

Adult growth hormone replacement therapy



Information for patients

This leaflet answers some of the questions you may have about growth hormone replacement treatment. It explains the risks and benefits of the treatment and what you can expect when you come to hospital. If you have any queries or concerns, please do not hesitate to speak to the doctors or nurses caring for you.

Confirming your identity

Before you have a treatment or procedure, our staff will ask you your name and date of birth and check your ID band. If you don't have an ID band we will also ask you to confirm your address.

If we don't ask these questions, then please ask us to check.

Ensuring your safety is our primary concern.

What is recombinant human growth hormone or somatropin?

Somatropin is the synthetic form of growth hormone, which is a protein that is made to be nearly the same as the main form of growth hormone which is naturally produced in the body.

It is used for long-term treatment of children with growth failure due to a lack of secretion of endogenous growth hormone. It is also used for long-term replacement therapy in adults with growth hormone deficiency in either childhood or adult onset.

There are a lot of brand names for somatropin, such as omnitrope, genotropin, humatrope, norditropin and nutropin. The main point to remember is the device is different but the medication is the same.

Why do I need this growth hormone replacement?

Growth hormone deficiency happens when the pituitary gland does not make enough growth hormone. Its diagnosis is based on the combination of pituitary disease, hypopituitarism (when you have deficiency in one or more pituitary hormones) and a decrease in the concentration of insulin-like growth factor I (IGF-I). It can also be diagnosed through a low growth hormone response to a stimuli during a dynamic test, for example, the insulin stress test.

What are the benefits of growth hormone replacement?

Growth hormones stimulate tissue growth, linear growth (height), and protein, carbohydrate, lipid and mineral metabolism. It decreases fat mass and risk of fractures,



and increases lean body mass, muscle strength, exercise performance, cardiac capacity and bone mineral density. Treatment aims to improve quality of life.

What are the risks of growth hormone replacement?

Common side effects include:

- joint stiffness
- arthralgia (joint pain)
- myalgia (muscle pain)
- paraesthesia (numbness, tingling or pricking, 'pins and needles', or a burning feeling in arms, hands, legs or feet)
- peripheral oedema (build up of fluid causing swelling, usually in lower limbs)
- some fluid retention (excess fluids build up inside your body)
- carpal tunnel syndrome (pressure on nerves of wrist causing tingling, numbness and pain in your hand and fingers)
- worsening of glucose tolerance (higher than normal blood glucose levels)

These hormonal side effects generally respond to dose reduction. Older and more obese patients are more prone to side effects from growth hormone treatment. There is no evidence that growth hormone replacement in adults increases the risk of new or recurrent malignancy (cancer that has come back).

The National Institute for Health and Care Excellence (NICE) guidelines state that growth hormone replacements should not be used during pregnancy. It is generally stopped at the



end of the first trimester (12 weeks) as the rise in placental growth hormone (at around 8 weeks) is felt to be the main determinant in maternal IGF-1.

Do I need to prepare for my clinic visit to start growth hormone replacement treatment?

There are no preparations needed. An endocrine nurse specialist will contact you to arrange a clinic visit.

What happens before my clinic visit?

Your endocrine doctor will discuss with you during an outpatient clinic visit if you need growth hormone replacement treatment. Your doctor will then refer you to an endocrine nurse specialist to start the treatment.

What happens during my initiation for growth hormone replacement visit?

Your endocrine nurse specialist will take your baseline hormone levels which includes your IGF-1 levels, and teach you how to give yourself growth hormone injections.

You will need to sign a written consent form to start the treatment. A registration form and prescription form will be requested for you for homecare delivery of medication supply. If you are unable to attend the growth hormone visit, verbal consent may be documented and nurse injection training can be given via healthcare at home service.

How long does the growth hormone replacement treatment take?

We will advise you to continue treatment for at least six to nine months. If therapy is tolerated, with a good clinical



response to treatment then there is no reason to stop therapy and treatment will be long-term. But if there is no perceived or biochemical benefit of treatment after at least one year of therapy, then stopping growth hormone replacement therapy may be appropriate.

How do I take the medication?

Growth hormone injections are taken daily, preferably at night time. It is injected via a subcutaneous route (injection under the skin into the fatty tissues). Common areas for injection are the upper outer area of the arm, the front and outer sides of the thighs, upper outer area of the buttocks and abdomen (except for a two inch area around the navel).

You will need to rotate your injection sites to avoid trauma, inflammation or infection to the site of injection.

Fixed grade phase

The fixed grade phase is the first three months of treatment. You will be started on a 0.3mg injection daily dose for the first four weeks, titrate up to 0.4mg injection daily for the next four weeks and titrate up to 0.5mg injection daily for the third month.

Individualised titration phase

The following three to six months will be the individualised titration phase, which ensures that a maintenance dose is achieved. The titration process will aim to reach the upper limit IGF-1 level age-related normal range and also consider any side effects or patient tolerance to treatment. Ideally, your IGF-1 levels will be monitored during the third, sixth and ninth month clinic visit, and then yearly after that.



If you miss a couple of doses due to forgetting to inject yourself, an accident at home or poor storage of medication causing it to expire, take your usual dose on the following day when the medication is available. Do not overdose.

What happens after my growth hormone treatment?

Follow-up visits will vary depending on your response to treatment. Once a maintenance dose is reached, you will usually be reviewed every year for both IGF-1 level and checking any side effects.

For patients who are not local to King's, we will aim to send your care back to your local endocrine team for your regular growth hormone monitoring and prescription supply.

Who can I contact?

If you have any clinical queries, please contact endocrine nurse specialists:

Leah Laniba and Nadia Gordon

Tel: **020 3299 4047** or **020 3299 2047**

Email: **kch-tr.endonurses@nhs.net**

Available Monday to Friday, 9am to 5pm

Further information

The Pituitary Foundation growth hormone factsheet has more information for growth hormone deficient patients:

www.pituitary.org.uk/information/publications/general/growth-hormone-factsheet/

Sharing your information

We have teamed up with Guy's and St Thomas' Hospitals in a partnership known as King's Health Partners Academic Health



Sciences Centre. We are working together to give our patients the best possible care, so you might find we invite you for appointments at Guy's or St Thomas'. To make sure everyone you meet always has the most up-to-date information about your health, we may share information about you between the hospitals.

Care provided by students

We provide clinical training where our students get practical experience by treating patients. Please tell your doctor or nurse if you do not want students to be involved in your care. Your treatment will not be affected by your decision.

PALS

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. The PALS office is located on the ground floor of the Hambleton Wing, near the main entrance on Bessemer Road - staff will be happy to direct you.

PALS at King's College Hospital, Denmark Hill, London SE5 9RS

Tel: **020 3299 3601**

Email: **kch-tr.palsdh@nhs.net**

You can also contact us by using our online form at **www.kch.nhs.uk/contact/pals**

If you would like the information in this leaflet in a different language or format, please contact PALS on **020 3299 1844**.

