Patient Information

1 The thyroid gland and thyroid cancer

Your tests and treatment

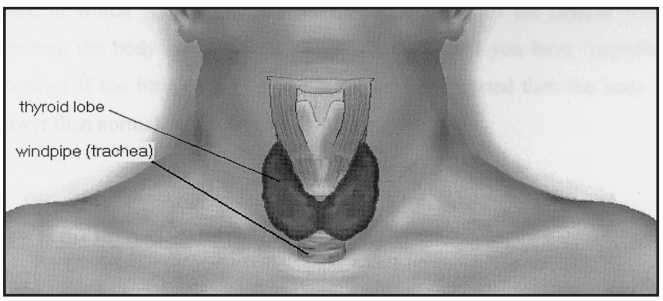
The thyroid gland

What is the thyroid gland?

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

Where is the thyroid gland?

The thyroid gland is at the base of the throat. It is made up of two lobes (each about half the size of a plum). The two lobes lie on either side of your windpipe, with the gland as a whole lying just below your Adam's apple. The thyroid gland and windpipe (with a cross-section of it above the thyroid lobes) are shown below.



What does the thyroid gland do?

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

- Thyroxine, often called T4.
- Triiodothyronine, often called T3. In the body, T4 is converted into T3 and this is what influences the way cells and tissues work.
- Calcitonin. This is involved in controlling calcium levels in the blood. With medullary thyroid cancer (MTC), too much calcitonin is produced.

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

What do the thyroid hormones do?

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

How is the thyroid gland controlled?

Most glands work together with other glands, and the thyroid gland works with the pituitary gland. The thyroid is controlled by the pituitary, which lies underneath your brain in your skull and senses the levels of thyroid hormones in your bloodstream. If the levels drop below normal, the pituitary reacts by releasing a hormone called the 'thyroid-stimulating hormone' or TSH. TSH stimulates the thyroid gland to produce more T3 and T4. If the thyroid hormone levels rise above normal levels, the pituitary senses this and stops releasing TSH and so the thyroid gland will produce less T3 and T4.

How is thyroid activity measured?

Your doctor will be able to get a good assessment of your thyroid gland activity by taking a history of your symptoms and by a physical examination. However, to gain an exact level of the thyroid hormones, it is necessary to take a small sample of blood, which when analysed in the laboratory will show how much T4 and T3 are being produced, and how active your pituitary is, by measuring the level of TSH. These tests are sometimes called thyroid function tests or TFTs.

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

Next to the thyroid gland is another set of glands called the parathyroid glands. There are normally four parathyroids, although this can sometimes vary. The parathyroids produce parathyroid hormone (PTH) and this controls the amount of calcium in the blood. Normal calcium levels in the blood are essential for healthy bones, blood clotting,

cardiac rhythm and function of the cells, as well as for general well-being. Too much calcium can make you feel sick and drowsy; too little can cause problems with the nerves such as pins and needles, and make your muscles twitch and jerk.

Thyroid cancer

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

Are all thyroid cancers the same?

No, there are different types:

- **Papillary carcinoma** – this is the most common thyroid cancer. It is more common in younger people, particularly women.
- **Follicular carcinoma** – this is less common, and tends to occur in slightly older people than those with papillary cancer.
- **Medullary carcinoma** – this is a rare cancer, which is sometimes hereditary (ie it is passed down through a family from one generation to the next).

Most thyroid cancers are very treatable and curable, but 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 lifelong follow-up is most important.

What is the cause of thyroid cancer?

The cause of thyroid cancer is unknown, but exposure to radiation is known to increase the risk of getting thyroid cancer. For example, after the Chernobyl accident, many more children in the area got thyroid cancer. Similarly, it has been found in people who had external radiotherapy to the neck 10 or 20 years earlier. Research into the causes of thyroid cancer is ongoing. Very occasionally papillary cancer is hereditary, and medullary cancer is quite often hereditary.

What are the symptoms of thyroid cancer?

- A painless lump in the neck which gradually increases in size.
- Difficulty in swallowing (dysphagia) – because of pressure of the enlarged thyroid gland on the oesophagus (gullet).

- Difficulty in breathing (dyspnoea) – because of pressure of the enlarged thyroid gland on the trachea (windpipe).
- Hoarseness of the voice.
- Symptoms of hyperthyroidism (overactive thyroid) and hypothyroidism (underactive thyroid) are rare, as cancer cells do not generally affect hormone production from the thyroid.

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

What tests will I need?

If you have one of the above symptoms, you will need further tests to check the diagnosis. Your GP will do a blood test to see if your thyroid hormone levels are within normal limits. This test on its own will not show whether you have cancer, but it will help your GP decide which specialist you need to see next. Many of the special tests that will help doctors make a diagnosis will be done in a specialist hospital clinic.

Fine needle aspiration. This is done in an outpatient hospital clinic. A very small needle is inserted into any swelling you may have in your neck and a sample of cells is taken out. These cells are then analysed under a microscope. This is one of the main tests that will help clarify your diagnosis.

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

Ultrasound scan. In this test, a picture of the thyroid gland is obtained by using sound waves and it will show any solid lumps or cysts. Again, this on its own cannot diagnose cancer but it can help with the overall diagnosis and in planning treatment.

Radioisotope scan. This type of scan is occasionally helpful in assessing thyroid lumps. A tiny dose of radioactive iodine is given as a capsule (or alternatively another radioactive substance called 'technetium' is given as an injection); then after a short time a gamma camera is placed over the neck. The camera measures the amount of radioactive substance taken up by the thyroid gland. Cancer cells do not absorb radioactive substances as well as normal thyroid cells, so a small cancer may show on the scan as a 'cold' nodule. However it is not a very good diagnostic test and many so-called 'cold' nodules are benign, not cancerous.

What treatment will I be offered?

You may be offered surgery (thyroidectomy)

Surgery is usually the first line of treatment for thyroid cancer. Usually the whole thyroid gland (total thyroidectomy) will need to be removed, though sometimes only one lobe has to be removed; it depends on various factors such as your age, the size of the lump and results of the tests mentioned above. The parathyroid glands may or may not be removed. After a thyroidectomy, you will need to take thyroxine tablets as prescribed for the rest of your life; regular blood tests will be needed to check that your thyroid hormone levels are within normal limits, and that the TSH level is suppressed. Eventually you should only need a blood test once or twice a year.

Following surgery you will need to have your hormone levels monitored

After your thyroid surgery, your GP will need to monitor your thyroid medication and get blood tests to check your hormone levels. When you are at home after your surgery, please contact your GP or treatment centre if:

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

This may mean you need to have your thyroxine or calcium levels checked and your medication dose increased or decreased, as the case may be. Once your body has settled you will be able to lead a normal life but you will need to continue to take the thyroxine tablets for the rest of your life and to have your thyroid levels checked regularly. It will be particularly important to have your thyroid hormones (TSH) checked if you become pregnant, as you may need to increase your dose of thyroxine (levothyroxine).

You will probably also need to have radioactive iodine treatment

Most people need to have radioactive iodine treatment after surgery to destroy any remaining thyroid or cancer cells. Your doctor will tell you if this is the case. Radioactive iodine treatment is painless – it means taking either one or two capsule-type tablets, or

as a liquid, in a single dose. You should not feel sick or lose any hair or have any other side effects with the usual dose required. It is a low dose of radiation but, for the safety of others, for the first 2–4 days a person needs to come into hospital and reduce their social contact. If you need this treatment you will be informed by your specialist consultant and given an information booklet like this one before you start treatment.

Most thyroid cancers are very treatable and curable

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

Useful contacts

The British Thyroid Foundation
PO Box 97, Clifford, Wetherby
West Yorkshire LS23 6XD
Tel: 01423 709707/01423 709448
www.btf-thyroid.org

Butterfly Northeast
PO Box 205, Rowlands Gill
Tyne & Wear NE39 2WX
Tel: 01207 545469
www.butterfly.org.uk

Thyroid Cancer Support UK
www.thyroidcancersupportuk.org

Association for Multiple Endocrine Neoplasia Disorders AMEND (MEN2/FMTC)
31 Pennington Place, Southborough
Kent TN4 0AQ
www.amend.org.uk
email: jo.grey@amend.org.uk

Cancerbackup
3 Bath Place, Rivington Street
London EC2A 3JR
Tel: 0808 800 1234
www.cancerbackup.org.uk

Macmillan Cancer Support
89 Albert Embankment
London SE1 7UQ
Freephone 0808 808 2020
www.macmillan.org.uk/home.aspx

Cancerlink
Freephone Information Helpline: 0800 132905
www.personal.u-net.com/~njh/cancer.html

CancerHelp UK
www.cancerhelp.org.uk

Thyroid Cancer Survivors' Association
www.thyca.org

Other useful sites can be found in the **British Thyroid Association** links page:
www.british-thyroid-association.org

Patient Information

2 Thyroid surgery for cancer

Your thyroidectomy

What is a thyroidectomy?

A thyroidectomy is the removal of the whole thyroid gland ('total thyroidectomy') or part of it ('hemithyroidectomy' or 'lobectomy'). You may need to have this done because you have a swelling or enlarged gland or for thyroid cancer treatment. Your specialist will explain to you whether a part or all of your thyroid needs to be removed, so that you can give fully informed consent. If you do not understand any of the information you are given, please ask, as it is very important for you to make the right decision.

Is it a safe operation and what are the side effects?

Thyroid surgery is safe. Before the operation you will be examined and have some additional tests in order to make sure you are fit enough to have a general anaesthetic. Even if you have other medical conditions such as heart or chest trouble, it is usually safe to have the operation.

- The total removal of the thyroid gland means that you will need to take replacement hormone tablets called thyroxine every day for the rest of your life, otherwise you will experience symptoms of hypothyroidism (underactive thyroid). Thyroxine tablets are the size of a sugar sweetener and safe to take. With monitoring by your specialist centre and/or your GP you should be able to lead an active and normal life.
- Thyroxine tablets are also given to suppress the level of thyroid-stimulating hormone (TSH). This is an important part of the treatment for thyroid cancer so most patients will be given thyroxine even if they have had only part of the thyroid removed. You will be advised on this before you go home from hospital.
- You will need regular blood tests to measure the levels of hormones in your blood, and your medication will be adjusted accordingly. You will be given appointments for this.

- Thyroidectomy does not affect your ability to have children, but if you are thinking of starting a family do ask your specialist for advice and information first.

Will it affect my voice?

The thyroid gland lies close to the voice box (larynx) and the nerves to the voice box. After your surgery you may find that your voice sounds hoarse and weak and your singing voice may be slightly altered, but this generally recovers quite quickly. In a very small number of cases voice change can be permanent.

Will my calcium levels be affected following thyroid surgery?

The parathyroid glands control the levels of calcium in the blood and are found close to the thyroid. Sometimes these glands are affected during surgery; if that is the case you may experience tingling sensations in your hands, fingers, in your lips or around your nose. Sometimes people may feel quite unwell. Please report this to the staff looking after you or, if you are at home, to your GP. Blood tests will be taken to monitor the levels of calcium in your blood following surgery. If the level of calcium is falling this can easily be treated by giving you calcium supplements, which may be given through a drip and/or by tablets. You may only need to take these tablets temporarily as the parathyroids usually get back to normal after removal of the thyroid. The medical and nursing staff will advise you about this.

Will I have neck stiffness, restricted shoulder movement or pain?

You will feel some discomfort and stiffness around your neck but you will be given some medication to help ease any pain and discomfort. Pain relief may be given in different ways, such as injections, liquid medicine or tablets. Most patients say the discomfort is not as bad as they expected and after the first day they are up and walking around. Two days after your surgery you will be given some gentle neck exercises to do; this may be given in an information sheet but please do ask staff if you are unsure what to do. After a few weeks your neck and shoulder movements should be back to normal.

Will I have a scar?

Whether all or part of your thyroid has been removed, you will have a scar, but once this is healed it is usually not very noticeable. The scar runs in the same direction as the natural lines of the skin on your neck.

When will the operation be done?

If you have been to an outpatient clinic you may have been given a date for your operation at that time. Otherwise you may receive a date through the post or by phone from your consultant's secretary.

What happens in a pre-admission assessment clinic?

Some hospitals (not all) run a pre-admission assessment clinic, and you may be invited to go there one or two weeks before your operation. This enables both the doctors and the nurses to assess your health needs and carry out routine tests which may be needed before surgery, such as blood tests, a heart tracing (ECG) and a chest X-ray.

The pre-admission assessment gives you the opportunity to meet the ward staff and to see where you will be admitted on the day of your operation. It is also a time when you can ask questions and discuss any concerns you may have about your operation and coming into hospital.

Time is allocated for each individual and you should expect to be there no longer than two hours. However, in unusual circumstances a delay may be unavoidable.

Some patients may have their tests carried out the day before surgery and in that case would not be asked to attend a pre-admission assessment.

What about smoking?

All hospitals operate a 'No Smoking' policy and smoking is not allowed on the ward. If you do smoke, it is in your own health interests to stop smoking at least 24 hours before your anaesthetic.

Please contact your GP's surgery for advice on stopping smoking.

What shall I bring into hospital?

Please bring nightwear, day wear, dressing gown, towels, toiletries, slippers, books/magazines and a pen. It will be helpful to arrange for a relative or friend to wash your nightwear etc and bring in fresh supplies. Hospital nightwear is available if required.

You must bring with you any medication you are currently taking, including inhalers.

Please do not bring any valuables with you, such as jewellery, large sums of money or bank cards. The hospital cannot take responsibility for your valuables. On your admission

you will be asked to sign a disclaimer form which gives you the responsibility for any valuables you bring with you.

Valuables may be taken for temporary safe keeping by the ward staff while you have your operation and you will be given a receipt.

Will there be a bed ready when I arrive?

Because the hospital runs an emergency service, it is not always possible to predict how many beds will be available. Also, operations are carried out every day and patients are discharged home every day. It is therefore difficult to predict early in the morning how many beds will be available.

You may be asked to take a seat in the waiting room until your bed is ready. You may be waiting for another person who has already had an operation to be discharged. The operation lists are planned and it is necessary to operate in a certain order due to many circumstances. That is why beds are allocated in order of operating lists and not in order of arrival. Please feel free to ask any member of staff for help and advice at any time. Hospital staff will do their best to accommodate you and to keep you waiting for as little time as possible.

What instructions or help will I have to get ready for surgery?

When you have been taken to your bed, the nurse will welcome you and check your details. You will need to wear a special theatre gown for your operation. This will be given to you by the nurse who will show you how to wear it and help you if you want.

Please only wear cotton pants/underpants under your gown. All other underwear must be removed to ensure your safety while equipment is used in the operating theatre.

You will also be given a pair of white elastic stockings to wear during and after the operation which will prevent blood clots from forming in your legs. They feel quite tight and you may need help in putting them on.

What preparation will I need for the operation?

Your operation will be carried out under a general anaesthetic which means that you will be fully unconscious for the whole operation. Removing all or part of the thyroid involves delicate surgery which means that the operation can take about two hours.

To prevent vomiting and other complications during your operation you will be asked not to eat or drink anything for at least six hours before your operation. You will be told

what time to start this period without eating food or drink when you attend the pre-admission assessment or by letter from the consultant's secretary.

You should expect to be in hospital for about four days, or longer if any complications arise.

If you would like to meet another patient who has had a thyroidectomy this can sometimes be arranged.

What will happen when I go to theatre?

Just before going to theatre a nurse will complete a checklist. You will then be taken on your bed to the operating theatre, usually by a theatre technician and a nurse. The nurse will stay with you in the anaesthetic room.

Dentures, glasses and hearing aids can be removed in the anaesthetic room and taken back to the ward by the nurse, or you may like to put them in your locker before your operation.

The anaesthetist will insert a small needle into the back of your hand and give you your anaesthetic through that. The nurse will stay with you until you are fully under the anaesthetic and fully asleep. You will not wake up until the operation is over. You will be taken, on your bed, to the recovery area where a nurse will look after you until you are awake. You will then be taken back to the ward, on your bed, by a theatre technician and a nurse.

What will happen when I get back on the ward following surgery?

Back on the ward you will be made comfortable. You will be sitting fairly upright in your bed supported by several pillows as this will help to reduce any neck swelling. Your nurse call bell will be situated close to you so that you can call a nurse at any time.

You will have your blood pressure, pulse and oxygen levels checked frequently. A machine will do this automatically – a blood pressure cuff is wrapped around your upper arm and a probe is clipped to one of your fingers.

There will be a fluid drip going into a vein, probably in the back of your hand; this will be removed as soon as you are drinking normally (usually within 24 hours). You will be able to sip drinks quite soon after your operation as long as you are not feeling sick, and you can eat as soon as you feel able.

What will I look like after thyroid surgery and what will I be able to do?

You will have a scar on the front part of your neck which will feel a little tight and swollen initially after the operation. It may feel a bit sensitive but should not cause any distress.

You may have one or two wound drains from your wound to collect wound fluid which naturally occurs after your surgery. The drains are small plastic tubes which are inserted into the neck at the end of your operation. The long length of tubing outside the neck is attached to a plastic bottle that collects the fluid. Wound drains help to speed up healing and reduce infection. The drains are not painful and you can carry them around with you. They will be removed by a nurse usually a day or two after your operation when there is very little fluid coming through.

You will feel some discomfort and stiffness around your neck but you will be given some medication to help ease any pain and discomfort. Pain relief may be given in different ways such as injections, liquid medicine or tablets. Most patients say it was not as bad as they expected and after the first day they are up and walking around.

For your own safety it is important that you do not get out of bed on your own immediately after your operation as you may be drowsy and weak. At first when you need to use the toilet a member of staff will need to help you with a commode or bedpan. You will soon be able to walk to the bathroom yourself.

You will have a nurse call bell within easy reach so that you can get help from the ward staff as needed.

After your operation you may not feel very sociable so it is wise to restrict visitors.

Will it affect my eating and drinking?

For a short period after your operation you may find it painful to swallow and you may need a softer diet. You may find that nutritious drinks are helpful in providing a balanced diet which is important to assist healing.

Will I have a sore neck?

You will probably find that your neck is quite sore and you will be given painkillers to take home to relieve the discomfort. Please take your painkillers as described on the packet and take care not to exceed the recommended number of tablets.

The painkillers should also ease the discomfort caused by swallowing. Your neck may appear swollen and hard to touch, with some numbness, which will gradually ease as healing takes place.

What should I do to reduce any risk of wound infection?

Keep your neck wound clean and dry. Initially the nursing staff will check your wound daily and clean it as necessary. A few days after surgery when you are feeling better you may have a shower or bath but take care to ask the nursing staff's advice first and gently pat the wound dry with a clean towel. Exposure to the air will assist wound healing.

If your neck becomes increasingly painful, red or swollen or you notice any discharge then please seek medical advice from ward staff or your GP. To reduce the risk of infection it is wise to avoid crowded places and take extra care of yourself. Use only clean towels on your wound area for the first few weeks.

What care do I need to take regarding my neck wound?

Take care not to knock your wound and remember to keep it dry if it becomes wet after bathing or showering by patting it dry with a clean towel.

Once the scar has begun to heal, you can rub a small amount of unscented moisturising cream on the scar so it is less dry as it heals. Calendula, aloe vera or E45 cream (available from health shops) is effective. The pressure of rubbing the cream in will also help to soften the scar.

What rest do I need?

You will need to take it easy while your neck wound is healing. This means avoiding strenuous activity and heavy lifting for a couple of weeks. Your neck will gradually feel less stiff and you will soon be able to enjoy your normal activities.

What about my medication and tablets?

Please continue to take the medication you have been prescribed and ensure that you have a good supply. If you are unsure about any of the tablets you need to take, please check this with a nurse before you go home. Repeat prescriptions can be obtained from your GP. When you go for your appointments at the hospital to check your blood levels

after your surgery, your medication may need to be altered so please check with the medical staff.

When should I return to work?

You will probably need to take about three weeks off work (or sometimes longer), depending on your occupation and the nature of your work. The hospital can issue you with a note for two weeks and then you should see your GP if more time is needed.

Will I need to be checked in an outpatient department following discharge home?

Following your discharge you will need to be reviewed in the outpatient clinic to check how your wound is settling down, your hormone levels and how you are feeling. You will usually receive the date and time for this appointment through the post or it may be given to you by the ward staff before you go home. Please contact the ward or the consultant's secretary at the hospital if you do not receive an appointment shortly after discharge. Depending on the problem with your thyroid and the results from the thyroid tissue that has been removed, you may be offered further treatment. This will be discussed with you by your specialist consultant at your clinic appointment. If you would like any further information, please do not hesitate to ask the nursing staff.

Will I be able to cope?

When most people are first told they need to have a thyroidectomy, they say they feel all sorts of mixed emotions; some might feel numb, and others say they knew all the time that they would need surgery. We are all individuals and cope in different ways so we need different lengths of time to adjust to the changes we face.

You do not have to face your treatment on your own.

Support and help is available from the staff.

Together we can help you through your investigations, treatment and recovery.

Useful contacts

The British Thyroid Foundation
PO Box 97, Clifford, Wetherby
West Yorkshire LS23 6XD
Tel: 01423 709707/01423 709448
www.btf-thyroid.org

Butterfly Northeast
PO Box 205, Rowlands Gill
Tyne & Wear NE39 2WX
Tel: 01207 545469
www.butterfly.org.uk

Thyroid Cancer Support UK
www.thyroidcancersupportuk.org

Association for Multiple Endocrine Neoplasia Disorders AMEND (MEN2/FMTC)
31 Pennington Place, Southborough
Kent TN4 0AQ
www.amend.org.uk
email: jo.grey@amend.org.uk

Cancerbackup
Bath Place, Rivington Street
London EC2A 3JR
Tel: 0808 800 1234
www.cancerbackup.org.uk

Macmillan Cancer Support
89 Albert Embankment
London SE1 7UQ
Freephone: 0808 808 2020
www.macmillan.org.uk/home.aspx

Cancerlink
Freephone Information Helpline: 0800 132905
www.personal.u-net.com/~njh/cancer.html

CancerHelp UK
www.cancerhelp.org.uk

Thyroid Cancer Survivors' Association
www.thyca.org

Other useful sites can be found in the **British Thyroid Association** links page:
www.british-thyroid-association.org

Patient Information

3 Radioactive iodine ablation and therapy

Things you need to know

Radioactive iodine 'ablation' is treatment with radioactive iodine, which is used to kill off any remaining thyroid tissue in the neck after a thyroid operation. Radioactive iodine 'therapy' refers to treatment with radioactive iodine which is used to kill off thyroid cancer cells in the neck or elsewhere in the body. Radioactive iodine therapy is given only if the tests show that there are still cancer cells in the body.

Most of what follows applies to both 'ablation' and 'therapy' and will be referred to as 'radioactive iodine treatment'.

This form of treatment (ablation or therapy) consists of swallowing radioactive iodine either as a capsule or a liquid. The radioactive iodine is taken up by the thyroid gland. The small dose of radiation is then concentrated in the thyroid cells and destroys them. To receive radioactive iodine ablation or treatment, you will need to be admitted into hospital and stay in a special room (called the iodine suite) so that the radioactivity that your body will be excreting can be safely contained.

Is radioactive iodine treatment (ablation or therapy) safe?

Radioactive iodine has been used to treat thyroid cancer for over 50 years. The greatest danger from radioactive iodine is to the thyroid gland but, as your thyroid has been removed, it is not at risk; the treatment is meant to destroy any thyroid cells that may have escaped surgical removal. Radioactive iodine treatment has been linked with an increased risk of developing other cancers, but this risk is small and has to be balanced against the benefits in treating the thyroid cancer. Your treatment team will discuss these issues with you in detail before the treatment.

The precautions described below are intended to protect other people, particularly pregnant women and young children. It makes sense to reduce everyone's exposure to radioactivity, as any one of us may need this form of treatment in the future.

Are there any side effects from radioactive iodine treatment?

Most patients do not have side effects from radioactive iodine treatment. Some patients may experience a feeling of tightness or swelling in the throat and/or feel flushed,

which usually lasts for no more than 24 hours. If this goes on longer, please inform the nursing staff, as an anti-inflammatory drug can be given to relieve this problem. Sometimes having radioactive iodine can result in a temporary taste disturbance, which can last for a few weeks. Drinking plenty of fluids after the treatment helps to wash out the radioactivity and reduce this problem. Please do talk through any of your questions with the specialist consultant or a member of the treatment team.

What if I am pregnant or breastfeeding?

It is very important that you **do not have radioactive iodine treatment if you are pregnant or think there is a good chance that you may be**. Please let your treatment team know if you are unsure before you have any treatment. It is important not to become pregnant when having investigations for thyroid cancer. You should use a reliable contraceptive during investigations, treatment and for at least 6 months after radioactive iodine treatment. In the long term, your fertility will not be affected even after repeated doses of radioactive iodine.

If you are breastfeeding, you should stop this at least four weeks and preferably eight weeks before you have the radioactive iodine treatment and you should not start again afterwards.

(Male patients) Will it affect my ability to have children?

Male patients are advised not to try for children (get their partners pregnant) for four months after radioactive iodine treatment and until they are sure they will not need any more radioactive iodine treatment. In the long term your fertility should not be affected but there may be a small risk if repeated radioactive iodine therapy is needed. Please discuss this with your specialist consultant or a member of the treatment team before trying for a family after this treatment: specialist advice and help is available.

Before having radioactive iodine treatment, what medication/tablets should I take?

If you are taking **T3 (triiodothyronine) tablets**, most specialist centres recommend that these should be stopped for two weeks before your radioactive iodine treatment.

If you are on **levothyroxine tablets**, most specialist centres will advise you to stop taking them for **four weeks** before the radioactive iodine treatment. In this four-week period your specialist may first change you to T3 tablets for 2 weeks, and then stop your

tablets altogether for the last two weeks before your treatment. You may feel weak and tired when you are not taking your tablets. This is normal and will disappear once you start taking them again, usually a few days after you have had your radioactive iodine.

It is important that you follow the instructions about stopping your thyroxine medication given to you by your specialist centre staff as it may vary in different centres. If you are unsure about your thyroxine medication, please contact your specialist centre one month before your planned date for radioactive iodine treatment.

Should I keep taking my other medication/tablets?

If you are taking any other tablets you should carry on doing so and bring a supply with you on admission and show them to the doctor and nurse team. If you are taking any vitamin or mineral supplements or cod liver oil, you should stop taking them around three weeks before your therapy to help reduce your iodine levels.

Before my radioactive iodine therapy what should I eat?

A diet which is rich in iodine can reduce the effectiveness of the treatment. Therefore, two weeks before coming in to hospital we recommend the following:

- **Do eat fresh** meat, vegetables, fresh fruit, pasta and rice. These are low in iodine.
- **Do not eat** glacé and maraschino cherries which contain the colouring material E127. Food coloured by spices is allowed.
- **Do not take** cough medicine, iodised table salt or sea salt, as these contain iodine. Ordinary table salt is allowed.
- **Try to cut down on** dairy produce such as eggs, cheese, milk and milk products as they all contain some iodine.
- **Avoid** fish, kelp and all seafood.
- **Avoid** vitamin supplements which contain iodine.

Do I have to come into hospital for radioactive iodine treatment?

Yes, you will probably need to stay in hospital for 3–6 days. How soon you go home depends on how quickly the radioactivity leaves your body.

What happens on admission?

On the ward you will be greeted and your details will be registered. You will then be given a hospital name band to wear, with your hospital registration number and a few details on it. One of the nursing staff will take your blood pressure, pulse and temperature as a routine procedure. You will be given an explanation of the treatment and details about the room where you will be staying. You will also have the opportunity to ask any questions that you might have.

Your doctor will then come to examine you and check that you have stopped taking your thyroid tablets before the treatment as this interferes with the absorption of the radioactive iodine. You will have been sent information about this with your appointment letter.

You will be asked to sign a form giving consent for the treatment.

Who gives the capsule?

The nuclear medicine (or medical physics) department within the hospital is responsible for dealing with the radioactive iodine treatment. One of their staff will come to the ward to give you the capsule (which is about the size of an antibiotic capsule) or the liquid (which is colourless and tasteless.

What happens next?

For the first two hours after taking the capsule you should not eat or drink anything to allow time for the iodine to be absorbed. After this time you should eat as normal and drink as much as possible so that you pass urine frequently. This will flush the excess radioactive iodine out of your system.

Are there any restrictions?

As the treatment you have received is radioactive, no young children or pregnant women will be allowed to visit. Others may visit for a short time. Because you are **radioactive**, staff will spend only short periods of time in your room. When they bring in your meals and drinks they may stand behind a lead screen and you should try to stay on the opposite side of the room. Do not expect them to stay and chat for long periods of time but do not hesitate to contact them if you need anything.

What happens at meal times?

The nursing staff will bring you meals in your room. These meals may be served on paper plates and you may need to use plastic cutlery. When you have finished your meal these should be thrown away in a bin provided. If there is any unwanted food this needs to be sealed in a plastic bag and put in the bin. Alternatively, if ordinary plates and cutlery are used, these will have to be washed up either in your room or in a special kitchen. A waste disposal unit may be available to dispose of any unwanted food. Each day you will receive a menu to fill in for the next day. Drinks are provided in the morning, mid-morning, lunch time, tea time and night-time. If you do not receive your meal for whatever reason please ring the nurses' station, and they will provide you with one. We will try our best to ensure that this does not happen.

What about washing and hygiene?

As you should be drinking a lot, you should also be using the toilet frequently. All your bodily fluids are radioactive so you must flush the toilet after use. If you spill or splash urine please contact the nursing staff.

Your sweat is also radioactive, so we advise you take a bath or shower daily.

What can I can bring in with me to help me relax or pass the time?

You can bring DVDs, CDs, laptops, iPods, books, clothes and toiletries with you, but they may need to be monitored for contamination before they can be removed from your room. It may sometimes be necessary for us to keep some of your belongings if they are contaminated, but they will be returned to you once they are no longer contaminated.

When can I go home?

The staff from the nuclear medicine or medical physics department will come to the ward to take measurements and they can then work out how much radiation is still in your body and if the level is safe for you to go home. You must stay in your own room until that time. Before going home you may have a whole body scan.

Will I still have any restrictions when I get home?

The nuclear medicine or medical physics staff will explain to you the restrictions you must follow when you go home, for example avoiding crowded places and limiting the

people you come into contact with. They can work out exactly how many days you need to restrict yourself. The restrictions you are given may be different from other patients as some patients may be lower or higher in their radioactivity. These restrictions are to protect other people, specially pregnant women and children.

Medical or nursing staff will organise a new supply of thyroid tablets for you to take home and you will be told when to re-start them.

Will I have to come back to the hospital?

You will need to be seen again in the outpatient department by your doctor. You will either be given an appointment when you leave the ward or this may be sent to you later.

When everything is organised, you are free to go home.

Will I need radioactive iodine treatment again?

The treatment may need to be repeated until all the remaining thyroid tissue has been destroyed. Some people require one ablation dose and some people require more than one treatment.

Please remember that this is a low dose of radiation and all these procedures are to protect you and others in case they should need to have radiation treatment in the future. The aim is to keep everybody's radiation exposure to a minimum.

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

Useful contacts

The British Thyroid Foundation
PO Box 97, Clifford, Wetherby
West Yorkshire LS23 6XD
Tel: 01423 709707/01423 709448
www.btf-thyroid.org

Butterfly Northeast
PO Box 205, Rowlands Gill
Tyne & Wear NE39 2WX
Tel: 01207 545469
www.butterfly.org.uk

Thyroid Cancer Support UK
www.thyroidcancersupportuk.org

Association for Multiple Endocrine Neoplasia Disorders AMEND (MEN2/FMTC)
31 Pennington Place
Southborough, Kent TN4 0AQ
www.amend.org.uk
email: jo.grey@amend.org.uk

Cancerbackup
Bath Place, Rivington Street
London EC2A 3JR
Tel: 0808 800 1234
www.cancerbackup.org.uk

Macmillan Cancer Support
89 Albert Embankment
London SE1 7UQ
Freephone 0808 808 2020
www.macmillan.org.uk/home.aspx

Cancerlink
Freephone Information Helpline: 0800 132905
www.personal.u-net.com/~njh/cancer.html

CancerHelp UK
www.cancerhelp.org.uk

Thyroid Cancer Survivors' Association
www.thyca.org

Other useful sites can be found in the **British Thyroid Association** links page:
www.british-thyroid-association.org