

What is growth hormone deficiency?

Growth hormone deficiency is a rare condition where the pituitary gland does not produce enough growth hormone (GH).

Growth hormone is essential for normal physical growth in children. Growth hormone also regulates muscle and fat mass and helps maintain bone health in children and adults. A deficiency in growth hormone can therefore lead to serious physical problems and emotional symptoms.

For some adults, growth hormone deficiency is diagnosed in childhood. This is known as childhood-onset growth hormone deficiency. For others, the growth hormone deficiency starts in adulthood (adult-onset).

It is estimated that growth hormone deficiency affects 2-3 per 10,000 people¹.

What causes growth hormone deficiency?

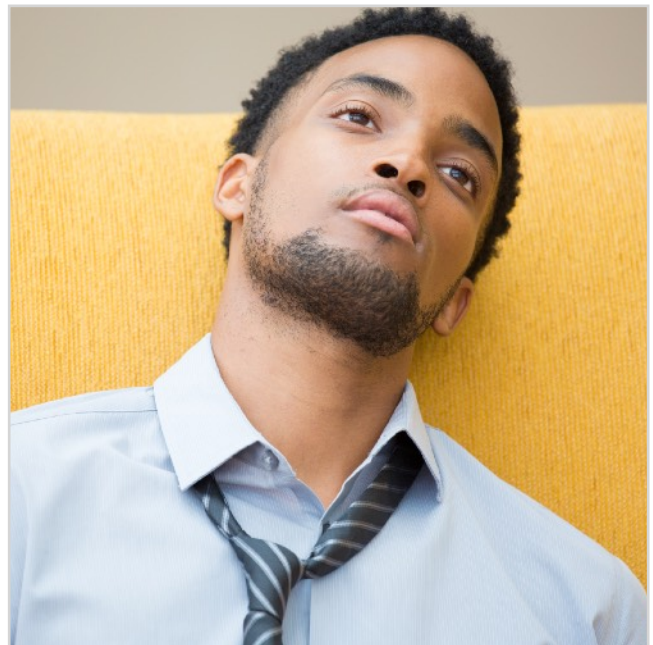
Growth hormone deficiency identified in adulthood can be caused by:

- Pituitary tumours.
- Tumours of the hypothalamus.
- Damage to the pituitary or hypothalamus following surgery or radiotherapy.
- Brain injury.
- A bleed (haemorrhage) in the brain.
- Infections in the brain or nervous system.
- Child-onset growth hormone deficiency can be due to:
 - Genetic abnormalities that result in an inability to produce or respond to growth hormone.
 - Abnormal development of the pituitary gland.
 - Structural defects of the brain or skull present since birth.

What are the signs and symptoms of growth hormone deficiency?

Symptoms of growth hormone deficiency in adulthood vary in severity, and can include:

- Reduced muscle mass and strength.
- Reduced bone mineralisation – which can cause osteoporosis.
- Increased body fat around the waist or abdomen.
- Reduced strength and ability to exercise.
- Decreased energy and easily fatigued (exhausted)
- Fatigue / tiredness
- Decreased sweating
- Impaired sense of well-being
- Anxiety
- Low mood and depression
- Poor concentration and memory
- Problems with sleep
- Thin, dry skin



How is growth hormone deficiency in adulthood diagnosed?

It is recommended that adults who have been previously diagnosed with childhood-onset growth hormone deficiency be retested at the end of adolescence, to assess whether they still have this condition².

1. Medical History and Physical Examination

Your doctor will ask you about your personal health and your health history. This will include questions about your symptoms, other medical conditions (including childhood-onset growth hormone deficiency and other hormone deficiencies), previous or current medications, any previous surgery, head injuries or accidents.

2. Test for GH deficiency

Growth hormone deficiency is diagnosed using a stimulation test³. This involves administering a medication (generally insulin*) that causes the pituitary to release growth hormone. Blood samples are then collected every 15 minutes over the next 2-4 hours to check whether growth hormone increases. To avoid repeat needles, the blood samples are collected through a very thin tube (called a cannula) which sits in a vein. This is also used to administer the medication.

*Insulin is not suitable for people with heart problems or epilepsy. Instead, other substances that stimulate the production of growth hormone can be administered, such as glucagon or arginine. Your doctor will choose the right test for you.

What do the results mean?

An appropriate increase in growth hormone after stimulation indicates no growth hormone deficiency.

No increase (or very little increase) in growth hormone after stimulation indicates growth hormone deficiency. Your doctor may conduct other tests to identify the cause, if unknown. This may include taking images of your pituitary using an MRI scan.

3. Blood test to measure other hormone levels

IGF-1 is a hormone made by the liver in response to growth hormone. The level of IGF-1 may be low in growth hormone deficiency but can also be normal. It is therefore not a sensitive marker of GH deficiency on its own.

To check how well the rest of the pituitary gland is working, other hormones are measured. This includes cortisol, thyroid hormone (T4), sex hormones (oestradiol for women /testosterone for men) and prolactin. This involves collecting a small amount of blood and sending it to a laboratory for tests.



How is growth hormone deficiency in adulthood diagnosed? *(cont'd)*



4. MRI scan

Your doctor may decide to scan your pituitary gland to identify the cause of your growth hormone deficiency. This is usually done using an imaging method called magnetic resonance imaging (MRI). A MRI scan uses a magnetic field and radio waves to take pictures of parts of the body. These pictures can help assess the health of the pituitary gland, and to check for pituitary tumours.

Your doctor will send you to a radiologist for a MRI. Before having an MRI, you will change into a gown and remove any watches or other metallic objects. You might be given earplugs or headphones, as the MRI machine can be noisy. For the scan, you will lie on a platform that slides into the MRI machine. You will need to lie very still while inside the machine, as movement can blur the images. When inside the machine, you will be able to talk to the operator through an intercom system. The scan can take up to an hour.

5. Other physical assessments

Growth hormone deficiency often results in a number of changes to body composition and metabolism. This can include:

- Low bone mass and increased risk of osteoporosis
- Increased fat mass
- Reduced muscle mass and strength
- Glucose intolerance
- Reduced insulin sensitivity
- High blood levels of fats, cholesterol and triglycerides

Your doctor will assess these conditions, and monitor them after growth hormone therapy is started.

How is growth hormone deficiency treated?

In Australia from 1 December 2018, growth hormone has been listed on the Pharmaceutical Benefit Scheme for adults who have severe growth hormone deficiency and a very poor quality of life. This includes adults with either:

- A documented childhood onset growth hormone deficiency due to a congenital, genetic or structural cause.
- Adult onset growth hormone deficiency due to hypothalamic or pituitary disease.

To be eligible for access to growth hormone through the PBS, your Endocrinologist will need to ensure you have had an appropriate dynamic test to diagnose growth hormone deficiency and you have to complete a questionnaire to demonstrate poor quality of life. Your Endocrinologist must then submit a PBS Written Authority application to the Department of Human Services. To continue growth hormone, you need to demonstrate an improvement in quality of life while you are taking it.

For more information about the changes to the Growth Hormone Program, see the Australian Government PBS Frequently Asked Questions page: <http://www.pbs.gov.au/general/changes-to-certain-s100-programs/faqs-growth-hormone-1-dec-2018.docx>

Growth hormone therapy is administered as a daily injection into the layer of fat under the skin of the stomach. This can be self-administered and is relatively painless. The dose of growth hormone needs to be tailored for each person, taking into account their sex, age and any other conditions or medications being taken. For example, higher doses may be required in young adults, women, and those taking medications that contain oestrogen (e.g. hormone replacement therapy, oral contraceptives).

Growth hormone therapy is started at a low dose³. Your doctor will then monitor your hormone levels over time. If needed, your doctor will adjust your dose to keep IGF-1 levels within a normal range and to avoid any side-effects.

Side effects can occur in some people. This can include swelling, joint or muscle pain, increased blood pressure and carpal tunnel syndrome (numbness, weakness or pain in your wrist and/or hand). These side effects disappear quickly by reducing the dose.

Once you have the dose right, your doctor will conduct check-ups every 6 months to ensure symptoms are under control, and your hormone levels are in a normal range. They may also send you for a bone mineral density test (DEXA) every two years to check your bone health.



What can I do to help?

Common symptoms of growth hormone deficiency are tiredness and a lack of strength and energy. Growth hormone therapy can improve these symptoms, but a healthy lifestyle is also important. This can include having a healthy balanced diet and ensuring you get enough sleep.

For current information about a healthy diet, see the Australian dietary guidelines, at <https://www.eatforhealth.gov.au/guidelines/about-australian-dietary-guidelines>

FAQs about growth hormone deficiency

How long do I need to take my growth hormone medication?

For children, growth hormone treatment may only be required until their full adult height potential is reached or late adolescence. In adults, growth hormone may be required for life. This mainly depends on whether you continue to benefit from its use. It is important to take your medication for the whole length of time your doctor has advised, as symptoms can return once medication is stopped.

How quickly will my symptoms improve?

Improvements in most symptoms are seen within a few months of taking growth hormone therapy, but may take up to a year to see full benefit. Some people notice an improvement in their feelings of well-being within a month of starting therapy.

Are there natural supplements I can take to increase my growth hormone levels?

Natural supplements advertised as “growth hormone boosters” do not contain growth hormone. These supplements also do not increase growth hormone levels to adequately treat growth hormone deficiency. These supplements contain amino-acids and proteins that claim to support muscle growth, but are not an alternative to growth hormone therapy.

Can growth hormone treatment be given to someone who does not have growth hormone deficiency?

Growth hormone is abused for body building and as an anti-ageing drug. The Endocrine Society of Australia does not endorse the use of GH for conditions other than for replacement for GH deficiency.

Does growth hormone therapy come in a tablet form?

A tablet form is not available.

Where to go for more information and support?

Your doctor (GP).

Your Endocrinologist

For further resources, see the Australian Pituitary Foundation: <http://pituitary.asn.au/>

For current information about a healthy diet, see the Australian dietary guidelines, at <https://www.eatforhealth.gov.au/guidelines/about-australian-dietary-guidelines>

When to see your doctor

It is a good idea to see your doctor if you develop symptoms of growth hormone deficiency, particularly if you have previously had a pituitary disease, head injury or have been exposed to radiation to the brain.

If you have previously been diagnosed with childhood onset growth hormone deficiency, it is recommended to see your specialist for a check-up when you have finished growing or reach late adolescence. Your doctor will conduct some tests to check you still need medication.

If you start growth hormone medication and develop side effects, such as painful muscles and/or joints, swelling, wrist pain or weakness, see your doctor who can advise how to adjust your medication.

If you are on growth hormone therapy and your symptoms change, see your doctor who can investigate the cause of your symptoms and adjust your medication if necessary.

Questions to ask your doctor

Growth hormone deficiency is a rare condition. If you have signs or symptoms, you will be referred to a doctor specialising in GH deficiency (an endocrinologist), who can help you understand and treat your condition appropriately. Your endocrinologist can answer any questions you may have. It can be helpful to write these questions down before your visit as a reminder.

Common terms and definitions

Benign – Not cancerous.

Congenital – A condition present from birth.

Malignant – Contains cancerous cells.

Tumour – An abnormal growth in the body. Tumours can be benign or malignant.

References

1. Stochholm K, Gravholt CH, Laursen T, Jorgensen JO, Laurberg P, Andersen M, et al. Incidence of GH deficiency - a nationwide study. *Eur J Endocrinol*. 2006;155(1):61-71.
2. Molitch ME, Clemmons DR, Malozowski S, Merriam GR, Vance ML, Endocrine S. Evaluation and treatment of adult growth hormone deficiency: an Endocrine Society clinical practice guideline. *J Clin Endocrinol Metab*. 2011;96(6):1587-1609.
3. Ho KK, Participants GHDCW. Consensus guidelines for the diagnosis and treatment of adults with GH deficiency II: a statement of the GH Research Society in association with the European Society for Pediatric Endocrinology, Lawson Wilkins Society, European Society of Endocrinology, Japan Endocrine Society, and Endocrine Society of Australia. *Eur J Endocrinol*. 2007;157(6):695-700.