Congenital hypothyroidism (CHT): further information for families

This information is intended for families where a baby is suspected of having CHT or has been diagnosed with CHT following their newborn blood spot screening test (‘heel prick test’). It will help you and your health professionals to talk through the next stages of your baby’s care. This information should support, but not replace, discussions you have with health professionals.

Public Health England (PHE) created this information on behalf of the NHS. In this information, the word ‘we’ refers to the NHS service that provides screening.

About CHT

About 1 in 2,000 babies born in the UK has CHT. Congenital means the baby is born with the condition.

Babies with CHT do not make enough of the hormone thyroxine, which is an important natural substance made in the body. Thyroxine is produced by a gland in the neck called the thyroid. Without thyroxine, babies do not grow properly and can develop permanent physical and mental disabilities. CHT cannot be cured but can be treated simply and successfully with thyroid hormone replacement (levothyroxine).

There is currently no reliable way to detect CHT before birth and no way to prevent babies being born with CHT.

Newborn blood spot screening is vital because it helps to identify babies with CHT before the low thyroid hormone levels cause permanent harm. A few babies born with CHT may have symptoms such as jaundice, dry skin, puffy eyelids, a large tongue, a hoarse cry, feeding problems, constipation and sleepiness.

Children with CHT are able to live full and active lives, like other children, as long as the thyroid hormone replacement (levothyroxine) is taken every day. A few children may develop problems with learning and clumsiness, and may need extra help.

Causes and types of CHT

CHT may happen by chance but in some cases it may be inherited. There is nothing the parents of a baby with CHT could have done to prevent it.

Babies may develop CHT for different reasons.

Abnormal development of the thyroid gland

The thyroid gland may not reach its proper place in the neck during development in the womb, or it may be too small, or even missing completely. There is usually no family history of CHT in these babies. The chance of a parent having another baby with CHT is very low.

Thyroid gland does not make thyroxine

For some babies with CHT, the thyroid gland is in the normal place and might even be enlarged, but it still does not produce enough thyroxine because of an underlying ‘production-line’ problem. In these families, there may be other relatives with thyroid conditions and there is a chance of having another baby with CHT. If you plan to have more children, you may wish to discuss this with your healthcare team.

Diagnostic tests

The newborn blood spot screening test measures the level of thyroid stimulating hormone (TSH) in the baby’s blood. A high level of TSH suggests the baby’s thyroid is not working properly to make enough thyroxine.

If your baby’s screening test showed that they have a high level of TSH, some further tests will be needed to find out whether they do have CHT.

Further blood tests

A repeat blood test will be done to check the results of the newborn blood spot screening test.

This measures the level of TSH again and also the level of thyroxine (measured as ‘free T4’) in the blood. A high level of TSH together with a low level of ‘free T4’ is the pattern that is usually seen in CHT.

Thyroid scans

A thyroid scan may be recommended. You will have the opportunity to discuss the advantages and disadvantages of the different types of scan with the healthcare team.

Thyroid scans can give information about the type of CHT and can help to determine whether this is likely to be a permanent problem. They can also help to find out whether there is a chance of CHT in future children.

Blood test for mother

The baby’s mother may also be asked to have blood tests to check for any abnormalities that may have affected the baby’s results.

Treatment

Levothyroxine

The treatment for CHT is to take levothyroxine by mouth once a day. This replaces the thyroxine that the body cannot make. Babies should be started on treatment during the first few weeks after birth. Studies of children taking levothyroxine show that this treatment is safe and effective because it puts back what the body is not making properly.

How to give levothyroxine

It is very important for your baby to begin taking levothyroxine as soon as possible and to continue to take it for as long as your healthcare team advises.

Your baby will need regular blood tests to make sure that they receive the correct dose of levothyroxine for their age and size. The dose will be increased over time as your baby grows up.

Give levothyroxine every day by mouth. It should be given at the same time each day so that your baby’s thyroxine levels are maintained at a constant level.

As levothyroxine is simply replacing a normal body chemical, giving the correct dose every day should not have any side effects.

Most babies with CHT will need to take levothyroxine for life. For some babies, it may be possible to stop treatment after 2 to 3 years if tests show that the child’s own thyroxine production is sufficient.

It is available in tablets or in liquid form (see below) and is prescribed in an amount measured in micrograms.

Tablets

Levothyroxine tablets are small and tasteless. For very young babies, the tablets can be crushed and dissolved in a little breast milk, formula milk or water. This can then be given from a small syringe or a spoon. Most babies accept the medication quite easily in this way.

Liquid medicine (oral solution)

Levothyroxine may also be prescribed as liquid medicine. This comes in different strengths, so it is important to make sure you are given the correct one when collecting a new supply. The liquid can be given in the same way as a crushed tablet, using a syringe or a spoon.

Important things to remember about giving levothyroxine

Mixing

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 full dose.

Forgetting a dose

If you forget a dose of levothyroxine, give it as soon as you remember, as long as this is at least 12 hours before the next dose is due. You do not need to wake up a sleeping child to give a missed dose. Do not give a double dose.

If your baby vomits

If your baby vomits immediately after taking the medicine, you should give another dose.

If they are unwell

Talk to your healthcare team about how to manage your baby’s thyroxine treatment if they are unwell.

Using a non-dissolved liquid mixture

Levothyroxine can also come as a suspension (a non-dissolved liquid mixture), but this is a less reliable form. A suspension is not the same as a solution. Do not use a suspension. If you are in doubt, please speak to a healthcare professional.

Helping your baby take tablets

Older babies can have their tablets crushed into a spoonful of cereal, mashed vegetables or fruit.

Soya products and iron medications

Certain foods, such as soya products and iron medications, may alter the amount of thyroxine that gets into the blood. Check with your healthcare team if you are unsure about anything you are giving your baby.

Follow-up checks

Your baby's first blood tests are usually 2 weeks after treatment starts, and then after approximately 4 weeks, 8 weeks, 3 months, and 4 months. They are then every 2 to 3 months until the baby is a year old.

These blood tests are frequent during the first year of life as your baby will be growing fast. Testing tends to be less frequent in the next 2 years, but should not be less than twice a year.

The healthcare team will also carefully monitor your child's growth.

Your child should have all the usual immunisations and any medical treatment needed for other conditions. They do not need to eat a special diet because of CHT.

There may be a slightly increased risk of hearing problems in babies with CHT. Speak to your healthcare team if you have any concerns about your child's hearing or any other questions about your baby's health.

Information, advice and support

The healthcare team responsible for your baby's care will be happy to discuss any queries you might have.

Other sources of useful information include:

- the British Thyroid Foundation at https://www.btf-thyroid.org/congenital-hypothyroidism
- Medicines for Children at https://www.medicinesforchildren.org.uk/levothyroxine-hypothyroidism
- the Child Growth Foundation at https://childgrowthfoundation.org/
- the British Society for Paediatric Endocrinology and Diabetes (BSPED) at https://www.bsped.org.uk/
- the NHS website, which has general information about NBS screening, at https://www.nhs.uk/conditions/baby/newborn-screening/blood-spot-test/

More information

The NHS Screening Programmes use personal information from your NHS records to invite you for screening at the right time. Public Health England also uses your information to ensure you receive high quality care and to improve the screening programmes. Find out more about how your information is used and protected, and your options at www.gov.uk/phe/screening-data.

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