

Understanding NICE guidance

Information for people who use NHS services

Human growth hormone (somatropin) for growth failure in children

NICE 'technology appraisal guidance' advises on when and how drugs and other treatments should be used in the NHS.

This leaflet is about when **human growth hormone (somatropin)** should be used to treat children with growth failure in the NHS in England and Wales. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence). It is written for children with growth failure and their families or carers but it may also be useful for anyone with an interest in the condition.

It does not describe growth failure or the treatments in detail – a specialist in treating growth failure in children should discuss these with you. You can get more information from the organisations listed on the back page.



A specialist in treating growth failure in children should talk to you about whether human growth hormone (somatropin) is suitable.

What has NICE said?

NICE recommends human growth hormone (somatropin) as a possible treatment for some children with growth failure (see below).

Who can have human growth hormone (somatropin)?

Children should be able to have human growth hormone (somatropin) if they have any of the following:

- growth hormone deficiency
- Turner syndrome
- Prader–Willi syndrome
- chronic renal insufficiency
- growth failure at 4 years or older and were born small for gestational age
- short stature homeobox-containing gene (*SHOX*) deficiency.

Treatment should continue until the child stops growing unless growth is slow in the first year of treatment or the child doesn't wish to carry on with the treatment. The specialist should carefully consider weight and height before stopping treatment in children with Prader–Willi syndrome.

Why has NICE said this?

NICE looks at how well treatments work, and also at how well they work in relation to how much they cost the NHS. NICE recommended human growth hormone (somatropin) because it increases growth in children with growth failure and works well in relation to its cost.

Growth failure

Some children do not grow as expected and are short for their age. This 'growth failure' may be caused by lack of a protein called growth hormone. It can also occur with other conditions such as Turner syndrome, Prader–Willi syndrome and long-term kidney disease, and in children with low birth weight and those with a particular genetic deficiency (called *SHOX* deficiency).

Human growth hormone (somatropin)

Human growth hormone increases growth and also affects the way the body uses proteins, fats and carbohydrates. Somatropin is a synthetic form of human growth hormone.

What does this mean?

When NICE recommends a treatment, the NHS must make sure it is available to those people it could help, normally within 3 months of the guidance being issued.

So, if a child has growth failure and a specialist in treating growth failure in children thinks that human growth hormone (somatropin) is the right treatment for them (see 'What has NICE said?' on page 2), they should be able to have the treatment on the NHS. Please see www.nice.org.uk/aboutguidance if you think they are eligible for the treatment but it is not available.

More information

The organisations below can provide more information and support for children with growth failure and their families or carers. NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

- Child Growth Foundation, 020 8995 0257
www.childgrowthfoundation.org
- The Pituitary Foundation, 0845 450 0375
www.pituitary.org.uk
- Prader–Willi Syndrome Association (PWSA) UK, 01332 365676
www.pwsa.co.uk
- Turner Syndrome Support Society (UK), 0845 230 7520
www.tss.org.uk

NHS Choices (www.nhs.uk) may be a good place to find out more. Your local patient advice and liaison service (usually known as 'PALS') may be able to give you more information and support. If you live in Wales you should speak to NHS Direct Wales for information on who to contact.

About NICE

NICE produces guidance (advice) for the NHS about preventing, diagnosing and treating medical conditions. The guidance is written by independent experts, including healthcare professionals and people representing patients and carers. They consider the evidence on the condition and treatments, the views of patients and carers and the experiences of doctors, nurses and other healthcare professionals, and consider the costs involved. Staff working in the NHS are expected to follow this guidance.

To find out more about NICE, its work and how it reaches decisions, see www.nice.org.uk/aboutguidance

This leaflet and other versions of the guidance aimed at healthcare professionals are available at www.nice.org.uk/guidance/TA188

*You can order printed copies of this leaflet from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N2160). The NICE website has a screen reader service called *Browsealoud*, which allows you to listen to our guidance. Click on the *Browsealoud* logo on the NICE website to use this service.*

We encourage NHS and voluntary organisations to use text from this leaflet in their own information about growth failure.