



# An Introductory Guide to Acromegaly

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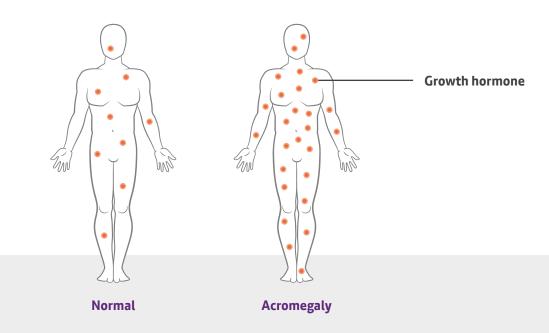
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# An Introductory Guide to Acromegaly

## What is acromegaly?

Acromegaly is caused by an **excess of growth hormone**. In most cases, this excess growth hormone is caused by a growth of the cells in the pituitary gland that produce growth hormone. The growth is known as pituitary adenoma which is a benign tumour that doesn't spread to other parts of the body.



Hormones are chemical substances that act like messengers in the body. Once made in an area of the body, they travel to other parts of the body and control how cells and organs work.



#### Where is the pituitary?

The pituitary gland dangles just below the brain, near the back of the nose.

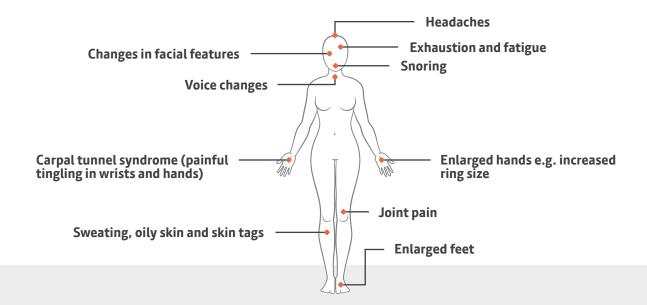
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### What are the symptoms?

The signs and symptoms of acromegaly can be caused by two things:

#### 1. Excess amount of growth hormone produced by the benign tumour

- ➡ Growth hormone travels round the body and causes the liver to produce a substance called Insulin-like Growth Factor 1 (IGF-1).
- In someone without acromegaly, IGF-1 helps with growth, influencing how the body uses and stores protein, carbohydrate and fat. But when there's too much of it, it can cause some changes to the body appearance and also some symptoms.



**Please note:** The symptoms of acromegaly can vary in terms of presentation and severity from person to person – and the list shown here is not exhaustive.

#### What is IGF-1?

Pronounced "eye-gee-eff one", IGF-1 is the short name for a hormone called Insulin-like Growth Factor 1. This hormone is measured with a blood test. Blood tests for IGF-1 are a key way to keep track of acromegaly and how it's responding to treatment. Whereas levels of growth hormone naturally go up and down throughout the day (in response to food and drink consumed), IGF-1 remains fairly constant throughout the day.

## What are the symptoms?

#### 2. The benign tumour located near the brain and optic nerves

Because the pituitary gland sits right under the brain and next to the optic nerves (which send signals from the eyes to the brain) a pituitary adenoma can cause:

#### ➡ Headaches

These can vary in intensity and duration, and may be much more severe than regular headaches.

#### ⇒ Problem with vision

The pituitary adenoma can grow and could sometimes put pressure on the optic nerves, causing loss of peripheral vision that may be reversible with treatment.

#### ⇒ Changes in normal levels of other hormones

As well as producing growth hormone, the pituitary gland also produces several hormornes essential for maintaining appropriate levels of other hormones in your body.

These hormones have roles in supporting the thyroid (and rate of metabolism), sex drive and fertility, among other things.

## How is acromegaly diagnosed?

If acromegaly is suspected, the patient is usually referred to a centre with expertise in acromegaly. This centre is usually an Endocrine clinic. An endocrinologist and/or specialist nurse will carry out an assessment, explore your symptoms and if appropriate, perform a **blood test** which usually measures the levels of growth hormone and IGF-1 in your body.

If acromegaly is suspected following the comprehensive assessment and initial blood test, an **oral glucose tolerance test (OGTT)** may be needed to confirm the diagnosis.

If a patient is found to have acromegaly, the healthcare professional will order **further tests and scans** to determine to what extent the pituitary gland has been affected as well as the size and location of the benign pituitary tumour.

The size and location of the benign pituitary tumour is assessed by an **MRI (Magnetic Resonance Imaging) scan** which takes detailed pictures of the brain.



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## What are the treatment options after diagnosis?

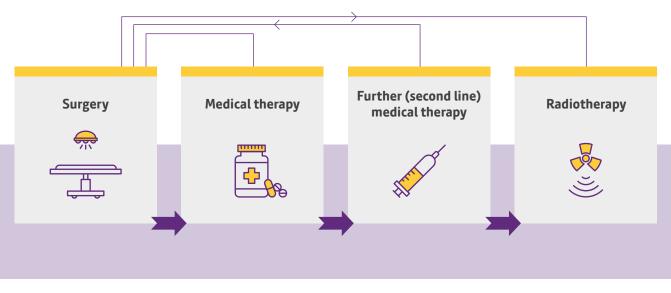
While acromegaly is considered to be a life-long condition and can seriously affect the lives of the people who have it, currently available treatment options allow most people with acromegaly to keep their condition under control.

Following confirmation of the diagnosis of acromegaly and the location of the benign tumour, the first line treatment for people with acromegaly is usually surgery to remove the tumour. Surgery can offer a possible cure of the disease in some cases. However, in cases where surgery has not been successful or is contra-indicated, other options of treatment include medications (tablet or injection), radiotherapy or combination of both.

To reduce the impact of symptoms, the main aims of acromegaly treatment are to:

- **1.** Reduce the levels of growth hormone and IGF-1 in the blood.
- 2. Reduce the size of the benign pituitary tumour.

#### Treatment



#### Main types

Transsphenoidal (or rarely craniotomy if indicated)

Dopamine agonist (bromocriptine)

SSA (somatostatin analogues), octreotide or lanreotide

Growth hormone receptor antagonist (pegvisomant)

Second generation SSA (pasireotide)

Conventional radiotherapy or stereotactic radiosurgery



In general, people with acromegaly will move from one step to the next if treatment goals are still not met or side effects aren't acceptable. However acromegaly treatment is not linear in all cases and will be individualised or similar.

A second surgery might be recommended if the first attempt was not successful in either removing all the tumour or controlling the disease (remission). If further surgery is not appropriate, medical therapy and/or radiotherapy may be recommended as part of the ongoing treatment.