

Congenital Hypothyroidism

Information and advice for parents and carers

Paediatrics

What is congenital hypothyroidism?

Congenital hypothyroidism is a disorder where a child is born with an underactive thyroid. The thyroid gland is located just below the Adam's apple and produces thyroid hormone (thyroxine), which helps control many bodily processes. An underactive thyroid does not produce enough thyroxine. A lack of thyroxine affects mental and physical development.

1 out of every 4000 babies is born with congenital hypothyroidism.

What causes congenital hypothyroidism?

The cause of congenital hypothyroidism in most babies is that their thyroid gland is too small, is in the wrong position or is completely missing. Some babies may have a normal-sized thyroid gland, but it is not able to produce enough thyroid hormone.

In some rare cases the condition can run in families, so any other baby the parents have has a 1 in 4 chance of having the same condition.

What are the symptoms of congenital hypothyroidism?

Your baby may not have any symptoms of this condition before it is diagnosed. Some babies may be slow to feed, develop jaundice (yellowing of the skin and whites of the eyes), have dry skin, be sleepy and be constipated.

How is congenital hypothyroidism diagnosed?

Congenital hypothyroidism is diagnosed by a small blood sample taken from a baby's heel in their first 5 – 8 days of life, as part of the newborn bloodspot screening test, where several other conditions are also tested for. If this test indicates congenital hypothyroidism the baby may then need a blood test taken from a vein and a scan of their thyroid gland to confirm the diagnosis.

How is congenital hypothyroidism treated?

Congenital hypothyroidism cannot be cured but can be treated very easily and effectively. The treatment is taking daily thyroxine (sometimes called levothyroxine) tablets to replace the thyroxine that the body is unable to produce naturally. Most babies with congenital hypothyroidism will need to take thyroxine for the rest of their lives.

Thyroxine tablets are small and tasteless. For babies the tablet can be crushed and dissolved in a little breast milk, formula milk, juice or water and then given from a spoon, dropper or small syringe. The tablets should not be mixed into a bottle feed because if the baby does not finish the bottle, he or she will not receive the right amount of thyroxine. Older babies can have their tablets crushed into a spoonful of cereal, mashed vegetables or fruit.

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Certain foods such as soya products and iron medications may alter the amount of thyroxine that gets into the blood, so speak to your child's doctor about this if your child has them.

It is important to establish a time each day to give the treatment so that you are less likely to forget; many parents choose to give the tablet just before breakfast each day.

If you forget to give a dose of thyroxine, give it as soon as you remember. If your baby vomits immediately after taking the tablet, you will need to give another dose.

What are the benefits of the treatment?

The benefit of treatment with thyroxine is that it will usually result in the normal growth and development of the child.

What are the risks of the treatment?

There are no side effects or risks of this treatment as the treatment is just replacing a hormone that the baby's body has not been able to make naturally. However, your baby will need regular blood tests to make sure that the level of thyroxine in their body is within the normal limits and that they are being given the right dosage.

What are the risks of not getting treatment?

If your child does not have treatment for their condition, or their treatment is not given regularly or is missed for several days at a time, this can have permanent serious consequences; their growth may be stunted and they may have delay in their development as well as learning difficulties.

Are there any alternatives to this treatment?

There are no alternative treatments for this condition.

Contact details

If you have any questions or concerns please contact your child's consultant:

Dr Agwu's secretary

0121 5073358

Monday – Friday, 9am – 5pm

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Further information

For more information about the NHS Newborn Blood Spot Screening Programme:

[www.newbornbloodspot.
screening.nhs.uk](http://www.newbornbloodspot.screening.nhs.uk)

For more information and support for people with congenital hypothyroidism and their families:

British Thyroid Foundation

www.btf-thyroid.org

For more information about our hospitals and services please see our website:

Sandwell and West Birmingham Hospitals NHS Trust

www.swbh.nhs.uk

Sources used for the information in this leaflet

- NHS Evidence Clinical Knowledge Summaries, 'Hypothyroidism', February 2011
- Patient UK Professional Reference, 'Childhood and Congenital Hypothyroidism', March 2011

If you would like to suggest any amendments or improvements to this leaflet please contact the communications department on 0121 507 5303 or email: swb-tr.swbh-gm-patient-information@nhs.net



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