Thyroid disorders
A young person’s guide
Thyroid disorders affect up to one in every 20 people and become more common with age. This means it is more likely for an adult to develop a thyroid problem than a child or young person.

Thyroid problems often run in families so you may be aware of other members of your family who have also been diagnosed with a thyroid disorder. Thyroid disorders may affect young people in different ways to adults.
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How to use this booklet

This information has been produced to help you understand more about your thyroid disorder. It also contains some suggestions and tips about how to manage the symptoms you may experience.

Where you see a word highlighted in bold text, you can look it up in the ‘What does it mean?’ section on pages 24-25.

Icons

Explanation about thyroid disorders

Answers to questions you may have

Information about lifestyle

Information about treatment

Sources of further information
The thyroid gland is a small butterfly-shaped gland situated in the front of your neck, just in front of your voice box. It makes hormones, or chemical ‘messengers’, that travel through your bloodstream to all the cells and tissues in your body. Thyroid hormones control your body’s metabolism and therefore affect the speed at which your body works. This in turn can affect your heart rate, breathing, circulation, digestion and how you think and feel.

Thyroid hormone plays a particularly important role in children and young people because their body and brain is still growing and developing. The amount of thyroid hormone that babies, children and young people produce varies depending on their age and size. In most people the body has a really efficient way of creating just the right amount of thyroid hormone for their body’s needs. However, there is also a small number of young people whose thyroid gland doesn’t work properly.

Some people will have been diagnosed when they were born, while others develop a problem with their thyroid during childhood or when they are a teenager. The most common disorders mean that the thyroid doesn’t produce enough (or any) thyroid hormone or that it produces too much.
Doctors can test whether a thyroid gland is working properly by looking at the level of thyroid hormone in the blood or the chemical messengers that tell the thyroid to work. All babies in the UK have a heel prick test (or Guthrie card) when they’re about five days old. This screening test checks whether their thyroid is working properly. If the test indicates a thyroid problem then follow up tests will be needed to confirm whether or not the baby has congenital hypothyroidism (CHT). Every year in the UK one in 2,000-3,000 babies are born with CHT.

Other children and young people may develop a thyroid disorder at a later stage as they grow up. They are likely to be diagnosed after they experience physical symptoms or signs of abnormal thyroid function and when blood tests then confirm that their thyroid isn’t working properly. Most thyroid disorders are more common in girls.
What is an autoimmune disease?

Most thyroid disorders are **autoimmune diseases (or autoimmune disorders)** which happen when the body makes antibodies that attack its own normal cells and tissues. Other examples of autoimmune disorders are type 1 diabetes, coeliac disease or rheumatoid arthritis.

Although someone with an autoimmune thyroid disorder such as **Graves’ disease** or **Hashimoto’s** is more likely to develop another autoimmune condition than someone who doesn’t have an autoimmune thyroid disorder at all, the risk is very small.

Thyroid problems often run in families so if other members of your family are unwell they should make an appointment to see their doctor.

“Autoimmune thyroid problems can happen at any stage when you are a child or an adult.”
Hypothyroidism

Hypothyroidism means that your thyroid is underactive. The thyroid is not making enough thyroid hormones and so your body’s metabolism can slow down. The two most common types of hypothyroidism that affect young people are congenital hypothyroidism (CHT) and Hashimoto’s thyroiditis.

**Congenital hypothyroidism** occurs very early in an unborn baby’s development as the result of one of the following:

- the thyroid gland doesn’t develop properly
- it develops in the wrong place and therefore is small
- it develops but doesn’t produce thyroid hormone

**Hashimoto’s thyroiditis** happens when the autoimmune system (the body’s system that protects you from disease and infection) produces antibodies that attack your thyroid gland and your thyroid gland doesn’t produce enough thyroid hormone.

Sometimes the thyroiditis causes inflammation and swelling of the thyroid gland. This may be noticeable at the neck but it may be small and go unnoticed. The thyroid swelling is also called a **goitre**.

When they are first diagnosed, young people with Hashimoto’s thyroiditis occasionally develop signs of an overactive thyroid gland because the inflamed gland makes too much thyroid hormone at the beginning. This period of overactivity doesn’t usually last long though and the thyroid gland usually then becomes underactive.
What symptoms might I have with hypothyroidism?

The most extreme signs of hypothyroidism in young people are slow growth and change in body shape even when you’re eating healthily. There’s a long list of other signs and symptoms typically seen in atrophic thyroiditis but not everyone with hypothyroidism will have all of them. Many people with Hashimoto’s thyroiditis will have no symptoms at all.

- feeling tired and sleepy all the time
- finding it hard to concentrate
- change in body shape
- feeling cold even in a warm place
- dry or thinning hair
- a hoarse or croaky voice
- muscle weakness, cramps and aches
- pins and needles in the fingers and hands
- slow speech, movement and thoughts
- low mood or depression and anxiety
- memory problems
- a slow heart beat
- slightly raised blood pressure
- raised cholesterol
- constipation

Bear in mind, the overall picture can be confusing because these symptoms are often experienced by people with completely normal thyroid function.
I do get tired and this can affect my productivity sometimes.

Cicely on hypothyroidism

I started to have severe headaches, lethargy and anxiety which were all very unpleasant.

Joe on hypothyroidism
Hyperthyroidism

Hyperthyroidism is when the thyroid becomes overactive and produces too much thyroid hormone. The body’s metabolism then speeds up. It is sometimes called thyrotoxicosis.

Graves’ disease is the most common form of hyperthyroidism. It’s named after Robert Graves, the Irish doctor who first described it. It’s caused by the body’s immune system producing antibodies that switch the thyroid gland ‘on’ all the time, a bit like flicking on the light switch at home. The thyroid gland becomes overactive and produces too much thyroid hormone. The gland can also swell up and lead to a goitre.

Viral thyroiditis can result in temporary overactivity that normally settles down without treatment. It is therefore important for doctors to find out what has caused the hyperthyroidism and how severe it is, as this will help them decide which treatment is appropriate.

There are currently three types of treatment available for hyperthyroidism:

- antithyroid drug therapy
- surgery
- radioactive iodine
What symptoms might I have with hyperthyroidism?

Hyperthyroidism leads to an increase in the body’s metabolism. In young people, the most obvious symptoms can be weight loss and rapid growth in height. There is a long list of other symptoms and signs associated with an overactive thyroid although not everyone will have all of them.

- heart palpitations or a racing heartbeat
- sweating
- not being able to stand heat
- being intolerant of warmth and warm conditions
- tiredness
- anxiety, nervousness and irritability
- shakiness
- a rapid pulse
- mood swings or aggressive behaviour
- loose bowel movements
- weak muscles
- warm, moist hands
- difficulty concentrating and sitting still
- thirst
- itchiness
- an enlarged thyroid gland (a goitre)

Symptoms can come on very quickly – within the space of a few days or weeks – or may develop over a long period of time.
I began to lose weight rapidly, was constantly hungry and felt like my body’s metabolism was going at double the normal speed. I often felt very hot and bothered too.

Ella on hyperthyoidism

I got a bit low and depressed. Sometimes I felt upset and angry. Also I couldn’t sleep even though I felt shattered.

Josef on Graves’ disease
Goitre, swellings and thyroid nodules

A swelling in the neck due to an enlarged thyroid gland is called a goitre. **Thyroid nodules** are lumps in the thyroid gland. Most are harmless but you should arrange an appointment with your doctor as soon as you find a lump or swelling. Doctors will investigate the swelling and let you know the best way of treating it. It’s possible that no treatment is necessary however your thyroid may have become over- or underactive in which case medicine may be appropriate.

What symptoms might I have?

- difficulty swallowing
- feeling of choking
- breathlessness

“

My mum noticed I had a goitre because when I put my bike helmet on it always felt too tight.

Marcus on goitre”
**Thyroid eye disease**

Young people with an overactive thyroid or **Graves’ disease** often have changes in their eyelids which can be slightly ‘pulled back’ and give a staring appearance. This is often associated with dry eyes and your doctor may prescribe some eye drops to help with this. This is different to **thyroid eye disease (TED)** which is an eye condition in which the eye muscles and fatty tissue behind the eye become swollen and inflamed.

TED is an **autoimmune disease**. It occurs when the body’s immune system attacks the back of the eye and causes inflammation. It’s mainly associated with an overactive thyroid gland that’s caused by Graves’ disease. However, it occasionally occurs in people with an underactive or normal thyroid. It’s also linked to smoking and can be made worse by swings in thyroid levels from overactive to underactive. There is some evidence to suggest that TED can be made worse if you are inhaling another person’s cigarette smoke on a regular basis (this is known as passive smoking). TED is much less common in young people with Graves’ disease than in older people.

**What symptoms might I have?**

- change in the appearance of the eyes (usually staring or bulging eyes)
- a feeling of grittiness in the eyes or excessive dryness in the eyes
- watery eyes
- intolerance of bright lights
- swelling or feeling of fullness in upper or lower eyelids
- new bags under the eyes
- redness of the lids and eyes
- blurred or double vision
- pain in or behind the eye, especially when looking up, down or sideways
- difficulty moving the eyes
**Thyroid cancer**

Thyroid cancer is very rare, and extremely rare in young people. It also has a very high cure rate and most young people who are treated for this will live a full and normal life.

“
My teacher noticed a lump in my neck and I had started to lose weight.

Jeanne on thyroid cancer

**What symptoms might I have?**

- swelling or lump (nodule) in the thyroid or lower neck area
- hoarse voice
- difficulty in swallowing and awareness of pressure when swallowing
- difficulty in breathing especially when sleeping
- changes to a previously known nodule

Although it’s extremely unlikely that you have thyroid cancer, if you notice a lump or swelling, even if it’s been there a long time, you should see your doctor and ask for it to be investigated.
Although there may be times when you feel upset about having a thyroid disorder and you may feel you are different from your friends, being diagnosed with a thyroid disorder shouldn’t stop you from doing or achieving anything that someone without a thyroid disorder is able to do.

Because of your thyroid disorder, you may sometimes feel very tired at school, struggle to concentrate in lessons and to keep up with your work. If this happens it’s a good idea to let your teachers know how you’re feeling and to give them some information about thyroid disorders and how they can affect young people.

What’s important is that you listen to your body and try to recognise symptoms that may be caused by your thyroid. Try to tell your parents or carers straightaway if something doesn’t feel right. It can sometimes help to write any symptoms down so you have a note of how you’ve been feeling. If necessary visit your doctor to discuss the symptoms that are worrying you. If you find it difficult to talk to your doctor about the way you are feeling, let your parents know and they may be able to find a different doctor who can look after you.

“When I found out my teacher had a thyroid condition too, it really helped. It was the first time I’d ever had the opportunity to talk to someone else about having the condition.”

Clare on hypothyroidism
What treatment options are there?

Treatment will vary according to your thyroid disorder and the main aim will be to ensure that your body is getting the right amount of thyroxine to enable it to function well. This is particularly important when you’re younger and your body and brain are still developing.

Thyroid medication

Levothyroxine

If you have hypothyroidism (underactive thyroid) then treatment with levothyroxine will replace the hormones that your body cannot produce.

The amount of levothyroxine you need will depend on your age, size and also on the results of your thyroid blood tests. This is why you need to have regular blood tests so that the amount of levothyroxine prescribed can be adjusted appropriately. As you grow you’ll usually need more levothyroxine.

Antithyroid drugs

If you have an overactive thyroid (or Graves’ disease) you’ll probably be treated with antithyroid drugs (ATD) that reduce the amount of thyroid hormone that your thyroid produces. The drug given is usually carbimazole (CMZ) and most people tolerate this well. There’s another ATD called propylthiouracil (PTU) but this isn’t usually prescribed to teenagers because of an increased risk of side effects in the young.

To bring your thyroid hormone levels under control quickly you’re likely to be given a high starting dose of the ATD drug CMZ. You’ll need to have regular blood tests to recheck the thyroid hormone levels and your doctor will adjust your medication as needed.
Usually the thyroid hormone levels are controlled in the first month or so and then most young people will need to continue taking the ATD for two to three years. You’ll have to go for regular blood tests, probably every two to six months depending on your response to treatment, and the dose may be adjusted throughout this period according to the results of your blood tests and your symptoms.

**There are two options for drug treatment of hyperthyroidism**

- **Antithyroid drugs** alone which are adjusted to control the amount of thyroid hormone that’s made by the body’s own thyroid gland

- Antithyroid drugs are given at a higher dose to ‘turn off’ the thyroid hormone produced by the body’s own thyroid and then levothyroxine is given to replace the thyroid hormone at the right amount - this treatment is known as ‘**block and replace**’

Your doctor will advise on which treatment is most suitable for you. They’ll also look at your blood test results to decide when it’s reasonable to stop the ATD to see if the overactivity or [Graves’ disease](https://en.wikipedia.org/wiki/Graves%27_disease) has settled.

Unfortunately, Graves’ disease can return after treatment with ATD but if your blood test results are within the normal reference range for a year after treatment this is unlikely. However, if you notice a return of any symptoms of hyperthyroidism, it’s important to see your GP and ask for a blood test. If your hyperthyroidism does come back, you may be given another course of ATD although you will need to discuss other treatment options. These are currently surgery or [radioactive iodine](https://en.wikipedia.org/wiki/Radioactive_iodine).

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**Thyroid Surgery**

Surgery is usually offered to people with large goitres or severe symptoms. It may also be suggested if your hyperthyroidism returns after a course of antithyroid drugs.

Surgery will remove all (total **thyroidectomy** or part (lobectomy or hemithyroidectomy) of the thyroid gland. You’ll be able to discuss the advantages and disadvantages of thyroid surgery with your doctor although most doctors recommend total thyroidectomy.

If you have a total thyroidectomy you will need to take replacement levothyroxine each day for life.
Radioactive iodine (RAI) has been used to treat overactive thyroid disorders since the early 1940s. RAI is taken up by the thyroid and destroys the cells in the thyroid gland. This has the effect of reducing the amount of thyroid hormone made by the thyroid gland and may also reduce the size of the gland.

It’s often used as a treatment when antithyroid drugs aren’t suitable or haven’t been successful in making the symptoms of your hyperthyroidism disappear.

If you have RAI for your hyperthyroidism, your treatment will take place in a hospital but you won’t need to be admitted to hospital as an inpatient. The dose is taken either as a simple capsule swallowed with mouthfuls of water, or as a drink.

After treatment you’ll be able to go home, but there are rules that need to be followed in the two to three weeks following treatment. These include avoiding close contact with other children which means that you’ll need to be off school or work during this time. More specific details will be provided by the doctors who are looking after you.
Treatment for thyroid eye disease

It’s rare for young people to develop thyroid eye disease (TED) but mild cases can be treated with artificial tear drops, which will help your eyes feel more comfortable. Treating the overactive thyroid gland (with the correct amount of medication) to make sure it doesn’t become underactive will help the eye disease settle.

Treatment for thyroid cancer

If you’ve been diagnosed with thyroid cancer your treatment and management will be the same as for adult patients. You may need both surgery and treatment with RAI. After surgery it’s likely that you’ll need to take levothyroxine for the rest of your life.

If you’d like more detailed information about thyroid cancer and its treatments please contact us or go to the BTF website.

“"My family has been a great support. Despite my thyroid cancer diagnosis, they made sure I lived normally.
Jeanne on thyroid cancer"
What help and support are available?

We hope this booklet answers the questions you may have but if you’d like to know more about thyroid disorders, or any of the issues raised, please visit www.btf-thyroid.org.

If you have any suggestions or feedback about ways we can improve future editions of this booklet, or if you’d like to share your experiences of living with a thyroid condition, we’d love to hear from you.

01423 810093
info@btf-thyroid.org
@britishthyroid
@britishthyroidfoundation
watch young people sharing their experiences of thyroid disorders

Sometimes it’s difficult to explain to people around us how we’re feeling. If you’d like further copies of this booklet to share with your friends, family or teachers please get in touch and we’ll send them to you.
**Antithyroid drugs (ATD)**
The group of drugs which include carbimazole (CMZ) and propylthiouracil (PTU) which reduce the amount of thyroid hormone produced by the thyroid.

**Atrophic thyroiditis**
This is where the thyroid gland is completely destroyed by antibodies and therefore cannot produce any thyroid hormone.

**Autoimmune disease (or autoimmune disorder)**
This happens when the body makes antibodies that attack its own normal cells and tissues, for example autoimmune thyroid disease (Graves’ disease and Hashimoto’s thyroiditis) and diabetes.

**Block and replace**
This is sometimes offered as the treatment for an overactive thyroid. ATD is given to block the thyroid from producing any thyroid hormone and then levothyroxine is given to replace the thyroxine the body should be producing.

**Congenital hypothyroidism**
This is when a baby is born without a thyroid gland or with one that is underdeveloped and doesn’t work properly.

**Goitre**
An enlargement or swelling of the thyroid gland.

**Graves’ disease**
An autoimmune disorder which is the most common cause of an overactive thyroid in the UK.

**Hashimoto’s thyroiditis**
An autoimmune disorder of the thyroid gland which may cause a swelling of the thyroid (goitre) and later causes hypothyroidism.

**Heel prick test (or Guthrie card)**
A blood test performed on newborn babies around a week after birth that’s used to detect certain medical conditions, including hypothyroidism.

**Hormones**
Chemical messengers that affect how all the cells and tissues in your body work.

**Hyperthyroidism**
When the thyroid gland is overactive because it produces too much thyroxine.
**Levothyroxine**
A synthetic form of the thyroid hormone (thyroxine) that’s contained in medication to treat an underactive thyroid gland.

**Metabolism**
The speed at which the body’s cells work. The speed is controlled by the thyroid gland. If there is not enough thyroid hormone the cells work too slowly; if there is too much thyroid hormone the cells work too fast.

**Radioactive iodine**
The radioactive isotope (a chemical part of an atom) of iodine which is used to treat hyperthyroidism.

**Radioactive iodine ablation (RAI)**
‘Ablation’ literally means destruction. This treatment is used for people with thyroid cancer. It destroys any remaining thyroid cells in the body after surgery.

**Thyroidectomy**
This is when your thyroid is removed by a surgical operation. It may be a complete removal (total thyroidectomy) or just partial (lobectomy or hemithyroidectomy).

**Thyroid eye disease (TED)**
An eye disease that’s associated with autoimmune thyroid disease, most usually Graves’ disease.

**Thyroid nodules**
Lumps on the thyroid gland.

**Thyrotoxicosis**
This usually refers to someone who has symptoms of thyroid overactivity.

**Viral thyroiditis**
This is believed to be caused by a viral infection of the thyroid gland and can cause temporary overactivity that normally settles down without treatment.
About the BTF

The British Thyroid Foundation (BTF) is a charity that provides information to support people who are affected by thyroid disorders. We believe that if patients have a better understanding of what’s going on with their body they can take control and cope better with their diagnosis.

Our work is funded by donations. If you would like to support the work we do please go to www.btf-thyroid.org

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This information is endorsed by the British Society for Paediatric Endocrinology and Diabetes (BSPED)

www.bsped.org.uk

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Disclaimer:

All information given is general and all patients are different. If you have specific questions you should raise them with your medical professionals e.g. your GP or endocrinologist.