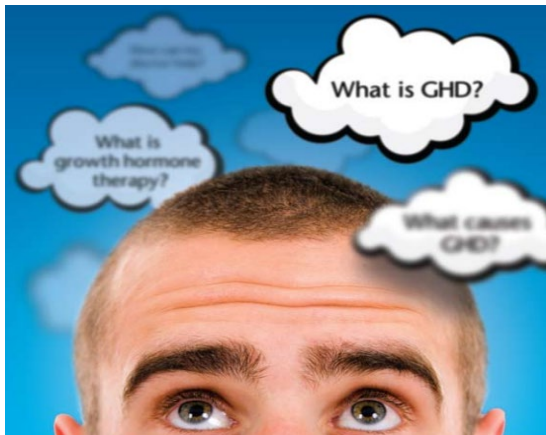


Scottish Paediatric Endocrine Group (SPEG)

Growth Hormone Deficiency (GHD) – a young person's guide

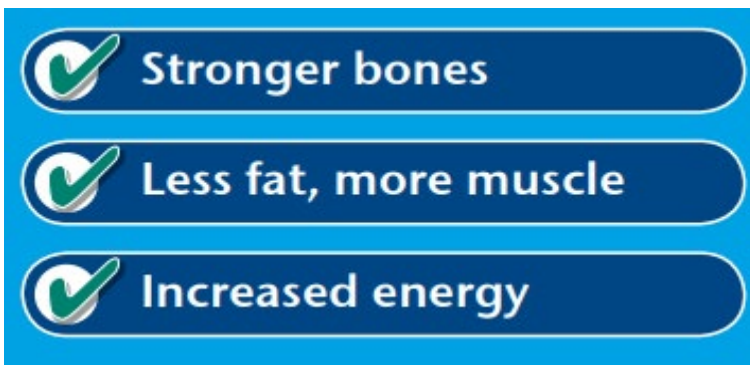
GHD and You



As someone who has lived with Growth Hormone Deficiency (GHD) since childhood, you will obviously be very familiar with growth hormone therapy.

Now that you are a young adult, you may be given the choice of whether to continue your treatment or stop. It is important that you can make an informed decision, so listed below are some of the benefits of carrying on taking your medication.

There may be a number of benefits to continuing your growth hormone treatment, including:



The choice is yours of course but remember that **you should not stop your treatment without first speaking to your endocrine doctor or nurse**, who will arrange a simple test that will assess your condition.

GHD: Some common questions

What is Growth Hormone Deficiency (GHD)?

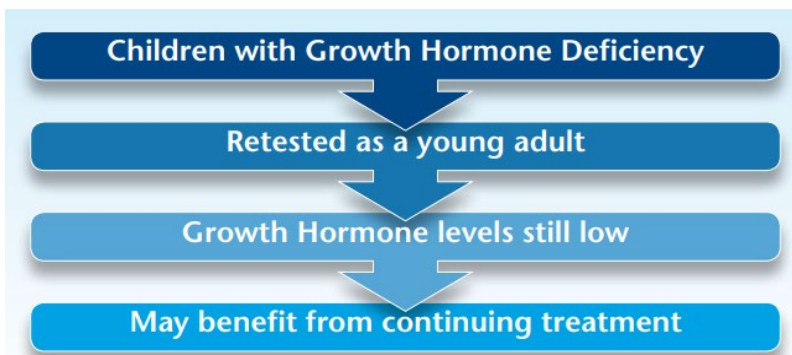
GHD occurs when the pituitary gland does not make enough growth hormone. This important hormone is responsible for the body's growth and development. In children, GHD slows the growth rate and can result in being shorter than expected. In adults, GHD can affect the way they feel and function.

When is GHD usually diagnosed?

Most often, doctors diagnose this problem during childhood and can treat it with success. After growth hormone treatment in childhood, some people still have GHD as adults.

Do I need to be tested for GHD as a young adult?

Most adults whose GHD started in childhood should be retested for GHD after they have reached their final height to see if they still have the condition. Childhood GHD does not always continue into adult years. If you had a tumour or surgery in the pituitary region, have several other pituitary hormone deficiencies, or if you have proven genetic causes of GHD, you may need only to have a simple blood test to confirm that you are still affected by GHD. This test is done after you have stopped GH treatment for at least 4-8 weeks. Some of you may need a more detailed test, which will be explained to you in more detail by your endocrine team.



What causes adult GHD?

Adults with GHD fall into two categories: childhood onset: GHD began during childhood and has continued; or adult onset: GHD developed after reaching adulthood. The causes of GHD include problems that are present at birth. The pituitary gland may be abnormal or there may be a genetic syndrome, such as defects in the gene in charge of making growth hormone. Causes of GHD that can take place at any age, even in adults, involve damage to the pituitary gland or the part of the brain that controls the pituitary.

What are the symptoms of GHD in young adults?

In young adults, even though they are not growing taller, GHD affects health in many ways. Symptoms of GHD in adults include:

- increased fat, especially around the waist
- lower muscle mass and strength
- mild bone loss
- thinning skin
- sleep problems
- decreased exercise performance
- decreased energy
- decreased well-being, mild depression, or moodiness

What is growth hormone therapy?

Growth hormone treatment involves injections of growth hormone made in a laboratory. The goal is to replace the natural growth hormone you are lacking and to reverse the symptoms of GHD. If you are a young person with GHD, this leaflet will give you some of the information you need to help you make an informed decision about your continued treatment.

How can my doctor help?

For growth hormone treatment, your endocrinologist (hormone doctor) will decide the dose based on your sex and age and on other medicines you might be taking. Doctors most often start by giving a low dose of growth hormone. The dose may change over time. Doctors adjust the growth hormone dose based on how you respond to treatment, blood tests, and on any side effects you may have. Most doctors and nurses, for example, who provide growth hormone treatment want to see their patient every two to three months at first to check for progress and any side effects.

Once the right dose is found and tests show that the growth hormone is helping you as much as possible, you may need to visit your clinic etc. only twice a year.

Your doctor will also make sure that all your medications work together as well as possible. Tell your endocrinologist about all the medications you take. After you start a drug, call them if you feel different or worse. Your new symptoms may be a side effect of the drug or an interaction from taking more than one drug. Your doctor can best explain all the risks and benefits of growth hormone replacement therapy and other treatments you may need.

What can I do to help my treatment process?

Treatment for GHD may continue for many years and possibly even lifelong. One of the most important things you can do as a patient is to keep taking your prescribed dose of growth hormone and any other medicines you take. Another is to report any side effects you may have to your doctor. You and your doctor should be partners in your care. Keep appointments with your endocrinologist, ask questions, and take part in your care to ensure the success of your treatment.

This leaflet was created by the SPEG Transition subgroup. SPEG is a network of healthcare professionals in Scotland who have a particular interest in the care of children and young adults who have endocrine conditions.

If you require this leaflet in an alternative format, please email: NSS.EqualityDiversity@nhs.scot or telephone **0131 275 6000**

For support with British sign language, please visit their [website](#)

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