal of the whole thyroid gland.

THYROID STIMULATING HORMONE (TSH): a hormone produced by the pituitary gland responsible for controlling the output of thyroid hormones.

THYROXINE (T4): a hormone produced by the thyroid gland that is converted into T3 in the body before it is active.

TOMOGRAPHY: multiple slices of high-definition x-ray film.

TRIIODOTHYRONINE (T3): a hormone produced by the thyroid gland.

TUMOUR: a lump or nodule that can be cancerous or non-cancerous (benign).

TYROSINE KINASE INHIBITORS: a group of drugs that interfere with cell communication and may prevent tumours from growing.

ULTRASOUND SCAN: a scan of part of the body using sound waves. It works by moving a probe over the part of the body being scanned that detects ‘echoes’ and sends them down the wire to the ultrasound machine where they are shown on a screen.

UNDIFFERENTIATED THYROID CANCER: the cells look and behave differently from normal thyroid cells. Anaplastic thyroid cancer falls into this category. Radioactive iodine ablation therapy is ineffective; treatment is normally External Beam Radiation.

UNSUPPRESSED: uninhibited, as in withdrawing levothyroxine (which suppresses TSH) so that the TSH level can rise.

WIDENED SCAR: a wide, flat scar that sometimes forms when a wound is closed under tension.

WHOLE-BODY SCAN (WBS): a medical imaging test that uses a small amount of radioactive iodine (1-131) to detect if there are any thyroid cells in the body after RAI ablation.
‘The BTA is delighted to endorse the updated BTF patient support booklet for thyroid cancer. The information follows the recently revised and published BTA guidance for specialists. It is evident that there is a great demand for clear and accessible information for patients with thyroid cancer in what can be a complex pathway through many specialities. As health professionals it is our duty to provide consistency to patients and their families. This booklet provides the recommended highest quality standards and support that health professionals should be delivering to their patients with thyroid cancer.’

Dr Mark Vanderpump, President, British Thyroid Association

‘Once again the BTF have raised the bar for the quality of their patient information. This well researched and written information booklet will, I am sure, be of great benefit to patients diagnosed with thyroid cancer. The checklist of what you should discuss with your surgeon is excellent.’

Mr Mark Lansdown, President, British Association of Endocrine and Thyroid Surgeons

‘A superb comprehensive go-to resource for thyroid cancer patients.’

Jo Grey, CEO and Chair of Trustee Board, AMEND

‘On behalf of Butterfly Thyroid Cancer Trust I am delighted to endorse this edition of the BTF Thyroid Cancer booklet. Patients will be able to relate to it with ease as it is straightforward and has been written by patients who know and understand how it feels to be affected by this disease. My congratulations and thanks to BTF for this excellent booklet.’

Kate Farnell, MBE, CEO, Butterfly Thyroid Cancer Trust

‘This booklet … helps answer many of the questions that patients have, but may not feel they can ask about. Our group sends a copy to any patient who contacts us. The feedback has been very positive. One patient, living in Trinidad and Tobago, was most grateful for all the information contained in the booklet as there was very little information available in her own country, especially relating to the low-iodine diet before radioactive iodine treatment.’

Cy Davies, Thyroid Cancer Support Group Wales

‘This detailed and comprehensive booklet is the complete resource for patients diagnosed with thyroid cancer. It gives clear guidance at every stage of the journey to help patients gain understanding, ask the right questions, and feel more in control of their situation.’

Liz Glenister, CEO, Hypopara UK

We hope you find this booklet helpful and would welcome your feedback and comments. Find out about how you can support the work we do at:

http://www.btf-thyroid.org/support-us/18-donate

http://www.btf-thyroid.org/support-us/join-btf
Designed to help patients facing a diagnosis of thyroid cancer, this booklet is largely written and reviewed by thyroid cancer patients who have themselves been through diagnosis and treatment. This is a third, revised and updated edition, with up to date medical and practical information, new photos and additional patient quotes.

Endorsed by:
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