

Children and young people with thyroid disorders – FAQs

1. What are the consequences of having no thyroid?

Some babies are born without a thyroid gland or with a gland that is too small. They don't have enough thyroid hormone (thyroxine) because their thyroid gland is not properly built. These babies are usually picked up by a blood spot test a few days after they are born and are treated with thyroid hormone replacement (otherwise known as levothyroxine) which is the same as the natural thyroid hormone.

Thyroid hormone replacement works very well so long as medication is taken regularly. Having a thyroid disorder (including having no thyroid) shouldn't stop someone from doing what they want.

If you are born without a thyroid gland, or one that doesn't produce enough thyroid hormone, this is known as congenital hypothyroidism. 'Congenital' means that it is a condition that is present at birth.

2. At what age do people develop autoimmune thyroid problems?

While congenital hypothyroidism occurs before birth, autoimmune thyroid problems, can happen at any stage when you are a child or an adult.

The most common form of hypothyroidism is Hashimoto's thyroiditis which 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 does not produce enough thyroid hormone.

The most common form of hyperthyroidism is Graves' disease. It is named after Robert Graves, the Irish doctor who first named it. It is caused when the body's autoimmune system produces antibodies that switches the thyroid gland 'on', a bit like flicking on the light switch at home. The thyroid gland becomes overactive and produces too much thyroid hormone.

3. Why do some people have a thyroid (like my brothers and sisters) and others don't?

In almost all cases doctors don't know what causes some babies to be born without a thyroid while their siblings do have a working thyroid. But there is a less common form of congenital hypothyroidism which is inherited and so it is more likely that children within the same family will be born with it.

4. Why do I have to have blood tests? Is there an alternative?

Thyroid hormone is essential to help your body and brain develop properly and getting the right amount of thyroid hormone is very important. This is especially true when you are growing up and your body's needs are changing all the time. Unfortunately, the only way to check this is to have regular blood tests when your doctor will measure the amount of thyroid hormone in your body and increase or alter your dose if necessary.

It's understandable that lots of people dislike blood tests: some are worried about the needle, and others just get fed up with having to have so many. This will get easier as you get older as you won't need to have so many. But in the meantime there are things you can do to help you deal with blood tests. Let the nurse know that you are worried and he or she may be able to give you a cream or spray that numbs your skin so you can't feel the needle. Some children have told us that having a small treat each time you have a blood test can be a nice distraction or something to look forward to!

5. What are the symptoms of having no thyroid, or an underactive thyroid?

Often the most obvious symptoms of an underactive thyroid in children and young people can be slow growth and gaining too much weight even though they are eating healthily. There is also a long list of symptoms that people with hypothyroidism often get although not everyone will have all of them. These include:

- feeling tired and sleepy all the time
- finding it hard to concentrate
- feeling cold even in a warm place
- dry and coarse or thinning hair
- a croaky voice
- muscle weakness, cramps and aches
- pins and needles in the fingers and hands
- a puffy face and bags under the eyes
- slow speech, movement and thoughts
- low mood or depression
- memory problems
- constipation

6. How do we know when we need more or less levothyroxine?

Once you are on the right dose your symptoms should disappear. But it is also important to have regular blood tests as these will help confirm whether your thyroid hormones are at the correct level and therefore that you are on the right dose for you.

Try to tell your parents or carers straightaway if something doesn't feel right. It can sometimes help to write down and keep a record or diary of your symptoms so you have a note of how you've been feeling when you go back to your doctor.

Sometimes you can still feel unwell even though your blood test levels are at the correct level (or are within the correct reference range). If this is the case, talk to your doctor about adjusting the levothyroxine dose as a small change may help. It is also possible that your symptoms are not caused by your thyroid so talk to your doctor about whether they think that there are any other tests that they should have.

7. Why does hypothyroidism make you feel cold?

Your thyroid gland helps control lots of your body's functions including your body temperature. So when you are not getting enough thyroid hormone you may be more sensitive to the cold.

8. Why do I get heart palpitations and what should I do if I get them?

A heart palpitation happens when someone feels that their heart is beating irregularly. Sometimes it feels like the heart is skipping beats, or is beating faster than usual when they are at rest, or not exercising.

Someone with an overactive thyroid (hyperthyroidism) may have palpitations because their body produces too much thyroid hormone. If someone with an underactive thyroid (hypothyroidism) gets palpitations this may be because they are taking too much thyroid medication (levothyroxine).

If you think you are having palpitations you should let your parent or carer know how you are feeling and arrange to see your doctor who will discuss the best way to manage these symptoms and help you feel better.

9. How does having a thyroid disorder affect your behaviour?

As well as causing physical symptoms, young people with thyroid disorders often can have emotional symptoms. Your thyroid disorder can make you feel more emotional than you felt before you were diagnosed and different from your friends.

These feelings may include:

- sudden or unpredictable mood changes, or 'moodiness'
- anxiety - a feeling of nervousness, or worrying that you can't manage the things you have to do, perhaps your heart will be racing and your hands will be trembling
- depression - low mood and difficulty enjoying things, tearfulness, loss of appetite and sleeping difficulties
- Difficulties with concentration or remembering things

Having these symptoms may make it seem to you (and to your family and friends and teachers who know you) that your behaviour has changed. And they can also affect the way you cope with your school work and out of school activities.

The important thing is to talk to your parents, or carers about how you are feeling and they can arrange for you to speak to your doctor and check your whether your medication needs adjusting.

It's important to remember however that from time to time lots of people (including those who don't have a thyroid disorder) will experience these symptoms and yours may not be caused by your thyroid.

10. Can you have changes in your behaviour even when your blood tests are normal?

If your thyroid blood tests are in the normal reference range but you still experience emotional symptoms that affect your behaviour it is likely that your symptoms aren't related to your thyroid. You should talk to your family about the way you are feeling and they can help you discuss your worries with your doctor who will investigate other possible causes.

11. What are the links between physical and mental health? Does feeling anxious make heart palpitations worse?

Having low or high thyroid hormone levels can affect both your physical health (e.g. your heart function) and your mental health (e.g. low mood, feeling anxious or hyperactive). In addition it is well known that poor physical health can affect your mental health. If you are taking your medication daily, having regular blood tests to make sure you are on the right dose and have normal thyroid hormone levels your mental health shouldn't be affected by your thyroid. However, you may still have mental health problems not related to your thyroid because they are common and you should talk to your parents/carers about how you're feeling so you can access the right help/resources.

Anxiety (not related to thyroid) can make you have heart palpitations and if your thyroid hormone levels are not well controlled or you forget to take your medication it may make palpitations worse.

12. Why do you get a goitre?

A goitre is a swelling of the thyroid gland that is visible from the front of the neck. Most nodules and swellings are harmless and don't mean you have abnormal thyroxine levels but it is always important to have them checked promptly. There are a number of possible causes including an underactive thyroid, an overactive thyroid, a temporary thyroid disorder (known as thyroiditis) or a diet which hasn't included enough iodine.

13. How can puberty affect my thyroid disorder? What about all the changes at puberty? Are there any that might be related to my thyroid disorder?

It's often difficult to work out whether how you're feeling is related to your thyroid disorder or is just a normal part of growing up.

Often in puberty you will have a growth spurt which may mean your thyroxine dose needs to be adjusted more frequently.

High or low levels of thyroid hormones (outside the normal range) can affect puberty so it's important that you are taking your medication daily and having regular blood tests to make sure you are on the right dose.

14. If you have a thyroid disorder does it help to have a gluten free diet?

There is no evidence that following a gluten free diet will help you to manage your thyroid disorder and following one isn't recommended for children with thyroid disorders unless they have been diagnosed by a doctor as having coeliac disease.

15. If you have a thyroid disorder and take your tablets regularly will everything for me be the same as for my friends?

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 anything or achieving anything that someone without a thyroid disorder is able to do.

What is important is that you listen to your body and recognise symptoms that may be caused by your thyroid. If necessary visit your doctor to discuss the symptoms that are worrying you and they will help you find a way to manage them.

16. Can I ask to change my doctor if I don't feel able to talk to them easily?

Sometimes people (young people and adults) find it difficult to talk to their doctor about the way they are feeling. If this happens to you let your parents or carers know and they may be able to find a different doctor who can look after you.

17. When is the best time to take my thyroid tablets? Should it always be on an empty stomach? How long do I have to wait before I can eat anything?

Ideally levothyroxine should be taken on an empty stomach, approximately an hour before or after food. This isn't always possible or convenient though and it's much more important that you take the tablet each day, consistently, or in roughly the same way. Some people find that the easiest time to remember to take their tablet is last thing at night.

18. What is the effect of taking other medication or vitamins and supplements alongside my thyroid medication? Are there any interactions?

There are some medications that if taken at the same time as levothyroxine, will decrease the absorption of your thyroid medication. It is therefore important that you let your doctor know if you need to take other regular medications and they can give you give you advice about the best way to take them.

If you take vitamins and supplements these should ideally be taken four hours apart from your levothyroxine.

19. How can I explain my thyroid disorder to my friends or to my teachers at school?

There may be times when because of your thyroid disorder you feel very tired at school, you may struggle to concentrate in lessons and to keep up with 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. You can suggest they look at the BTF website or give them information about your diagnosis. You or your parents and carers can contact the BTF and we can send you printed leaflets if you think this would help as well. Your doctor will also be able to provide you with information too.

Letting your friends know can also be helpful.

20. What would happen if I stopped taking my levothyroxine tablets for a year?

For a few weeks you would probably feel OK but after that the symptoms of hypothyroidism would creep up on you and your body and brain will begin to slow up and feel unwell. Also, when your doctor takes your blood tests and sees the results they will soon spot that you haven't been taking your tablets!

21. Are there any new medicines that might be developed in the future that will mean I can stop taking levothyroxine?

It is possible that at some point in the future doctors will develop a new treatment for hypothyroidism. Unfortunately though there are no safe alternatives at the moment.

22. What is the difference between primary and secondary thyroid problems?

Primary thyroid disorders are when there is a problem with the thyroid itself so it produces too much or too little thyroxine. Secondary thyroid disorders are when there is a problem with signal from brain to the thyroid causing it to produce too much or too little thyroxine

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