

Patient information

Acromegaly

Diabetes and Endocrinology Department

What is Acromegaly?

The name acromegaly comes from the Greek words for extremities and great, and reflects one of its most common symptoms, the increase in size of the hands and feet. Acromegaly usually occurs as a result of chronic excess growth hormone production from your pituitary gland.

What does growth hormone do?

Growth hormone affects all the organs in your body. It ensures that children grow and develop at the correct rate and it maintains wellbeing in adults.

What causes acromegaly?

Some of the cells in the pituitary gland, which normally produce growth hormone, start to divide more rapidly than normal. Continued growth of these cells ultimately results in the development of a benign (non-cancerous) pituitary tumour.

If there is a tumour, have I got cancer?

No - in more than 99% of cases, acromegaly is caused by a benign (non-cancerous) tumour in the pituitary gland. These tumours grow very slowly within the pituitary gland. Patients with acromegaly have often had the condition for many years before diagnosis is made.

If I don't have cancer why do I need treatment?

Although the tumour is not cancerous, it is important that you receive treatment in order to reduce the amount of growth hormone produced. Untreated acromegaly will increase your risk of developing heart disease, strokes and bowel cancer.

How common is acromegaly?

This condition is rare, with approximately four to six out of every million people being diagnosed each year. Forty to sixty out of every million people suffer from the condition at any time. It affects men and women equally, and in most cases is not hereditary. The majority of patients are diagnosed between the ages of thirty to fifty.

What symptoms does acromegaly cause?

Most common is the increase in size of hands, feet and other 'soft tissues' such as your lips, nose and ear lobes. You may develop a more prominent lower jaw and your teeth can become more widely spaced.

Headaches can be troublesome and are due to the tumour causing an increase in pressure on the surrounding brain tissue.

You may have some loss of vision, especially at the edges of your field of vision. This is because the tumour is pressing on the nerve which sends signals from the eye to the brain. Other problems include profuse sweating, snoring and sleep disturbance, acne, high blood pressure and type two diabetes mellitus.

Are there any other problems acromegaly may cause?

Along with growth hormone the pituitary gland produces hormones responsible for the correct output of thyroxine, testosterone or oestrogen and cortisol. Pressure from a tumour on the normal pituitary tissues can cause an alteration in the production of these other hormones. If this happens you will develop symptoms of deficiency which include tiredness, weight gain and menstrual problems for women, men may find they need to shave less often. Both sexes may report a reduced sex drive and a general lack of interest in daily life.

How is acromegaly diagnosed?

Growth hormone is secreted in spurts, its concentration in the blood varying widely from minute to minute so a single measurement of blood growth hormone level is not enough to diagnose acromegaly. A more accurate method is to have a glucose tolerance test.

Glucose Tolerance Test

This test involves you having a series of blood samples taken before, and after, a sugary drink. A high level of blood sugar should lower growth hormone levels. If you have acromegaly your growth hormone levels will remain high throughout the test.

You will generally have a clinic appointment soon after the test so that your results can be discussed with you. If the diagnosis is confirmed, you will have further blood tests to see if any of the other pituitary hormones have been affected.

What other tests may I have?

Magnetic Resonance Imaging (MRI) or Computed Tomography (CT) provides information about the exact location and size of the tumour. Both of these are scans of your head. The scans do not hurt but you will need to be inside the scanner for about half an hour, which can make some people feel claustrophobic.

What treatment will I be given?

Currently three treatments for acromegaly exist - surgery, radiotherapy and drug therapy.

- **Surgery** - is the first stage for many patients, and is performed at the Walton Centre NHS Foundation Trust.

If the surgery is successful, facial appearance and soft tissue swelling will resolve within a few days.

It can also ease some of the other problems caused by the tumour such as headaches and visual disturbance. The success rate depends on the size of the tumour and level of growth hormone before the operation.

- **Radiotherapy** - is usually offered to patients who have some tumour remaining after surgery. Radiotherapy is usually given in divided doses each day for five weeks.

After radiotherapy, the damaged tumour cells slowly die. It may take several years before your growth hormone levels are back within normal range. Radiotherapy can lead to loss of production of other pituitary hormones. You will be checked regularly for this by blood tests taken at clinic. Occasionally you may need in depth tests to check your hormones. These will usually be in the investigation unit at the Royal Liverpool University Hospital; they can sometimes be performed at your local hospital depending on which hospital you were first referred from

- **Drug therapy** - you may be treated with either tablets (dopamine agonists) or injections (somatostatin analogues or growth hormone receptor antagonists).

As some of these drugs are specialist use only, they are often only available on prescription from the endocrine team here at the Royal Liverpool Hospital

Please remember that no single treatment is effective for all patients.

What happens to me with the treatment?

The aim of each of these treatments is to bring down the raised growth hormone levels to less than 0.4ug/l. If this happens some of the changes in your appearance (bigger fingers, lips, nose etc.) can be reduced and may even return to normal.

Some patients may notice these changes within a few days if the growth hormone level has been reduced by surgery. Over time symptoms of sweating and high blood pressure may decrease. Your headaches will usually improve, as can problems with your sight. It takes a little longer for you to notice changes with the tablet or injection treatments.

What happens after these treatments?

People with acromegaly may develop loss of normal pituitary function either because of the tumour or its treatment. This means that patients need to be assessed over their lifetime to check for this.

Regular blood tests will be done to check your growth hormone levels and also to check that the pituitary gland is working properly. If any of your hormone levels are below the normal range, you will need to take replacement hormones such as hydrocortisone, thyroxine, oestrogen and testosterone. These work very well and we have information leaflets on each hormone to help you understand about these replacements.

You will need to attend clinic at least every six months so that the doctors can check on your progress and review the treatments that you are taking. Your clinic visits can be to both the Royal Liverpool University Hospital and to the Walton Centre NHS Foundation Trust.

This means both the Endocrinologist and Neurosurgeon can monitor your condition. You may find that your treatment is changed at some clinic visits. This can be because you are improving and so medication doses can be reduced. It can sometimes be an increase in dose or change of drug if your growth hormone level isn't well controlled. Any changes made will be monitored through the clinic.

Will I be cured?

Currently a cure would be defined as growth hormone levels less than 0.4ug/l on glucose tolerance testing. Generally patients will reach this five to seven years after starting treatment, but it can take longer.

Even when tests have shown your growth hormone to be at this level you will continue with your regular clinic visits.

Feedback

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

Further Information

Please feel free to contact the Endocrine Specialist Nurses with any questions you may have. There is an answer machine where you can leave your name and contact details. We will return all calls.

The Endocrinology Specialist Nurses

Tel: 0151 706 2417

Text phone number: 18001 0151 706 2417

Related Patient information leaflets:

- **Medical treatments for acromegaly (PIF 1057)**
- **Trans-sphenoidal surgery (PIF 249)**
- **Pituitary radiotherapy (PIF 1062)**
- **Colonoscopy for patients with acromegaly (PIF 991)**

There is also a very good patient support group, which offers excellent advice via leaflet and telephone contact. They also hold local area group meetings.

**National Support Office
The Pituitary Foundation
86 Colston Street
Bristol
BS1 5BB
Tel: 0117 370 1320
Email: helpline@pituitary.org.uk
www.pituitary.org.uk**

**Author: Diabetes and Endocrinology Department
Review date: March 2026**

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