British Thyroid Association Patient Information Leaflet 3: Surgery for thyroid cancer

What is a thyroidectomy?

Thyroidectomy is a common operation. Some patients will have half the thyroid removed (the medical terms for this are hemithyroidectomy or lobectomy), others will have the whole thyroid gland removed (the medical term for this is total thyroidectomy). Total thyroidectomy may be performed in two stages – a hemithyroidectomy followed by a 'completion thyroidectomy'.

Some patients with papillary thyroid cancer may require more extensive surgery. Total thyroidectomy may be combined with neck dissection – removal of the lymph nodes in the central (front) compartment and sometimes the lateral (side) compartment in your neck.

If medullary thyroid cancer has been diagnosed, total thyroidectomy and central lymph node dissection is routinely undertaken to remove lymph nodes. Lateral neck dissection is sometimes required.

Your surgeon will explain to you whether a part or your entire thyroid needs to be removed. They should explain the possible risks of each procedure so that you can give fully informed consent. If you do not understand any of the information you are given, please ask. It is important for you to make a choice that you are comfortable with.

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

Thyroid surgery is generally safe but there are some possible risks you need to be aware of.

Whether you are having a hemithyroidectomy or a total thyroidectomy there is a very low risk of bleeding or infection after the operation. There is also a risk of temporary voice change, which in a few cases may become permanent. Despite the surgeon's best efforts some people will have a poor neck scar.

If you are having a total thyroidectomy or neck dissection there is a risk of more significant voice change. If that happens you will be offered an examination of the vocal cords by a specialist. Occasionally breathing and swallowing difficulties can arise. Very rarely a tracheostomy (an artificial opening in the windpipe to help you breathe) may be needed. There is also a risk of a low blood calcium as a result of the parathyroid glands not working. The low calcium in the blood and need for calcium/vitamin supplements to treat this may be temporary or permanent.

A lateral neck dissection involves a longer incision. Your surgeon will explain this to you. During this procedure there is a risk of injury to an important nerve in the neck which helps with neck and shoulder function (accessory nerve). This may be temporary or permanent and can result in pain and stiffness around the shoulder.

Don't hesitate to ask your surgeon about the number of thyroid operations they perform each year, and their complication rates, and whether they are core members of the thyroid Multi-Disciplinary Team (MDT). The risk of complications is lowest if thyroid surgery is undertaken by an experienced endocrine or head-and-neck surgeon who regularly does thyroid and parathyroid surgery, preferably working as part of an MDT. Department of Health Cancer Standards require that surgeons who operate on patients with thyroid cancer should perform a minimum of 20 thyroidectomies per year.

Before the operation you will be examined by your surgeon, and may have additional tests to assess your suitability for a general anaesthetic.

Will it affect my voice?

The thyroid gland lies close to the voice box (larynx) and the nerves to the voice box. If you depend on your voice in your work or hobbies, or if you are a singer, you should discuss this with your surgeon.

Before the operation you will have a vocal cord check. A local anaesthetic may be sprayed into your nose to make the procedure as painless as possible. A thin flexible camera (endoscope) is then gently passed into one nostril and over the back of the nose into your throat.

After your surgery you may find that your voice sounds hoarse and weak, and your singing voice may be altered. The changes may be due to changes in muscle function in the neck, rarely to injury to the recurrent laryngeal nerve which causes a vocal cord palsy (reduced movement of the voice box muscle). In most cases this recovers within a year. Speech therapy may be required prior to recovery of the nerve.

Temporary voice change can occur in up to 10% of cases, but permanent injury is uncommon and happens in less than two percent of cases. If this happens, ask your surgeon about possible treatment such as speech therapy or further surgery.

Will surgery affect my calcium levels?

The thyroid gland lies close to four tiny parathyroid glands, each about the size of half a pea. They produce parathyroid hormone (PTH) that regulates levels of calcium in your blood. The calcium level in your blood will be checked after your operation.

After total or completion thyroidectomy PTH levels can fall which causes the calcium level in your blood to drop. A low calcium level in the blood (hypocalcaemia) may cause symptoms such as tingling in your lips or fingers or cramps. If you have symptoms you should tell a doctor or nurse immediately. You will have a blood test and, if low calcium is confirmed, you will be given some calcium in tablet form or through a drip in your arm.

You may need to take vitamin D and calcium tablets after the operation. In about 30% of cases this is temporary. In <10% of cases this may be permanent in which case you may require life-long vitamin D and calcium tablets. Your blood calcium will need to be monitored regularly by the hospital or by your GP. If you are left on supplements longer than 6 months ask your specialist to check your PTH level to see if it is possible to be weaned off the tablets. This is successful in many cases.

If you need long-term calcium and/or vitamin D supplements, follow-up is necessary to monitor your blood, bones and kidneys and sometimes adjustment of your medication. Your GP will care for you between hospital appointments and will organise regular blood tests, particularly during medication adjustments. Once your levels are stable you should be able to lead a normal life.

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

You may 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. After a few weeks your neck and shoulder movements should be back to normal.

If you have had more extensive neck surgery to remove some of your lymph nodes you may need to be referred to a physiotherapist.

Will I have a scar?

Whether all or part of your thyroid has been removed, you will have a scar, but this is usually not very noticeable once it has healed. 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 run a pre-admission assessment clinic to which you will be invited before your operation. This enables both the doctors and the nurses to assess your health needs and carry out the routine tests needed before surgery. 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.

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

What about smoking?

All hospitals operate a 'No Smoking' policy. Smoking is not allowed on the ward. If you do smoke, it is in your own health interests to stop smoking at least 24 h before your anaesthetic. Please contact your GP's surgery for advice on stopping smoking.

What should I bring into hospital?

The hospital will provide you with a list. This will include: nightwear, dressing gown, slippers, toiletries, things to occupy you such as books and magazines, a small amount of money, and a notebook and 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. This gives you 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?

If the hospital runs an emergency service, it is not always possible to predict how many beds will be available. Beds are allocated in the same sequence as the operating lists. 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.

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 are 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.

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 2 h.

To prevent vomiting and other complications during your operation you will be asked not to eat or drink anything for at least 6 h before your operation. You will be told what time to stop eating and drinking when you attend the pre-admission assessment or by letter from the consultant's secretary.

You should expect to be in hospital for 1–3 days, depending on the extent of surgery, or longer if any complications arise.

If you would like to talk with another patient who has had a thyroidectomy we suggest you contact one of the patient support organisations listed at the end of this leaflet before you go to hospital.

What will happen when I go to theatre?

Just before going to theatre a nurse will complete a checklist. You will then be taken 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 should be removed beforehand and given to the nurse or stored in your locker.

The anaesthetist will usually 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 be monitored closely during the first hours after surgery. 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.

If you have had a total or completion thyroidectomy your calcium levels will be checked. 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 h). 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.

Surgeons use a variety of techniques to close the wound: stitches, staples, or a pull-through single thread or 'bead'. Some surgeons spray the wound. Others cover it with a waterproof dressing.

You may have one or more wound drains from your wound to collect wound fluid which naturally occurs after your surgery. These are thin plastic tubes which are inserted into the neck at the end of your operation and attached via a long length of tubing outside the neck to a plastic bottle or bag that collects the fluid. 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.

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 from the anaesthetic. At first when you need to use the toilet a member of staff will need to help you. You will soon be able to walk to the bathroom yourself. Most patients are up and walking around after the first day.

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

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.

Will I have a sore neck?

Your neck will probably be 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 and clean it as necessary. 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.

How should I take care of my neck wound?

When you leave hospital you will be given advice how to look after the wound. If the stitches need removing you will be given an appointment. Take care not to knock your wound and remember to dry it carefully if it becomes wet during 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. Creams such as calendula, aloe vera or E45 cream (available from health shops) are effective. The pressure of rubbing the cream in will also help to soften the scar.

Sometimes the scar is raised, red and itchy. Some flatten in time but others develop into keloid scars which tend to remain thickened. Vitamin E oil, topical steroid creams, and silicone gel sheeting may help. Steroid injections may be worth considering if these fail.

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 medication will I need?

The total removal of the thyroid gland means that you will need to take replacement hormone tablets called levothyroxine (T4) every day for the rest of your life, otherwise you will experience symptoms of hypothyroidism (underactive thyroid). Levothyroxine tablets are the size of a sugar sweetener and safe to take. With monitoring by your specialist centre and/or your GP you will be able to lead an active and normal life.

Levothyroxine 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 levothyroxine even if they have had only part of the thyroid removed.

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.

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. The dose of levothyroxine should NOT be altered without discussion with a member of the Joint Thyroid Cancer Clinic clinical team.

If you have had a hemithyroidectomy and no cancer is found, the remaining thyroid tissue in two out of three patients will produce sufficient thyroid hormone for your needs. In about a third of patients the remaining thyroid gland is not able to produce enough thyroid hormone. The blood tests that you will have in the follow up clinic will identify if thyroxine replacement is needed. If this is the case you will need to take levothyroxine for life.

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

When should I return to work?

This depends on your occupation, the nature of your work, and how you are feeling. The hospital can issue you with a note for 2 weeks and then you should see your GP if more time off 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 may 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 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?

A diagnosis of cancer can bring all sorts of mixed emotions, but you do not have to face your treatment on your own. Support and help is available from the medical and nursing staff and from patient support organisations. Together they can give you information and emotional support to help you through your investigations, treatment and recovery.

Patient support

The following patient-led organisations have collaborated in writing this leaflet. Each provides information and support and

the chance to speak to other patients who have been through surgery and treatment for thyroid cancer.

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

The Warehouse, Draper Street, Tunbridge Wells, Kent TN4 0PG
Tel: 01892 516076
Website: www.amend.org.uk
Email: info@amend.org.uk

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

Address: 2nd Floor, 3 Devonshire Place, Harrogate, West Yorkshire GH1 4AA
Tel: 01423 709707/709448
Website: www.btf-thyroid.org
Email: info@btf-thyroid.org

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

Address: PO Box 205, Rowlands Gill, Tyne & Wear NE39 2WX
Tel: 01207 545469
Website: www.butterfly.org.uk
Email: enquiries@butterfly.org.uk

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

Address: 6 The Meads, East Grinstead, West Sussex RH19 4DF
Tel: 01342 316315
Website: www.hypopara.org.uk
Email: info@hypopara.org.uk

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

Address: 'Morcote', Sunlea Crescent, New Inn, Pontypool, Gwent, South Wales NP4 8AD
Tel: 0845 009 2737
Website: www.thyroidsupportwales.co.uk
Email: thyroidgroup@tiscali.co.uk