



# Thyroid Disorders A Guide for Parents and Patients



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SERIES 7



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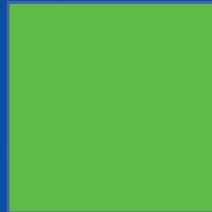
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### GROWTH AND GROWTH DISORDERS – SERIES NO: 15

(REPRINT SEPTEMBER 2000).

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### CGF INFORMATION BOOKLETS

The following are also available:

**No.** Title

1. Growth and Growth Disorders
2. Growth Hormone Deficiency
3. Puberty and the Growth Hormone Deficient Child
4. Premature Sexual Maturation
5. Emergency Information Pack for Children with Cortisol and GH Deficiencies and those Experiencing Recurrent Hypoglycaemia
6. Congenital Adrenal Hyperplasia
7. Growth Hormone Deficiency in Adults
8. Turner Syndrome
9. The Turner Woman
10. Constitutional Delay of Growth & Puberty
11. Multiple Pituitary Hormone Deficiency
12. Diabetes Insipidus
13. Craniopharyngioma
14. Intrauterine Growth Retardation [including Russell Silver]
15. Thyroid Disorders

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# **INTRODUCTION**

This booklet aims to provide information about a broad range of thyroid disorders that are found in babies, children and adolescents. Thyroid problems are more common in adults than children, but there are some special features of childhood thyroid disorders that differ from adults. Inevitably, this booklet cannot cover every aspect of these conditions, but we hope that it will give you a better understanding of your child's condition and can form the basis for discussions with your GP or Paediatrician.

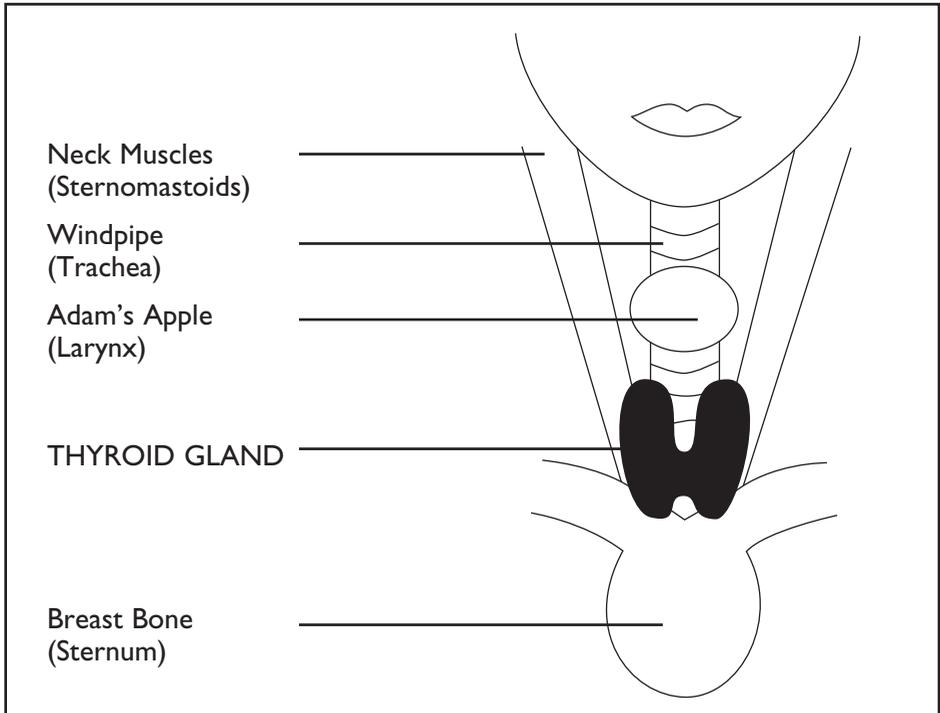
When parents are told their child has a thyroid problem there can be the temptation to attribute all subsequent medical problems to their child's thyroid disorder. Remember that a child with thyroid problems will experience many of the same ups and downs of growing up as children without thyroid problems.

## **THE THYROID GLAND**

The thyroid gland is found in the neck just above the sternum (breastbone), below the larynx ('Adam's apple') and is partly covered by the two strong neck muscles called the sternomastoids. It has two lobes, which in adults are about 5 cm (2 inches), long and the whole gland weighs about 25 grams (just under 1 oz.). In children it is proportionally smaller. The two lobes of the thyroid gland are joined by a central part, which lies over the windpipe (trachea). The thyroid gland can be felt quite easily in older children but not in babies.

The thyroid gland makes and releases two hormones - triiodothyronine and thyroxine. It also stores iodine, which is needed to make the thyroid hormones. Foods that contain iodine include fish, shellfish, seaweed and some vegetables. If there is not enough iodine in the diet, the thyroid gland enlarges and can produce a swelling in the neck which is called a **goitre**. However, this rarely occurs in the UK as iodine is added to cooking salt. There are other conditions that cause the thyroid gland to become enlarged and these will be discussed in this booklet.

Figure 1: The Thyroid Gland



## WHAT DO THE THYROID HORMONES DO?

A hormone is a chemical messenger that travels through the blood stream to all parts of the body and effects the way all the cells in the body work. The hormones produced by the thyroid gland are **thyroxine (T4)** and **triiodothyronine (T3)**. The body can make T3 from T4 so when there is a lack of thyroid hormone it is only necessary to replace the T4.

The thyroid hormones have a number of effects on the body's functions, the main one being to control the metabolic rate, i.e. the amount of energy used by the body to maintain vital processes such as breathing, circulation and digestion. Too much thyroxine makes the body work too fast, whereas too little allows the body to slow down.

The thyroid hormones also have the important function of being involved in brain growth and metabolism in babies while they are growing in the womb and up to the age of about two years.

## Typical Effects of Abnormal Levels of Thyroid Hormones

High Levels - Hyperthyroidism	Low Levels - Hypothyroidism
Irritable/excitable Weight loss/weakness Vomiting Diarrhoea Rapid heart rate Excessive growth in children Feeling too warm	Slow/sleepy Weight gain/fluid retention Dry skin and hair loss Constipation Slow heart rate Slow growth in children Feeling too cold

## WHAT CONTROLS THE THYROID GLAND?

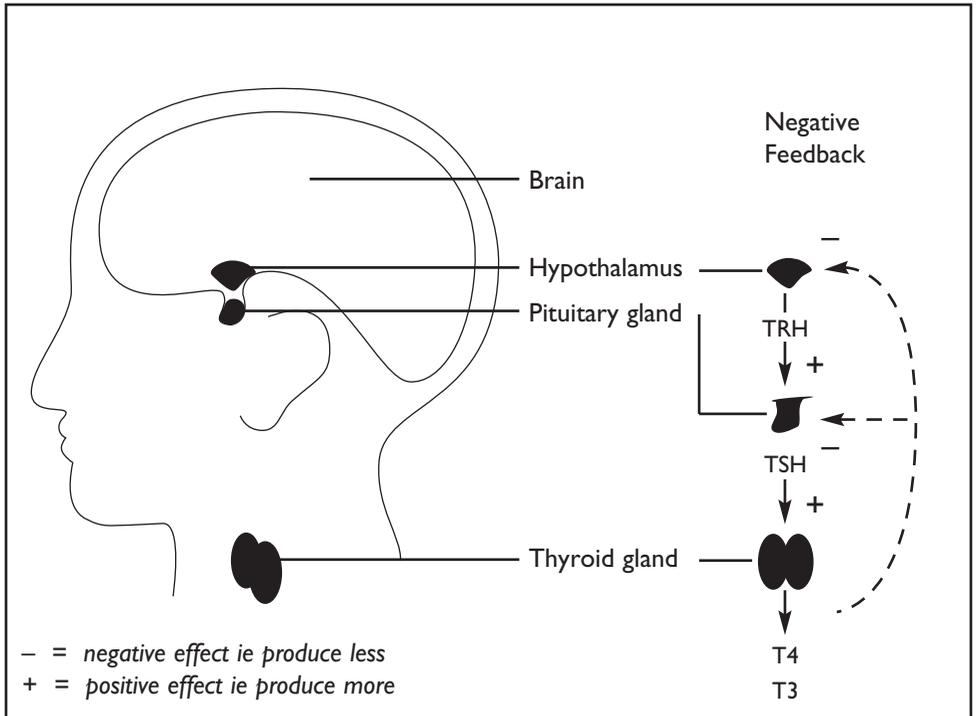
The pituitary gland is a pea-sized gland that is found at the base of the brain just below the hypothalamus. It receives signals from the hypothalamus which stimulate the release of hormones, which in turn affect many of the body's functions.

One of the hormones that the pituitary gland produces is called **thyroid stimulating hormone (TSH)**. TSH encourages growth of the thyroid gland as well as stimulating it to release thyroxine. The release of TSH from the pituitary is triggered by another hormone called **thyrotrophin-releasing hormone (TRH)** which is released from the hypothalamus. These glands and hormones control the levels of thyroxine in the body as follows:

- If levels of thyroxine in the body are **low**, this is detected by the hypothalamus and TRH is released. The TRH stimulates the pituitary gland to produce more TSH and this triggers the thyroid to increase the amount of thyroxine released.
- If levels of thyroxine are **high**, production of TRH and TSH are stopped and so the thyroid gland stops releasing thyroxine until it is again required to do so.

The hormones and glands involved in this process are shown on Page 7 in Figure 2 – The Control of the Thyroid Hormone System.

Figure 2: The Control of the Thyroid Hormone System



## HOW DOES THE THYROID GLAND DEVELOP?

Very early during development of a baby in the womb, the thyroid appears as a small lump at the back of the tongue. By the 7th week of pregnancy, it has reached a position at the base of the neck. There is gradual development of the hypothalamic - pituitary - thyroid gland system which matures by about the 22nd week of pregnancy. These processes of development can occasionally go wrong and lead to underdevelopment or absence of the thyroid gland.

HYP0 means under active : HYPER means over active

## HYPOTHYROIDISM

When the thyroid gland is poorly developed or absent, it is unable to produce the thyroid hormones (T3 and T4) and the levels in the blood become low or even undetectable. This condition is called **hypothyroidism**.

In children there are two main ways that hypothyroidism can occur:

- Hypothyroidism which is present from birth is called **congenital hypothyroidism**.
- Hypothyroidism that develops later in a child's life is called **late onset** or **acquired hypothyroidism**.

There are important differences between these two forms of hypothyroidism that will be described below. There is a third, much less common, form of hypothyroidism where the problem is not with the thyroid gland itself but with the pituitary gland, which fails to produce TSH. This means that the thyroid gland is not triggered to secrete thyroxine. This is commonly called **secondary hypothyroidism** and is discussed in Booklet No. 11: Multiple Pituitary Hormone Deficiency (MPHD),

## **CONGENITAL HYPOTHYROIDISM**

Congenital hypothyroidism occurs in about 1 in every 3000- 4000 babies. It is usually the result of something going wrong with the development of the thyroid gland, but the reasons for this are still not fully understood. It occurs more commonly in girls than boys, and seems to be more common in people of Asian origin.

Hypothyroidism is usually caused when the thyroid gland does not reach its proper position at the base of the neck while the baby is developing in the womb, The gland remains at the back of the tongue and this is called an **ectopic thyroid**. In some children with an ectopic thyroid gland it does not develop fully and in others it completely fails to develop, a condition called **thyroid agenesis**.

In a small proportion (about 15%) of babies with hypothyroidism, the thyroid gland is present, and may even be enlarged, but it fails to produce thyroxine. This form of congenital hypothyroidism is much more likely to be inherited and is called a **dysmorphogenesis**, which means there is a block that prevents the hormones being produced.

### *What are the Symptoms of Congenital Hypothyroidism?*

Symptoms include slow feeding, sleepiness, constipation and prolonged jaundice after birth. Unfortunately, these are very common symptoms in babies, even when they do not have hypothyroidism, and so there used to be a long delay before the diagnosis was confirmed, if the diagnosis is not made early on, a child's development may be delayed, Thus, **all babies are now screened at birth** for congenital hypothyroidism using a heel prick test, which is described on page 9.

Additional physical characteristics typical in babies with hypothyroidism are mottled skin, protruding tongue, thin hair and umbilical hernia (a protruding “belly button”).

#### *Why Are Babies Screened For Congenital Hypothyroidism?*

Before 1982, when the national screening programme for congenital hypothyroidism started in the United Kingdom, delayed diagnosis of congenital hypothyroidism was common. In children where the diagnosis, and therefore thyroid hormone replacement treatment was delayed, problems with subsequent educational development often occurred. In about a quarter of these children, special schooling was required and many others had behaviour problems, were poorly co-ordinated and had squints. It became clear that early diagnosis and treatment could prevent many of these problems.

During pregnancy, the baby is mainly dependent on its own thyroid gland to produce the necessary thyroid hormones as only small amounts cross the placenta from the mother. Thus, many babies who are born with hypothyroidism have had this deficiency for some time in the womb. If treated soon after birth, brain development and growth can be successfully stimulated.

#### *How Screening For Congenital Hypothyroidism Works*

Since 1982, there has been a national screening programme for congenital hypothyroidism caused by abnormalities of the thyroid gland. Before the baby is ten days old, a heel prick blood specimen is taken, put onto a filter paper card and posted to a central regional laboratory to be tested for hypothyroidism and other disorders.

When testing for hypothyroidism, most laboratories are looking for a high level of TSH produced by the pituitary gland, which will be detected in the blood. This is because the pituitary gland keeps trying to trigger the thyroid gland to release thyroid hormones and so is continually releasing TSH. TSH screening has been found to be very reliable, although the possibility of missed cases must never be forgotten. If your child has symptoms that may be caused by hypothyroidism, it is sensible to have their thyroid function rechecked with a blood test.

If the TSH level from the baby’s blood test is very high, the family are contacted straight away through their GP or local paediatrician as further tests may be necessary.

When samples are unsatisfactory or the result is borderline, (i.e. when the TSH is only slightly raised), a repeat heel-prick specimen will probably be requested. This is simply to enable the test to be repeated with a further blood sample that should give a clear result and is not a cause for concern.

### Confirming the Diagnosis

It is important that high TSH values detected by screening are further checked, This is done by taking a blood sample from a vein so that the levels of TSH and thyroxine can be measured, Your baby will need to be carefully examined and the results and reasons for the screening programme explained to you. Other tests that may be performed include the following:

- An X-ray of the knee to establish the bone age as bone maturation may be delayed.
- A thyroid scan to give more information about the hypothyroidism. This test involves giving a *small* dose of a radioactive chemical (such as radioiodine) which enables a picture of the thyroid to be obtained. These scans are entirely safe even when performed in very young infants. However, the decision to start treatment or not will usually be made on the results of the blood test alone.

Most parents find a diagnosis of hypothyroidism in their child very worrying, raising doubts and fears for their child's future. They should be reassured that the outcome for their child should be excellent.

### Treatment And Follow Up

Once hypothyroidism has been diagnosed, your child will need to start treatment and will almost certainly stay on this for the rest of their life. Treatment with thyroxine is relatively straightforward and is given as a tablet taken once a day by mouth.

Thyroxine is not easily available as a syrup although some pharmacies will make one up for babies if necessary. It is more common, and convenient, to use tablets that are easily crushed in a teaspoon. A small quantity of milk is then added to the teaspoon and the mixture given to your baby, Most babies do take their thyroxine treatment very easily this way. The crushed tablets *should not* be added to the normal bottle-feed. Thyroid tablets are available in three strengths:

- 25 micrograms (mcg)
- 50 micrograms (mcg)
- 100 micrograms (mcg)

A typical starting dose for a baby is around 25 mcg to 50 mcg per day. If your baby *immediately* vomits after taking their tablet mixture, you will need to give them another dose. If they vomit more than about 30 minutes after they have had their tablet, don't worry, the tablets will already have been absorbed. If you forget to give your baby's dose *give it as soon as you do remember* - it does not matter what time the thyroxine is given but having a routine helps to reduce the risk of forgetting. Most parents give their babies their thyroxine before breakfast.

It is very important that your child receives their thyroxine treatment regularly.

If your child has any of the ordinary childhood illnesses, they need to be continued on the thyroxine treatment and there is no worry about giving other medications at the same time. Immunisations should also be given. As your baby grows, their dose will need to be increased. In order for this to be done accurately, your child's growth and development will need to be followed. In addition, most doctors will regularly check your baby's/child's levels of thyroxine in the blood to make sure that they are on the correct dose. If the dose is much too high, symptoms of *hyperthyroidism* may develop, with restlessness, weight loss and mild diarrhoea.

If there is any doubt about the diagnosis, for instance if the levels of TSH measured were borderline, it is perfectly safe to treat the baby and then stop treatment when the baby is older and reassess. However, this should not be done until brain development is complete, i.e. around 2-3 years of age.

Most doctors believe that children with congenital hypothyroidism should remain under the care of a paediatrician with experience in treating the condition as many GP's have limited experience of treating this condition in children and treatment in children is more complex than in adults.

#### *What Is The Outcome For Children With Congenital Hypothyroidism?*

Compared to the years before screening, there has been a dramatic improvement in the outcome for children with hypothyroidism. A lot of information has been obtained from a UK national follow up study of all the children diagnosed and treated during 1982 and 1983. Their progress was compared with a large group of children who did not have hypothyroidism. Severe learning difficulties in children with hypothyroidism were very unusual unless there were other complicating factors. Most children with hypothyroidism will attend mainstream schools although a small number may have special educational needs.

Detailed studies showed that a small group that had the most severe hypothyroidism at birth did slightly less well on an IQ test than the children without hypothyroidism. There is no doubt that a few children with hypothyroidism do continue to have problems of clumsiness and difficulties in attention even though they are receiving appropriate thyroid hormone replacement therapy. These problems can be helped and additional assistance in school may be provided. However, most children with congenital hypothyroidism lead entirely normal lives and so should be treated normally.

# ACQUIRED HYPOTHYROIDISM

When the thyroid gland becomes under-active in later childhood, this is called late onset or acquired hypothyroidism. The most common cause is an autoimmune process whereby the body's tissues are gradually destroyed by its own antibodies. Autoimmune problems result in a number of different types of thyroid disorders, including **Hashimoto's disease**, and they are tested for by measuring the auto-antibodies in the blood.

In other cases of acquired hypothyroidism, the cause may be due to a congenital abnormality where the gland gradually stops working over time. Many of these cases are now detected by early screening. The signs and symptoms of acquired hypothyroidism are described below:

## 1. Growth problems

Children with acquired hypothyroidism may have slow growth associated with a tendency to put on weight. If there is a problem with excessive weight gain, even though growth appears normal, it may be worth rechecking thyroid levels in the blood. Slow growth can be the only symptom of an under-active thyroid and may be detected during regular growth monitoring by health visitors or school nurses. However, if tests show that the thyroid gland is working properly, and yet growth is still slow, this may need further investigation and a referral to a specialist. In children with untreated hypothyroidism, the onset of puberty is often delayed although in very severe cases precocious puberty can develop. In either case, some treatment may be appropriate.

## 2. Physical changes

Children with hypothyroidism may develop a gradual change in facial appearance, but this may only be apparent by looking back at old photographs. The face may develop a rather pale, puffy appearance caused by the accumulation under the skin of a watery fatty substance called **myxoedema**. Occasionally fluid develops in other places such as the chest cavity. Other changes may include constipation, a slow heart rate, some hair loss and slow reflexes.

## 3. School, behaviour and personality

One of the surprising things about acquired hypothyroidism is how little change there is in school performance. There may be some increased sleepiness but this does not usually become a major problem. For this reason parents often do not identify the problem, or seek medical help, until the physical changes are apparent. Thus the thyroid hormone deficiency may have remained undetected for some time, particularly as tiredness and sleepiness may be considered as normal behaviour. Once treated, your child may become much more lively and outgoing than when they were untreated!

When a diagnosis of hypothyroidism is suspected, the doctor may need to undertake some further tests to confirm the diagnosis. Hypothyroidism can affect bone maturation and taking an X-ray of the left hand and wrist to look at the maturation of the bones can assess this. From this a doctor can see whether skeletal development is delayed, in line with, or advanced compared to your child's chronological (actual) age. In hypothyroidism, the bone age is often quite delayed compared to the chronological age.

Because of slow growth, it is likely that your child's height will be more appropriate for their bone age than their chronological age. When replacement thyroid hormone treatment is started, their growth will accelerate and enable them to "catch up" their height and skeletal development and so their final height should not be affected. Only if the diagnosis is made very late, and a child is therefore not treated for many years, will final height be affected.

Treatment of acquired hypothyroidism is with thyroxine. This is given as a once daily tablet and the dose will vary according to an individual child's needs. Generally, a child will be given 50 to 100mcg a day and your child's dose will be reviewed from time to time with you by your doctor as it may take a few weeks to build up to the full replacement dose. The outcome for your child should be excellent and the symptoms should go within the first 3 months of treatment. If the response is not good, and this can often be assessed by their rate of growth, further investigation may be needed.

It is very important that treatment is taken **every day** and this can become difficult with older children as they become responsible for taking their own treatment. So, as children with hypothyroidism become young adults, the importance of taking their treatment regularly should be explained to them.

## **WHO IS AT RISK OF DEVELOPING HYPOTHYROIDISM?**

### *A Family History:*

As already mentioned, thyroid problems may be genetic or familial, i.e. they will tend to run in families. Around 40% of children with acquired hypothyroidism have relatives who also have some type of thyroid gland problem. There may also be a family history, or a history in your child, of an autoimmune problem such as:

- Prematurely greying hair
- Alopecia (early unexplained hair loss)
- Vitiligo (de-pigmented patches of skin)
- Pernicious anaemia (a type of anaemia caused by vitamin B12 deficiency)
- Diabetes mellitus (sugar diabetes)

Girls and women are much more commonly affected than boys or men. In addition, there are a number of other conditions, described below and overleaf, where hypothyroidism is more frequently seen.

*Down's Syndrome:*

Congenital hypothyroidism is a little more common in children with Down's syndrome. However, acquired hypothyroidism is very common and 20-40% of adults with Down's syndrome also have hypothyroidism. The similarity between the physical features of Down's syndrome and the onset of hypothyroidism means that the diagnosis of hypothyroidism in children with Down's syndrome may be missed. For this reason, it is recommended that children with Down's syndrome have regular blood tests for thyroid hormone levels so that replacement therapy can be given as early as possible. A thyroid function test should have been performed at the very latest by the age of 5 years, and this should continue to be checked every 1 to 2 years thereafter.

*Turner Syndrome:*

Girls and women with Turner syndrome (see Booklets Nos. 8 & 9) have an increased risk of developing hypothyroidism and it is sensible to check thyroid hormone levels, especially if any other form of hormone treatment, such as growth hormone, is being considered or given.

*Metabolic and Blood Conditions:*

In some rare metabolic and blood disorders, the thyroid gland is gradually destroyed as a complication of the disease. These include rare disorders such as cystinosis and more common conditions such as thalassaemia. Doctors looking after children with these problems will usually check thyroid function regularly.

*Pituitary Gland Problems:*

Any child who has a known deficiency of one pituitary hormone is potentially at risk of having, or later developing, TSH or TRH deficiency and this will lead to secondary hypothyroidism. Children who have growth hormone deficiency alone do not usually develop secondary hypothyroidism but it is much more common in children who have multiple pituitary hormone deficiencies (MPHD) (see Booklet No.11). Secondary hypothyroidism is often quite mild and is not always easy to diagnose as it may develop gradually. For example, it may only appear after growth hormone treatment has been started, it is therefore very important to monitor thyroid hormone levels at regular intervals.

# COMMON QUESTIONS ABOUT HYPOTHYROIDISM

- 1. Q Did I do something wrong in my pregnancy which resulted in my baby having congenital hypothyroidism?**

**A** The answer is most certainly NO. In the vast majority of cases, no cause can be identified and no link has been found with drugs, smoking or any particular foods?
- 2. Q I am worried that I might miss giving my baby a dose of thyroxine. Would this matter?**

**A** Fortunately, thyroxine lasts in the body for quite some time and so even if a day's dose is missed, your child will still benefit from the previous day's dose. Clearly it is important to maintain a regular daily treatment and it will certainly matter if several days are missed.
- 3. Q Are there any side effects of thyroxine treatment?**

**A** No. Thyroxine is identical to the natural hormone produced by the thyroid gland and is a relatively simple chemical substance. It is really a replacement hormone treatment rather than a drug, so any side effects only occur if the dose is wrong. If too much thyroxine is given, symptoms of hyperthyroidism will occur. If not enough is given, the hypothyroid symptoms will return. Thyroxine tablets can be stored at room temperature, last a long time, and are widely available throughout the world.
- 4. Q What is the risk of having other children with hypothyroidism?**

**A** In the commonest form of hypothyroidism, ie when the gland has not developed properly, the risk of having another affected child is small, perhaps about 1 in 100. When the cause of hypothyroidism is due to a block in the production of the hormone, rather than normal development of the gland, the risk of having an affected child is much higher and is usually 1 in 4 in each pregnancy, with boys and girls equally affected. The late onset form of hypothyroidism also has an increased risk of brothers, sisters and other relatives having thyroid problems.
- 5. Q If my child is at risk of developing hypothyroidism, for instance they have Turner or Down's syndrome, how often should they have a blood test?**

**A** Probably every one to two years, but your specialist will advise you on this.
- 6. Q How long will treatment last for?**

**A** We must assume that the treatment is for life as the thyroid gland will not grow again or recover, but the treatment is easy and well tolerated. While temporary or transient hypothyroidism does exist, it is uncommon, and most children will need to continue on thyroxine through adulthood. The dose will need to be increased to match their growth, but by the time adult life is reached the dose usually remains stable with the need for only an occasional blood test.

# ***HYPERTHYROIDISM***

When the thyroid gland becomes overactive and secretes excess thyroid hormone, this is known as hyperthyroidism or thyrotoxicosis. These two terms are almost the same and are often used interchangeably. Hyperthyroidism and hypothyroidism are often confused because of the similarity of the words. However great care is needed as they are very different and the treatments are very different.

HYPER means over active : HYPO means under active
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## *What is the Cause of Hyperthyroidism?*

By far the most common form of hyperthyroidism is a condition called Graves's disease, after the Irish doctor, Robert Graves, who first described it. Hyperthyroidism may be caused by overactivity of the gland, a hormone secreting benign tumour of the thyroid, or Graves disease in which there are additional symptoms including swelling of the neck (goitre) due to enlargement of the gland, and protrusion of the eyes.

In Graves's disease, the overactivity of the gland is caused by abnormal production of antibodies which stimulate the TSH receptors in the thyroid. This in turn leads to excessive production of thyroid hormones by the thyroid gland. The tendency to produce these antibodies often runs in families and it is common for children with hyperthyroidism to have a brother or sister, parents or other close relatives with either hypo- or hyperthyroidism.

There is a rare form of hyperthyroidism that develops soon after birth (neonatal hyperthyroidism). This is caused by antibodies crossing the placenta from the mother, which over-stimulate the baby's thyroid gland, In babies who do have hyperthyroidism, the thyroid is usually enlarged and the baby may have typical symptoms such as a rapid heart rate, irritability and mild diarrhoea. This is a temporary condition that resolves within 3 to 6 months. Some treatment may be required but there are no long-term problems. Although many pregnant women do have an overactive thyroid, the condition in babies is surprisingly rare.

Other causes of hyperthyroidism are very rare. There are some syndromes associated with hyperthyroidism, such as the McCune-Albright Syndrome where there is also irregular skin pigmentation, precocious puberty and bone problems. Viral infections or inflammation of the thyroid (thyroiditis) can also cause hyperthyroidism.

If a pregnant woman has a thyroid disorder, whether treated or not, it is very unlikely that the baby will be affected. However, there are occasions where the baby could have a thyroid problem as a result. It is therefore important that babies born to mothers with thyroid problems are very carefully checked.

## *What are the Symptoms of Hyperthyroidism?*

Symptoms directly due to raised hormone levels include:

### **1. Effects on the circulation**

High thyroid hormone levels usually lead to a high heart rate, often in the region of around 100-140 beats/minute. This high heart rate even persists at night, when the heart would normally slow down during sleep. In extreme cases, this can lead to heart strain particularly in adults, but this would be unusual in a child.

### **2. Growth, weight and appetite**

Children who develop hyperthyroidism often start growing at a much faster rate than is normal for their age and so become tall in relation to their peer groups. If this happens during the early teenage years it can be confused with the normal teenage growth spurt. Leg growth is accelerated more than upper body growth. This increased growth rate is often associated with increased appetite although there is often weight loss that may be extreme. These symptoms can be mistaken for anorexia nervosa. Hyperthyroidism is easily diagnosed by a blood test.

### **3. Anxiety and behaviour problems**

These can be quite marked in hyperthyroidism. The child may be restless, fidgety and have poor concentration which results in difficulties at school. They have shaky hands giving problems with delicate tasks. These children are frequently moody, emotional and prone to tears. They may be unable to sleep well and may have nightmares.

### **4. Other symptoms**

Children with hyperthyroidism often have mild diarrhoea. This problem goes away when the hyperthyroidism is treated. Also, they do not tolerate heat well - for example, complaining of being too hot in an unheated room in the middle of winter. They may also complain of sweating, tiredness and weakness that may be caused by wasting of the muscles.

Frequently, the thyroid gland becomes enlarged in hyperthyroidism, and this may be the first noticeable physical sign. It can result in swallowing difficulties and a feeling of having "a lump in the throat". The antibodies which stimulate the thyroid gland can also affect the muscles and fat around the eye, leading to thyroid eye problems. The eyes may appear large and bulge outwards (proptosis), leading to a rather startled expression, and there may even be difficulty with eye movements.

The eye changes can interfere with vision, and make the eye feel gritty, red and sore, and if your child has any eye problems they may be referred to an eye specialist. Physical changes to the eyes do improve after treatment, especially if the changes are only minor, but it may take several years to return to full normality. The longer the eye changes are left untreated, the less likely they are to be reversible.

Any child with eye symptoms, such as unusually large or bulging eyes, should be referred for an early assessment.

#### *How is Hypermyroidism Diagnosed?*

This is normally done by taking a single blood test to check for levels of the two main thyroid hormones, thyroxine (T4) and triiodothyronine (T3). In hyperthyroidism, the levels are raised above the normal levels for age and gender and conversely thyroid stimulating hormone (TSH) levels are low. This is because the high levels of T4 and T3 in the blood stop the pituitary releasing TSH.

#### *How is Hyperthyroidism Treated?*

The treatment of hyperthyroidism has two main aims; to control the symptoms and to treat the underlying cause. The distressing symptoms such as the fast heart rate and over-excitability, which are caused by the high thyroid hormone levels, can be treated straight away with a therapy known as beta blockers (such as propranolol), This will treat the symptoms but not the underlying cause. Beta blockers need to be used with caution in children with asthma as they can cause an attack.

In addition, thyroid hormone blocking drugs such as carbimazole or, less commonly, propyl-thiouracil (PTU) must be used. These are powerful treatments with important side effects that you need to discuss with your doctor. These treatments work by preventing the production of the thyroid hormones within the cells of the thyroid gland. At higher doses they may also act to reduce the production of the abnormal antibodies which cause Graves disease.

An important side effect of this type of treatment is that it also suppresses the body's own natural immune system which can lead to an inability to fight infection. Children who are started on thyroid hormone blocking drugs should have their blood tested regularly to check their white cells as these are indicators of the status of the immune system. They can be at risk of serious infection from just a sore throat. Other side effects include rashes and, more rarely, liver problems.

Thyroid hormone blocking drugs are started at a relatively high dose that is then gradually reduced over a period of two months as the hyperthyroidism comes under control. Thyroid hormone levels are regularly checked. Alternatively, the dose can be kept high and when the thyroid gland action is completely blocked, and the child becomes hypothyroid, thyroid hormone replacement therapy is given. Treatment needs to be continued for a reasonably long time, typically about 18 months to 2 years, and then the anti-thyroid hormone drugs are gradually stopped.

Unfortunately, in a proportion of children, perhaps up to 40%, a return of the hyperthyroid symptoms are seen once drug treatment stops. This may take up to one year to occur. Other children are not well controlled on the treatment. In teenagers this

may be because they do not like taking the tablets, which are taken 2 or 3 times daily. For these young people a curative treatment is needed and this is either radioiodine treatment or surgery.

#### *Permanent Treatment for Hyperthyroidism*

If a decision is being considered for curative treatment, it should only be made after a full and detailed discussion of the pros and cons with you and your child. Most teenagers, and many younger children, are able to understand the issues involved. To the child, avoiding an operation may seem attractive and they may prefer the idea of radioiodine treatment. Parents may worry about the long-term consequences of radiotherapy, in particular if there is any increased risk of cancer or the possibility of damage to the ovaries in girls.

Until recently, it has been more common for surgery to be preferred in children but information available from the United States does suggest that radio-iodine treatment is safe.

#### *Surgery*

Without doubt the most important aspect of surgery is finding an experienced surgeon! Surgery will leave a scar, but most neck scars become difficult to see after a while. Very occasionally some people, especially those of Afro-Caribbean origin, can develop excess scar tissue (a keloid).

Your child will probably need to be in hospital for a few days after the operation. The surgeon will often aim to remove just enough of the thyroid to control the hyperthyroidism but it may be necessary for the whole gland to be removed.

It is well recognised that there are complications of surgery due to damage that may happen to the other very important structures near or in the thyroid gland. Within the thyroid gland there are glands called the **parathyroids** and these are important in controlling the levels of calcium in the body. If the parathyroid glands are damaged, calcium levels fall and this can lead to severe muscle cramps. This problem can be temporary after the operation or, occasionally, permanent. If permanent, calcium replacement will be needed. In addition, there is a risk of damaging one of the nerves which helps control the vocal chords. The risk of this type of complication is small but must still be considered carefully,

#### *Radioiodine Treatment*

In contrast to the surgical approach, radioiodine therapy can appear to be very simple. Your child is treated as an outpatient with iodine being given by mouth. In addition, they will need to stay at home for a few days afterwards. The thyroid gland traps iodine very efficiently and so very little of the iodine will reach other important parts of the body, such as the ovaries. Typically, the radiation exposure to the ovary is less than that of X-rays used in standard diagnostic procedures such as barium meal tests.

The radioiodine works by destroying the cells in the thyroid gland through local irradiation. Naturally, people may have concerns about radiation treatment and these concerns need to be acknowledged and discussed along with any rare, but possible, side effects. Very occasionally, individuals may have flu-like symptoms as a side effect of the treatment. Because of concerns about side effects, it may be better not to use radioiodine in children younger than 10 years of age.

Unfortunately, following either surgery or radioiodine treatment hypothyroidism is likely to result because the thyroid gland ceases to function. This means that thyroxine replacement treatment will be needed and will be continued through life. At present, there is no clear difference between surgery and radioiodine treatment in terms of this outcome.

## **LUMPS IN THE NECK**

Lumps in the neck are very common in children and are mostly not anything to do with the thyroid gland. Enlarged glands usually cause them, for example during infections. However, a lump at the front of the neck may be in the thyroid. These are much less common in children than in adults. If there is any concern about a lump, it should always be investigated.

### *Thyroglossal Cysts*

These are small rounded lumps in the middle of the neck just above the Adam's apple, which can arise during the development of the thyroid gland in a baby developing in the womb. These cysts are usually removed surgically and this is mainly for cosmetic reasons. A careful preoperative ultrasound assessment is needed before surgery as this helps the surgeon to accurately confirm the diagnosis.

### *Goitre*

When the thyroid gland is enlarged it can produce a swelling of the neck which is called a goitre. In many parts of the world this is commonly due to a lack of iodine in the diet. The enlarged thyroid gland may be associated with hyperthyroidism, hypothyroidism or a normal level of thyroid hormones (euthyroid). While there may be no serious symptoms with the goitre, it may cause discomfort on swallowing or, very rarely, difficulty in breathing.

In adolescence, especially in girls, a minor degree of thyroid swelling is quite common and is probably entirely normal, although the reason for the swelling is unknown. Also, a thick fat neck may be confused with a goitre.

### *Thyroid Tumours*

Any form of thyroid tumour in children is very rare and most thyroid lumps or nodules that are removed are non-cancerous. A major cause of thyroid cancer is radiotherapy,

which may have been given for another form of head or neck cancer or for Hodgkin's disease. Usually, where there is this risk from radiotherapy, the child will be followed up for a long time as it may take at least 10 years for such a tumour to develop.

There is no evidence that the very small doses of radiation used in thyroid scans, or in the treatment of hyperthyroidism, lead to an increased risk of thyroid cancer.

### *Assessing Thyroid Lumps*

Any child with a lump that can be seen or felt in the neck should be carefully examined as, although it is very uncommon, early detection of thyroid cancer is very important. Most neck lumps are not in the thyroid and are caused by other things such as swollen glands associated with tonsillitis. When there is a thyroid lump, a number of tests may be performed such as ultra-sound or nuclear medicine scans.

Usually the diagnosis is confirmed by either removing the lump completely or by taking a very small piece (called a biopsy) of the tissue from the lump with a small needle. In both cases your child would need a general anaesthetic. The tissue is then carefully assessed and examined to determine whether or not it is cancerous.

Any child with a lump in the neck should be seen and fully assessed.
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### *Treating Thyroid Cancer*

The treatment will depend very much on the type of cancer and how far it has spread. If it is still only in the thyroid, the gland and the tumour may be completely removed surgically and the child can then be given thyroxine replacement treatment. Careful and prolonged follow-up will be needed. Rare types of thyroid gland cancer can sometimes be treated with radioiodine therapy. It is very rare for a child to die of thyroid cancer.

### *Medullary Carcinoma*

It is worth mentioning a rare form of thyroid cancer that arises from cells in the thyroid gland which are not involved in producing thyroid hormones. These are called the C cells and they produce a hormone called calcitonin that is involved in controlling calcium levels in the body. This type of thyroid cancer is called a medullary carcinoma and it is important because it is one of a group of cancers that tend to run in families. The other cancers in this group occur either in the adrenal glands or the nerves.

When the tumours occur in all these areas at the same time the condition is called Multiple Endocrine Neoplasia (MEN) Syndrome. If an individual in a family is found to have the MEN syndrome, other family members should be checked and genetic tests are sometimes useful. A child found to be at risk of developing a medullary carcinoma of the thyroid may need to have their thyroid gland removed to prevent the cancer developing.

## **SUMMARY**

There is a wide range of thyroid problems in children and adolescents and the way that they appear can be very variable – from a lump in the neck to learning difficulties in school through to growth problems. What may be common to all of them is that it may be difficult to make an early clinical diagnosis and that there is the need for long-term follow up.

There will always be some unanswered questions and there may sometimes be a difference of opinions between doctors about some of the details of treatment, Hopefully this booklet will help you in discussions with your specialist about the issues involved, and in making the right decisions for your individual child.

## **PATIENT EXPERIENCES**

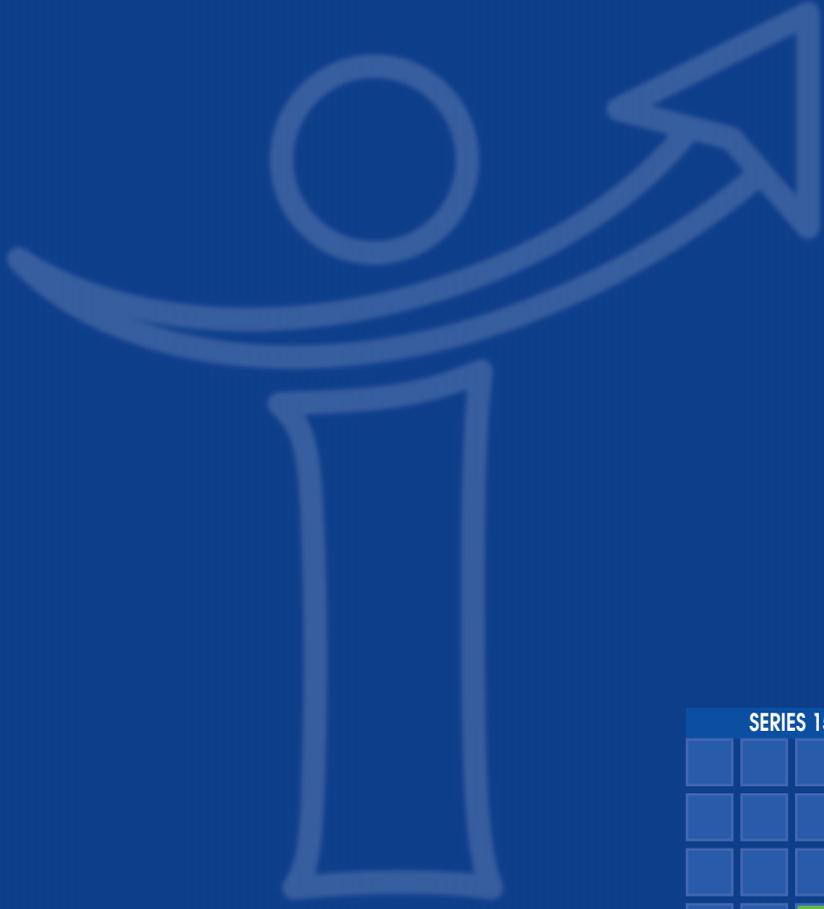
### *Hypothyroidism*

Lisa went to see her G.P. when she was 13 years old complaining of aches in her fingers and legs. Her family said that she had not grown since she was 11 years old and indeed she was very small, her height being 15 cms below the 3rd centile. She had developed a rather rounded face, particularly in comparison with old photographs, and she complained of the cold. When examined she was found to have signs of a severely underactive thyroid including a pulse rate of only 60 beats/minute and she was also anaemic. It was only when she started to take thyroxine and she started to grow and feel much better, that her family realised quite how unwell she had really been. However, she will now need to continue taking thyroxine for all her life.

### *Hyperthyroidism (Thyrotoxicosis)*

At the age of 11 years, Sarah was referred to the Paediatrician with a story of weight loss, excessive eating, sickness and moodiness for the previous 2 months. Her father had received tablets for an overactive thyroid in the past and other relatives also had thyroid problems. She was found to have a goitre, a pulse rate of 120 beats/minute and blood tests showed a very high thyroxine level,

She was treated with anti-thyroid drugs and beta-blockers for 1 year and did very well so the drugs were stopped and after 6 months the blood tests were normal. However, after 9 months all the symptoms returned and so she was started on treatment again, this time using higher doses, However this time the thyrotoxicosis proved very difficult to control and she also had lots of problems with her periods. After a detailed discussion with her and her family she was treated with radio-iodine and was then able to come off tablets altogether.



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JULY 2004 P150604