

# Congenital hypothyroidism

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## What is congenital hypothyroidism?

This is a disorder affecting the thyroid gland, which is in the neck. The thyroid gland produces a hormone (chemical substance) called thyroxine, which is needed for normal growth and development. If the thyroid gland does not produce enough thyroxine, it causes hypothyroidism. If the disorder is present at birth, it is called congenital hypothyroidism.

## How is congenital hypothyroidism diagnosed?

In the UK, all babies are tested for congenital hypothyroidism soon after birth, using a tiny amount of blood taken from pricking their heel. If this test shows that your baby possibly has hypothyroidism, it will be recommended that they have further blood tests to confirm the diagnosis. They will also have a scan of the neck that allows doctors to see if your child's thyroid gland is present and in the right place.

The scan is painless, but your child may have a cannula inserted so that a fluid marker can be administered into the vein to get clearer scan results. If this is required your child may feel a small scratch as the cannula is inserted, and may become upset at being held still for the procedure, but attempts will be made to distract them.

## What are the symptoms of hypothyroidism?

Most babies with congenital hypothyroidism are diagnosed very early, before they have any symptoms. These may include:

- feeding difficulties
- sleepiness
- constipation
- jaundice (the skin may look yellow).
- puffy eyelids
- a large tongue
- hoarse cry
- dry skin.

It is very important that the above tests are carried out soon after the heel prick blood test results are known. This is because if congenital hypothyroidism is not diagnosed and treated soon after birth, it can cause problems with mental development, learning and clumsiness.

## What causes hypothyroidism and is it inherited?

During the early months of pregnancy, when your baby's organs are developing, the thyroid gland moves from the back of the tongue to its normal position in the neck. In some babies this does not happen, which means that the gland cannot work properly. In some cases the thyroid gland does not

develop at all. If you have one child with this type of congenital hypothyroidism, the chance of having another baby who is affected is very low.

There is another very rare type of hypothyroidism in which a child's thyroid gland is in the right place, but it cannot produce thyroxine. This type is inherited and so there is a risk that if you have another child in the future they may have the same condition.

## How is congenital hypothyroidism treated?

Congenital hypothyroidism is treated by replacing the thyroxine that the body cannot produce. The medicine only needs to be given once a day. Try and make sure that your child takes their medicine regularly each day and therefore keeps a steady level of thyroxine in their blood.

For the first couple of years, your child will need regular blood tests to check these levels. Doctors use the information from these tests to work out the right dose of thyroxine for your child, which changes as they gain weight and develop.

Once your child is two or three years old, they will need fewer blood tests as the dose of thyroxine will be calculated according to how he or she is growing. They will need to take thyroxine for the rest of their life, but this quickly becomes routine. Because thyroxine medicine is simply replacing a normal chemical produced by the body, giving the correct dose every day should not have any side effects.

If you have any further questions please do not hesitate to contact ward 10 on 01493 452010

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