



Adult Growth
Hormone Deficiency

Condition guide →

Adult Growth Hormone Deficiency

This booklet covers growth hormone deficiency in adults, including symptoms, diagnosis and treatment.

The
● Pituitary
Foundation

For hormones • For health • For life



This booklet has been produced and supported by funding from pharmaceutical companies. For more information, see the back page of this booklet.

Contents

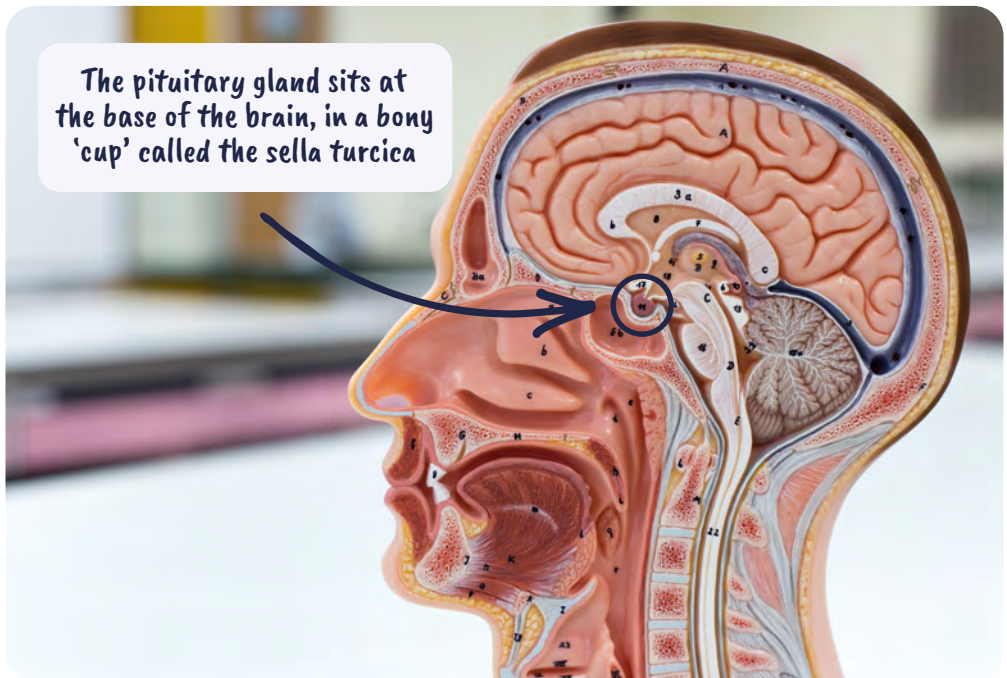
What is adult growth hormone deficiency (AGHD)?	1
What causes AGHD?	3
Symptoms of AGHD	5
How is AGHD diagnosed?	6
Treatment for AGHD	9
Support during treatment	14
Common questions about treatment	16
Notes	18
More information	20

What is adult growth hormone deficiency (AGHD)?

Growth hormone deficiency happens when the pituitary gland does not make enough growth hormone. It can happen in children and adults. When it occurs in adults, it is usually because of damage to the pituitary gland. This booklet will focus on growth hormone deficiency in adults.

AGHD is a rare condition. It is thought that one in every 10,000 people in the UK have AGHD.

The pituitary gland is a small gland at the base of the brain that makes lots of hormones. It is controlled by the hypothalamus, which sits above the pituitary gland and controls different hormones and bodily functions.



Your pituitary gland makes and releases lots of hormones. Hormones are chemicals that carry messages around the body. These messages can tell your body what it needs to do. One of the many messages that hormones can send is to tell your body when to start and stop growing.

Growth hormone is made by the pituitary gland and it has many roles. These include:

- helping children to grow
- bone and muscle development between when you stop growing as a child to around 25 years old
- the maintenance of normal body fat and muscle in adults
- keeping your bones strong
- wellbeing in adults



What causes AGHD?



If the pituitary gland is damaged, this can stop it from making enough hormones, like growth hormone. For AGHD, the main reasons that this happens are:

- **A pituitary tumour:** This is a tumour of the pituitary gland. Pituitary tumours are almost always benign (non-cancerous). Doctors may use the words “tumour”, “adenoma”, “growth”, or “pituitary neuroendocrine tumour” to describe a pituitary tumour. These words all mean a growth on the pituitary gland. These tumours grow very slowly. Many do not seem to grow at all, or can even shrink.
- **Radiotherapy:** Radiotherapy is when high energy radiation is used on an area of the body. You may have had radiotherapy to treat cancer. If you have radiotherapy in an area near the hypothalamus or pituitary gland, this may cause AGHD.

A pituitary tumour and radiotherapy are the most common causes of AGHD, but there can be other causes. Other causes can include:

- brain tumours
- inflammatory conditions that affect the pituitary gland or hypothalamus
- a traumatic brain injury (TBI). A TBI is a head injury that causes damage to the brain

As AGHD usually happens because of damage to the pituitary gland, people will often have AGHD alongside other pituitary hormone deficiencies. Having multiple pituitary hormone deficiencies is called hypopituitarism.

Your healthcare team may refer to your pituitary tumour as a **pituitary neuroendocrine tumour (PitNET)**. This means a tumour that affects hormone-producing cells, such as the cells in the pituitary gland. The term pituitary neuroendocrine tumour is just another name for a pituitary adenoma, which are almost always benign. Some neuroendocrine tumours can be cancerous and occur in other areas of the body, like the lungs and intestines.

It is important to know that whilst a pituitary tumour may be called a neuroendocrine tumour, it is not the same as the cancerous neuroendocrine tumours. If you are worried or do not understand your diagnosis, you should speak to your endocrine team.



Symptoms of AGHD



The symptoms of AGHD in adults can sometimes be difficult to spot. They can include:

- increased body fat, especially around the waist
- loss of muscle mass
- having less strength and feeling weaker
- having less stamina and finding it difficult to exercise
- weak bones that break more often (known as osteoporosis).
- high cholesterol
- extreme tiredness
- anxiety and depression
- feelings of loneliness and social isolation (this is because growth hormone is important for emotional wellbeing in adults)
- overall reduction in quality of life

If you have been diagnosed with a pituitary condition and have symptoms from the list above, you should talk to your endocrinologist or endocrine nurse about being tested for growth hormone deficiency.

How is AGHD diagnosed?



If you have symptoms of AGHD and have reason to believe you may have this condition (for example, you have an existing pituitary condition or have had radiotherapy in the past) it is important to get tested. In the UK, if your wellbeing and quality of life are affected, you will likely be tested for AGHD.

If you are deficient in other pituitary hormones, it is very likely that you will also have a growth hormone deficiency.



Testing for growth hormone deficiency

You will have blood tests to see if you have low levels of growth hormone. Growth hormone levels are often measured by having a blood test, called an **IGF-1 test**.

IGF-1 tests

Insulin-like growth factor 1 (IGF-I) is a protein in the blood. The amount of IGF-1 your body makes is partly dependent on how much growth hormone is produced. This means that if you have low growth hormone levels, your IGF-1 levels may also be low.

It can be hard to record your IGF-1. This is because growth hormone levels cannot be recorded during most of the day. Throughout the day, small “pulses” of growth hormone are released that only last for a short period of time. Also, most of these small ‘pulses’ of growth hormone happen when you are sleeping, which makes it even harder to measure them.

An important note on the IGF-1 test

As well as growth hormone, lots of other things can affect IGF-1. Your metabolism and what you eat can affect it, and it drops naturally as you age. This means that while the IGF-1 test is important, a low IGF-1 test on its own cannot accurately diagnose AGHD. It is therefore important that you also have a **growth hormone stimulation test** if you are being tested for AGHD.

If you are deficient in other pituitary hormones, it is very likely that you will also have a growth hormone deficiency.

Growth hormone stimulation tests

As it is hard to measure growth hormone levels, your pituitary gland needs to be stimulated to measure how much growth hormone it makes. This is called a **growth hormone stimulation test**, or **dynamic function test**.

There are many different types of growth hormone stimulation tests used to diagnose AGHD. Each test involves using drugs to stimulate the pituitary gland to release growth hormone.

The most common tests involves injecting you with **insulin** or **glucagon**. You may instead be given a drink containing a drug called **macimorelin**.

Once you have been given the injection or drink, you will then have repeated blood tests over a few hours. These blood tests can measure how much growth hormone is released after stimulation.

It is important to know that not all endocrine departments do growth hormone stimulation tests. If you have the symptoms above, and your endocrine department does not do these tests, you should be referred to a pituitary department that is able to do this. You can speak to your endocrine team about this.

Treatment for AGHD



Treatment is available for AGHD but you must meet certain criteria to be able to have it.

Who can be treated?

You will generally be offered treatment if you meet the following criteria:

- You have been tested for AGHD and are **deficient in growth hormone**
- If you are deficient in any other pituitary hormones, you must be **on treatment to replace these hormones and have stable levels of these hormones for at least three months**
- There is a questionnaire called the **Adult Growth Hormone Deficiency Assessment (AGHDA)**. The AGHDA consists of 25 questions about your quality of life, and you will need to answer “yes” or “no” to each question. If your AGHDA results show that you have a low quality of life, you may be treated for AGHD

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What does treatment involve?

AGHD is treated with growth **hormone replacement therapy called somatropin**. This is a man-made version of growth hormone.

You will be given growth hormone through injections that you inject yourself. You will normally inject your inner thigh or tummy with an injection pen device every night.

The injection pen device is similar to the injections used by diabetic patients. The needle size is very small and thin. It is usually only half a centimetre in length.

The amount of growth hormone you will be injected with every day is also very small. Adults are normally given a starting amount (dose) of 0.2–0.3 milligrams of growth hormone each day. 1 milligram is 1000 times smaller than 1 gram.

If you have active cancer, you will not be given growth hormone. This is because IGF-1 causes growth and may cause cancer cells to grow.

How will I know if treatment is working?

Throughout your treatment, you will have appointments at an endocrine clinic. You will have many appointments during the first nine months of treatment.

At these appointments, you will have blood tests to check your response to treatment. Your growth hormone dose may also be adjusted based on your blood test results and your symptoms.



Checking your IGF-1 levels during treatment

IGF-1 levels cannot be used alone to diagnose AGHD. However, your IGF-1 levels should be checked often during treatment. This is because IGF-1 levels are used to work out how much growth hormone you should be taking, and if your dose is right for you. When starting treatment, your IGF-1 will probably be checked every few weeks. Once stable, it will be checked around once a year.

If you are taking the right dose of growth hormone, **your IGF-1 level should be in the middle or upper part of the normal range.** If your IGF-1 levels are high while you are taking growth hormone injections, this can mean your growth hormone dose is too high.

Possible side effects of treatment

You may experience the following side effects while taking growth hormone:

- soreness, redness or bruising by the injection site
- joint pain
- swelling in parts of your body, like hands and feet (known as fluid retention, or oedema)
- carpal tunnel syndrome, which is a condition that causes pain, tingling, and numbness in your fingers and hands
- increased insulin resistance, which may cause tiredness, hunger, thirst, skin tags and weight changes

If your growth hormone dose is too high, it can cause high IGF-1. Your blood tests will pick this up. If you experience any of the side effects above, this can be a sign that your dose is too high.

What if I forget to take my treatment?

It is important to try and remember to have your injections regularly. If you have missed your growth hormone injections before your blood test, your IGF-1 levels can be low.

If you do miss an injection, you should take your dose when it is next due. You should also let your clinician know at your next appointment. This is so they can accurately work out your results and treatment plan.

You should let your clinician know if you have missed any growth hormone injections.

Continuing treatment

After you have had treatment for nine months, you will be asked to complete the AGHDA questionnaire again. This is to see if growth hormone replacement has improved your wellbeing.

Your endocrine clinic will review your AGHDA and blood test results. These results will then help decide if you should continue taking growth hormone replacement or not.

If there has been no improvement in your blood test results or AGHDA, you will stop your treatment. It is very unusual that this happens. If you continue to have a good reaction to treatment, you will likely take growth hormone replacement for the rest of your life.



I had not heard of growth hormone until I was tested for this, eight years after my pituitary surgery.

Injecting subcutaneously each night was much easier than I expected. After 3 months from starting growth hormone replacement, I wasn't sleeping every afternoon and slept better at night – and I was dreaming again! I also noticed my body shape improved, my energy returned and I actually felt “me” again.

Growth hormone, for me, was the ‘cherry on top of the trifle’ – layers of other hormones replaced, but this completed it, thankfully.

Pat was diagnosed with hypopituitarism and has taken growth hormone for 32 years.

Support during treatment



Treatment for AGHD is usually given with support from an endocrinologist and endocrine nurse. Your endocrine team will support you throughout your treatment and answer any questions you may have.

When you start your treatment, an endocrine nurse will teach you how to use your injections. You may also be offered a free 'home service' for your growth hormone treatment. This free home service can deliver a treatment starter pack to your home. This includes your injection pen device, needles, and boxes to store used needles. You may also get access to information on your growth hormone treatment.

Home service can also deliver your growth hormone treatment to your home on a regular basis. This means you will not need to see your GP practice or chemist for repeat prescriptions each month.



Most home services also have a helpline. You can ring this helpline if you have any questions about your treatment. This could be for things like needing a new supply of needles or if your pen device is not working.

AGHD treatment for adults under 25

During childhood, growth hormone is needed for your bones to grow. Your bones keep growing until you reach your final height. After this, growth hormone is still important as it helps your bones become stronger.

Growth hormone continues to strengthen your bones until around the age of 25. At this point, your skeleton will have reached full growth and maturity. This is called **peak bone mass**.

Growth hormone is important to help you reach peak bone mass. Therefore, if you are under 25 years old and have growth hormone deficiency, you should have treatment until you reach peak bone mass. You will not need to do an AGHDA questionnaire to have treatment. Your bone mass will be measured with a **bone mineral density** scan. This is a painless scan that measures bone density using X-rays.

In adults older than 25 who have reached peak bone mass, growth hormone treatment is only continued if your quality of life is impacted. In particular, if your energy levels are affected you may have treatment. You will need to complete an AGHDA questionnaire to see if your quality of life is impacted enough to need treatment. The results of your AGHDA, as well as your blood tests, will be used to work out if continuing treatment is right for you.

Common questions about treatment



I have previously had cancer. Can I take growth hormone?

You cannot take growth hormone if you have active cancer that is being treated. If you had cancer in the past that is now in remission, you should be able to have growth hormone. Your endocrinologist will help decide this.

Can I take growth hormone while pregnant?

There is no data to show if growth hormone is safe to take during pregnancy. It is thought that taking growth hormone while pregnant is not needed, because the placenta makes a lot of growth hormone. Standard advice is that growth hormone should be stopped after a positive pregnancy test. You should speak to your GP or endocrine team if you want to become, or are, pregnant.

When should I take growth hormone?

Most people take their growth hormone before bedtime. If you work night shifts, you can take your growth hormone before you go to sleep.



Will growth hormone cause my pituitary tumour to grow bigger, or grow back?

No, this is not likely to happen. Research data has shown that growth hormone treatment does not cause pituitary tumours or craniopharyngiomas to grow.

Should I continue taking growth hormone into old age?

In a normal person, growth hormone levels do decline with age. As you get older, your endocrinologist may look at reducing your dose, or stopping treatment. If growth hormone treatment is still helping your quality of life, you will likely keep taking as you age.

Notes

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More information

We have a full range of booklets to support people with their pituitary conditions, as well as information across our website. You can find this at www.pituitary.org.uk.

If you would like more support then we have a range of services that may be suitable:



Scan to see our website

Endocrine Nurse Helpline

Our specialist endocrine nurses can provide medical guidance.



Information and Support Helpline

Our volunteer- and staff-run helpline allows you to speak to others with pituitary conditions, and ask practical questions about living with a pituitary condition.



Telephone Buddy

This service provides one to one support with someone with a similar pituitary journey as you. For example someone with the same condition, or a parent of someone with a condition.



Support Groups

We have a number of volunteer-led support groups across the UK, which host meetings with endocrinologists and provide peer support for patients.



Events

We host online and in-person events with endocrinologists on specific conditions and topics. These give people the opportunity to hear from professionals and ask questions.



Psychological Support

You can find out more about our psychological support services on our website.



About

The Pituitary Foundation

We're a dedicated team offering practical, emotional and peer support to everyone living with or impacted by a pituitary condition, to feel empowered and live with a greater sense of wellbeing.

For over 30 years, we've been amplifying voices and striving towards positive developments for the pituitary community. We work alongside healthcare professionals, clinical research teams and specialist organisations to raise the profile of pituitary conditions, finding better solutions for everyone affected by these life changing illnesses now and in the future.

Become a member and support our work

Becoming a member is an excellent way to show your support for our work at The Pituitary Foundation.

As a member, you'll enjoy a range of benefits including free copies of Pituitary Life magazine – full of great articles from endocrinologists and inspiring stories from people living with pituitary conditions. You'll also be able to have a say on how the charity is run, and get early access to our fantastic events.

A yearly donation of £25 allows us to continue our work now and in the future.

You can become a member at: www.pituitary.org.uk/membership

Have you found this booklet helpful?

If you have found this booklet useful, please help us to create more by donating to us. Your donation will help make sure more people can access the information they need to live well with a pituitary condition.

Scan here
to donate!



All information in this guide is general. If you have any concern about your treatment or any side effects please read the Patient Information Leaflet enclosed with your medication, or consult your GP or endocrinologist.

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This booklet was produced in collaboration with medical experts and patients with lived experience of pituitary conditions. All information has been verified as accurate by clinicians from our Medical Committee. This booklet holds the PIF TICK quality mark for health information.

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