



Growth Hormone Deficiency

Information for Parents and Children



About Us

The Child Growth Foundation (CGF) is a UK charity dedicated to supporting people living with rare child growth conditions. We provide information and support to those directly affected, their parents and the healthcare professionals who will work with them.

We also raise awareness of growth conditions among the general public and health professionals and we fund research to increase medical understanding of these conditions.

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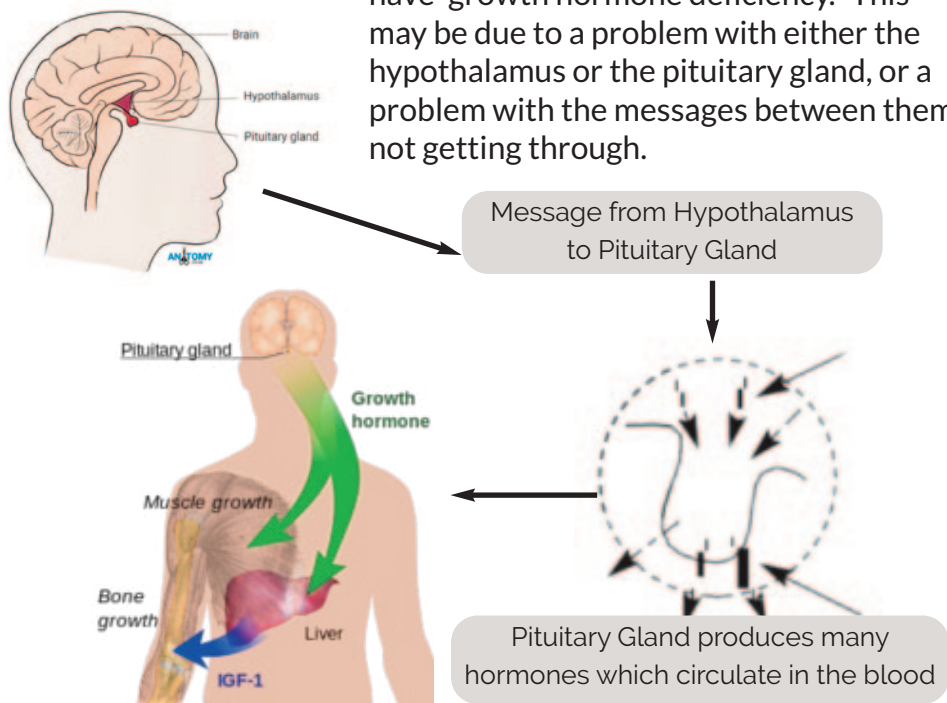
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What Are Hormones?

Hormones are chemicals that carry messages from one cell to another. Growth hormone is made by the pituitary gland, which is a small gland in the brain. Another gland in the brain called the hypothalamus sends messages to the pituitary telling it to make growth hormone.

When children do not make enough growth hormone, they are said to have 'growth hormone deficiency.' This may be due to a problem with either the hypothalamus or the pituitary gland, or a problem with the messages between them not getting through.



In many children the reasons for the deficiency is not known; this is sometimes called 'idiopathic' growth hormone deficiency. Other reasons for deficiency include problems with the development of the pituitary gland or damage caused during birth or by a head injury.



Children who have had a brain tumour may have growth hormone deficiency caused by damage to the pituitary from the tumour itself, or by surgery or radiotherapy. Treatment for some other childhood cancers includes radiotherapy to the head, which can lead to growth hormone deficiency.

The pituitary gland also makes several other hormones, which are very important for growth and health. In some cases, the production of these hormones may also be affected. Your child's specialist will talk to you about this and how they will check these hormones if your child needs this.

How Does GHD Affect Children?

Children with growth hormone deficiency are shorter than expected for family size with normal body proportions. They often look young for their age and may still have the chubbiness often seen in toddlers, as growth hormone helps to control the amount of fat under the skin.

How is GHD Diagnosed?

Tests for growth hormone deficiency are only considered after a clear pattern of slow growth has been seen and other things that may affect growth have been ruled out. This may take more than a year of monitoring. This wait can be frustrating for families, but it is very important to make sure that the child has no other medical conditions and has a diet with enough nutrients and calories to grow normally. Children who have growth hormone deficiency can be treated by giving them growth hormone – but this does not work well if there are other underlying conditions that have not been addressed first.

Growth hormone levels cannot be measured by a single blood test as the pituitary gland releases it in bursts, mainly at night during sleep.



There are two main ways that doctors use to measure growth hormone levels in children.

- 1 Bring the child into hospital overnight and take blood samples from a cannula every 20 minutes – this is known as a physiological test. This is only available in a few specialist centres as it is very labour intensive and expensive.
- 2 Bring the child in to hospital for the morning for a specialised test to stimulate the pituitary gland to release a burst of growth hormone. There are several tests used in this way including the insulin tolerance test (ITT), glucagon, clonidine, arginine and growth hormone releasing hormone. These are known as provocation tests.

None of these tests are pleasant for the child to have and due to concerns about safety, all these tests should only be performed by staff with further training and experience. The insulin tolerance test should only be carried out in highly specialist centres.

Your child's doctor will discuss which test is most suitable for your child and give you more information about this at the time.

Results from these provocation tests give a measurement of the amount of growth hormone a child is able to make at this time. Results cannot always be directly compared between different hospitals as they may vary because of the laboratory equipment and assays (type of analysis used). Many hospitals use a level of 7 micrograms per litre as the amount of growth hormone that a child should make to support normal growth.

If a child's results are lower than this then this would support the diagnosis of growth hormone deficiency.

Other hospitals may have different levels that they use. If you want to know more about these measurements, then please ask your consultant or specialist nurse.



How is GHD Treated?

Treatment of growth hormone deficiency is by giving a daily dose of growth hormone to replace their missing hormone. As we know that children usually make growth hormone overnight during their sleep the doctors usually ask for the injection to be given in the evening. If this is difficult for family routine then it can be given at any time of day, it needs to be given at around the same time every day to work best.

The growth hormone used is made in a laboratory and is an identical copy of the natural human growth hormone. There are several companies that make growth hormone that can be prescribed in the UK. There is no difference in how well each of the growth hormone works, but there are differences in the injection devices and price.

The following brands (listed in alphabetical order) are currently available in the UK.

Brand Name	Pharmaceutical Company
Genotropin	Pfizer
Norditropin	Novo Nordisk
Nutropin AQ	Ipsen
Omnitrope	Sandoz
Saizen	Merck Serono

As growth hormone is very expensive the choice of brand available in many areas is limited. Your child's doctor or nurse specialist will help you find a device that you will be most comfortable using.

The dose (amount) of growth hormone your child needs will be based on their weight. The dose will go up, as they get older and larger.



The doctors working in the UK follow guidance issued by the National Institute for Clinical Excellence, commonly known as NICE. This gives clear guidance on who would benefit from and should receive treatment with growth hormone, as well as information on how this treatment should be managed. The guidance can be found at:

www.nice.org.uk/guidance/ta188

Questions Around GHD Treatment

Are there any side effects?

As with all medicines there can be side effects. But growth hormone is considered to be a safe drug and most children do not have any problems.

Some children have headaches in the first few weeks of starting the daily injection. Usually this settles quickly. If not, then please contact your child's nurse or doctor.

A rare side effect is something called 'benign cranial hypertension.' The growth hormone affects the retention of fluid in the body, leading to severe headaches, which don't go away. Some children also have problems with their vision and vomiting. This is very rare – but if you are concerned about your child then contact your nurse or doctor. If this is confirmed, the growth hormone is stopped for a short while, and the headaches and other symptoms get better very quickly. Growth hormone is then restarted at a lower dose and then increased slowly – usually with no further problems.

Some children have a reaction on the skin at the injection site. This can be reduced by using different sites each day – but please mention it to your doctor or nurse as sometimes they can be sensitive to chemicals in the growth hormone liquid and will need to change to another product.



How do we get supplies of growth hormone?

Prescribing and supply of growth hormone is managed in different ways across the UK. This may be:

- Prescribed by your family doctor (GP). This is done as 'shared care' with your child's endocrinologist looking after your child and advising on the dose and your GP simply issuing the prescription, as this is more convenient for the family. The prescription may be taken to the local pharmacy (chemist), or some GP's send the prescription to a home care company who deliver the growth hormone directly to the family home.
- Prescribed by your child's specialist team and collected from the hospital outpatient pharmacy
- Prescribed by your child's specialist team and delivered to the family home by a healthcare company.

Sometimes doctors will only prescribe a month's supply each time which can be difficult to manage. If you have any problems getting supplies of growth hormone then please let your doctor or specialist nurse know as soon as possible. If you still have difficulties after this then please contact the Child Growth Foundation for advice.

How do I store the growth hormone?

Storage of growth hormone varies, but almost all the growth hormone available, must be kept cool and should be kept in a fridge. (Check patient information for full details). It should be taken out of the fridge for a short time before doing the daily injection, as if you give the injection while the growth hormone is cold, this will sting. You should put the growth hormone back in the fridge when the injection has been done (if applicable).

There are some brands that do not need to be kept in the fridge all of the time – your specialist nurse or doctor will be able to give you more information about this. It can be helpful to think about how the growth hormone needs to be stored when choosing the device that you want to use.



Should we miss the injections when my child is unwell?

It is best to try and miss as few injections as possible. We would recommend that unless your child is very unwell you continue with the daily injections. If your child is very unwell or becomes very distressed and you miss a day or two then do not worry, just let your doctor or nurse know next time you see them.

However – if your child had low blood sugars before starting treatment with growth hormone, then please talk about this with your doctor or nurse. Some babies and young children will again have low blood sugars if they miss their injection of growth hormone. They may need their blood sugar to be monitored carefully or even be admitted to hospital if they cannot have their daily injection.

What about going on holiday?

All of the companies that make growth hormone, should supply cool bags for when you are travelling. Your specialist nurse or doctor will be able to order this for you.

It can also be very helpful to take a letter from the hospital with you when travelling, as this can be needed to pass easily through customs with the growth hormone.

If you are flying, you should pack the growth hormone in your cabin baggage as it may freeze in the hold.

Will my child grow up and go into puberty like their friends?

The pituitary gland also makes the hormones needed for your child to go through puberty when their body changes from a child into a young adult.

The normal age for puberty to start is 8-13 years in girls and 9-14 years in boys. This is influenced by the trend in your family – children with parents who had a later puberty are more likely to start puberty later. Children with a chronic illness or who do not eat enough are also likely to have a later puberty.

We know that some children who have growth hormone deficiency, will also have deficiency of these hormones (called gonadotrophins). Once your child



reaches the age that puberty may be expected to start, your child's specialist team will need to examine your child to assess their development. In girls this means assessing the size and shape of the breasts and amount of pubic and underarm hair. In boys the size of the testicles, development of the penis and amount of pubic and underarm hair is assessed.

Although many young people find this embarrassing it is a vital part of the assessment and only takes a few moments in clinic. For growth specialists it is a routine part of examination – in the same way as the GP may measure your blood pressure. Preparing your child for this, so that they know it is needed and does not come as a shock, is very important.

If your child has not started puberty at the normal time, then the treatment for this is straightforward. This will give your child the physical development into a young adult, but further specialist treatment may be needed if they wish to have children of their own. Your child's specialist will be able to give you more information about this.

Will the growth hormone treatment stop when my child has finished growing?

Adults also need growth hormone, but they need less than a child. Some young people are found to have low levels of growth hormone and go back onto treatment on an adult dose. Others are found not to need this any longer. Your child's specialist will discuss this with your child when they have finished growing and are fully physically mature.

Further Support

If you are still unsure, or concerned about anything you have just read, the Child Growth Foundation operates a support service, by telephone or email, that may be able to help further.

Email us at: **info@childgrowthfoundation.org**

We also manage a number of closed patient support groups through Facebook visit our main page to find out more:

facebook.com/childgrowthfoundation/



Acknowledgements

Many thanks to: PAULINE MUSSON | SALLY TOLLERFIELD | JENNY CHILD

These booklets are supported through an unrestricted educational grant from Merck Serono Limited, Bedfont Cross, Stanwell Road, Feltham, Middlesex TW14 8NX.

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REVISION DATE: 06/2019 | Review Date: 06/2021 | Version: 1.0

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FEEDBACK

Your feedback helps us to ensure we are delivering information to the highest standard. If you have any comments or suggestions, please contact us at: info@childgrowthfoundation.org

FUNDING

The Foundation funds research into many aspects of growth conditions such as the causes, effects, treatments and psychological impact. It also offers essential advice and experience to parents of children who have been diagnosed with growth problems. The annual convention provides a great forum for people to get together to discuss problems and solutions with others in a similar position. It also provides a chance to meet and learn from the doctors and professors dealing with child growth in the UK.

The CGF is entirely self-sufficient and is an independent charity. It relies on donations and membership subscriptions to keep going. If you have found this information leaflet helpful, please consider becoming a member and/or making a donation - www.childgrowthfoundation.org.



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