Seeing differences

Pfizer

A Guide to Living with Acromegaly

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A Guide to Living with Acromegaly

Important note: acromegaly and its impact is as unique as you are – just because something is listed here, it doesn't mean that it will impact you. Please speak with your healthcare team about which conditions and management approaches may be relevant to you.

What is acromegaly?

Acromegaly is caused by an excess of growth hormone in the body. In most cases, this 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.

The effects of acromegaly

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

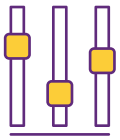
- Causes the body to produce an excess of a substance called Insulin-like Growth Factor 1 (IGF-1).
- IGF-1 helps with growth and influences how your body uses and stores protein, carbohydrates and fats. But when there is too much of IGF-1 and growth hormone, it can cause several changes to the body including: headaches, changes in facial features, fatigue, voice changes, painful tingling in wrists and hands, enlarged hands, and joint pain.

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

- Headaches
- Problems with vision
- Changes in normal levels of other hormones

Although a high proportion of people with acromegaly can achieve stable control of the pituitary adenoma with treatment, the condition is considered lifelong. So even with successful treatment, on-going check-ups are likely to be recommended.





Check-up overview 1/2

A summary of the variety of different regular and periodic check-ups you might need to help you manage your acromegaly and any related conditions you might get as a result of it.

Recommended test/ assessment	Recommendations
Sleep check	Questionnaire about any daytime sleepiness (Epworth sleepiness scale), or undergo an overnight sleep study, at diagnosis or before surgery.
Echo (echocardiogram) + ECG (electrocardiogram) checks for heart health	➡ At diagnosis ➡ Every year, if abnormal
Bowel check	Colonoscopy: Every 10 years; more frequently if IGF-I remains persistently elevated or if abnormal colonoscopy or family history of colon cancer.
Quality of life check	AcroQol questionnaire to aid identifying specific factors for follow up* (or equivalent quality of life assessment tool): Every year.
Eye test	When required, where tumour affects the Optic nerve.
Blood pressure check	➡ At diagnosis ➡ Every 6 months ➡ When any antihypertensive (treatment for high blood pressure) is changed

Please note that the above tests and assessments are recommendations based from national and international guidelines. The types, availability and frequency of these tests/assessments will vary according to the institution and also according to patient's condition and needs.

*AcroQol questionnaire: acromegaly quality of life questionnaire. A measure used to monitor the quality of life of patients with acromegaly.

Check-up overview 2/2

A summary of the variety of different regular and periodic check-ups you might need to help you manage your acromegaly and any related conditions you might get as a result of it.

Recommended test/ assessment	Recommendations
Blood tests	➡ IGF-1 check: At diagnosis, throughout treatment and periodically thereafter ➡ Glucose check: Blood test for glucose every 6 months if your IGF-1 levels are above normal, you're having certain types of acromegaly treatment, or you have diabetes ➡ Cortisol check: You might need a blood test at 8-9am if your healthcare team think you might have an insufficiency of cortisol-stimulating hormone
Scans	➡ MRI/CT (Magnetic Resonance Imaging/Computed Tomography) scan at diagnosis, around surgery and every 1-2 years to check pituitary adenoma ➡ DEXA (Dual-energy x-ray absorptiometry) scan to check bone mineral density, every 2 years (particularly if osteoporosis is present) for those at risk of sustaining fragility fracture and those with active disease despite treatment

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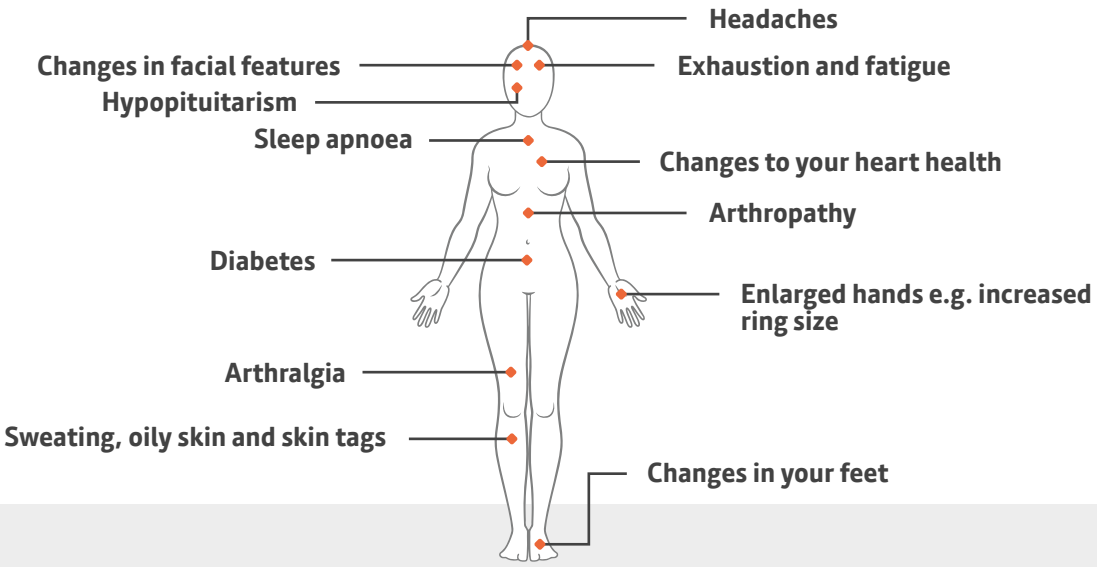
Potential complications associated with acromegaly

Patients with acromegaly would require life-long monitoring as even those with controlled disease (in remission) are potentially at risk of developing other health-related issues and complications. Those with active disease, despite multiple treatments, are at particular risk of developing complications and should continue their on-going engagement with their healthcare professionals to manage any potential health-related issues.



Diabetes

Having acromegaly can put you at increased risk of developing problems with the way your body processes glucose (sugar), such as insulin resistance and type 2 diabetes (T2D).

How common are these problems?

Of every **10** people with acromegaly, **2 to 5** will also **develop type 2 diabetes**.

➡ **What can I do about this?** It's important that your acromegaly, growth hormone, and IGF-1 levels are managed and controlled, as doing this can prevent or reduce other health problems such as type 2 diabetes. Please discuss this and any other concerns you may have with your healthcare team, who will recommend the best approach to take in your circumstances.

Long term implications

Body changes

Acromegaly can cause your body to change shape, particularly around your hands, feet, your nose, cheekbones, forehead and lips. Your skin may also become more sweaty (especially at night), oily and thickened, and you might frequently grow skin tags.

How common are body changes?

Body changes and swelling are common with acromegaly, especially if the condition has been undetected for several years. Around **7** out of every **10** people with acromegaly **have skin changes**.

➡ **What can be done about it?** Acute direct complications of acromegaly may decrease with treatment - bringing your growth hormone level down and getting your IGF-1 levels into the normal range for your age and gender gives you the best chance of achieving this.

Cardiovascular risks

You might have an enlarged heart (known as myocardial hypertrophy), changes in your heart structure and the way your heart pumps blood round your body, and/or high blood pressure (known as hypertension). These can all lead to potentially serious complications, such as heart failure, and so will need to be monitored and treated appropriately.

How common are heart problems?

Of every **10** people with acromegaly, around **half** have an abnormal heart beat; **3** in every **100** people with acromegaly may get heart failure.

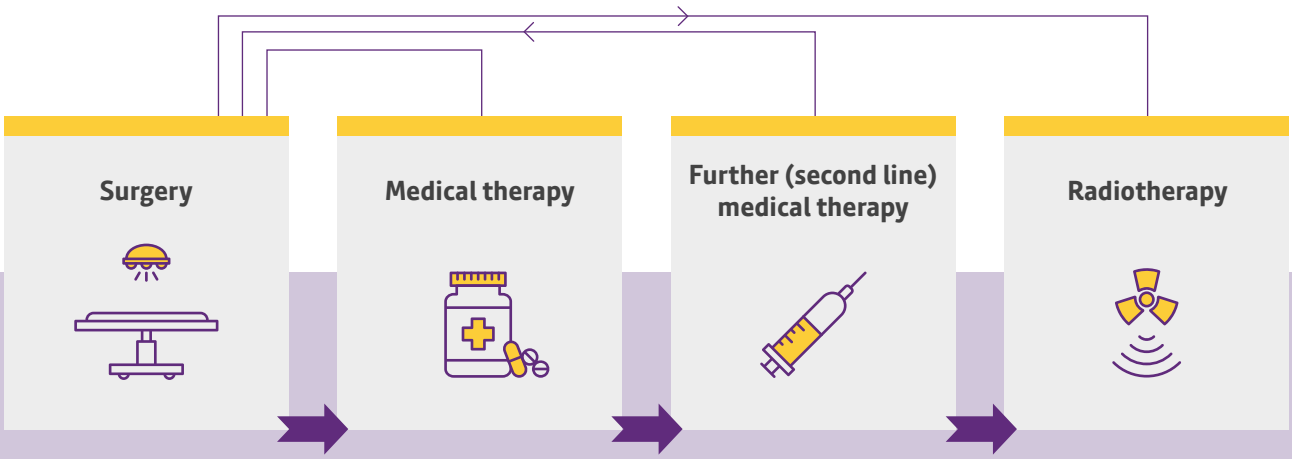
➡ **What can be done about it?** Although some changes in heart structure may be permanent, many of the heart problems associated with acromegaly can improve with successful treatment and control of growth hormone and IGF-1 levels. Your GP/family doctor, cardiology and endocrinology healthcare teams will discuss this with you and any further treatment you may need – for example, to help bring your blood pressure down.

Treatment

Treatment goals

1. Removal of the pituitary adenoma
2. Maintaining normal pituitary function
3. Normalising growth hormone and IGF-1 levels
4. Minimising acromegaly symptoms
5. Managing and preventing related health conditions

Treatment options



Main types

Surgery	Medical therapy	Further (second line) medical therapy	Radiotherapy
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.

Wellbeing

Mental health

Supporting your emotional wellbeing

What are the possible problems?

Living with acromegaly and its symptoms, let alone going through all the different types of health checks and treatments as mentioned in this guide, can be overwhelming. Some people may suffer from mental health problems such as depressions, anxiety and low self-esteem.

Why can this happen?

Acromegaly and its management in itself is a source of considerable emotional strain; furthermore the changes in hormones caused by the condition and its treatment may impact thinking ability, personality and behaviour.

What are the symptoms?

Mental health problems affect everyone differently, for example, you might feel sad, anxious or panicky, more tired than usual, hopeless, angry, or experience depression.

How is it monitored?

Your healthcare team may ask you to complete a questionnaire when you are diagnosed, and as needed thereafter. Sometimes referred to as AcroQol (acromegaly quality of life), the questionnaire asks about the impact of both physical symptoms and psychological symptoms on quality of life day to day.

What can be done about it?

If you feel your mental wellbeing is suffering in a way that's overwhelming you, it's important to consider professional help. Your GP/family doctor, or any of the members of your wider healthcare team may be able to refer you for an appointment with a psychiatrist or health psychologist. They can help assess whether you may need further psychological treatment, which can come in the form of either medication and/or talking/ cognitive behaviour therapies.