

Acromegaly and health

A guide for people with acromegaly

Knowing what's going on is a key step in finding solutions



You might have initially felt relief when you were diagnosed with acromegaly. Or, if the diagnosis was sprung on you without any warning signs or symptoms, you might have felt the opposite.

Either way, finding out that you have acromegaly was important in enabling you to get treatment.

This guide will quickly recap what acromegaly is, how it impacts your body and your health in general, and how this knowledge can help you get the support you need, when you need it.

There's no denying that learning to live well with acromegaly can be a long process. But hopefully, together with the rest of the Acroline™ series, this guide will provide a helpful map to support you along the way.

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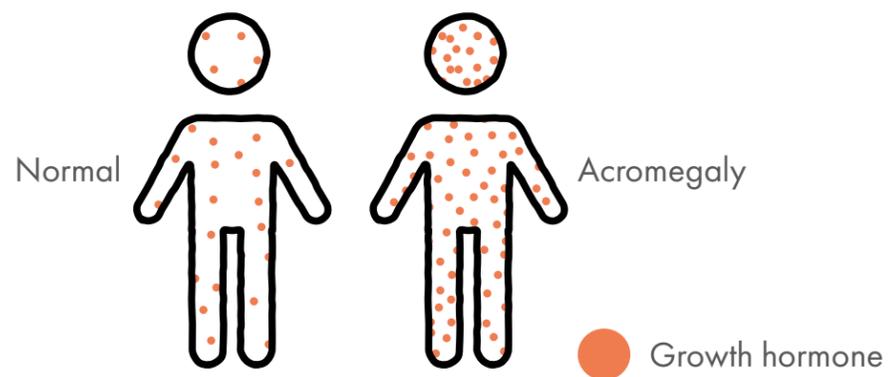
Important note: Your body's response to acromegaly will be as unique as you are. Just because something is listed here, it doesn't mean that it will impact you. Please speak with your healthcare team about which conditions and management approaches may be relevant to you.

What is acromegaly?

A reminder of the cause, signs, and symptoms of the condition

It's mainly about growth hormone

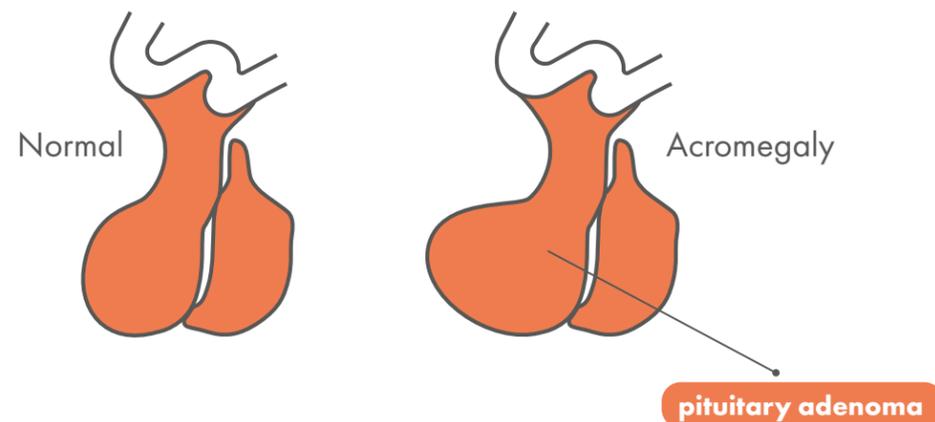
Acromegaly is caused by an excess of growth hormone.



HORMONES

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.

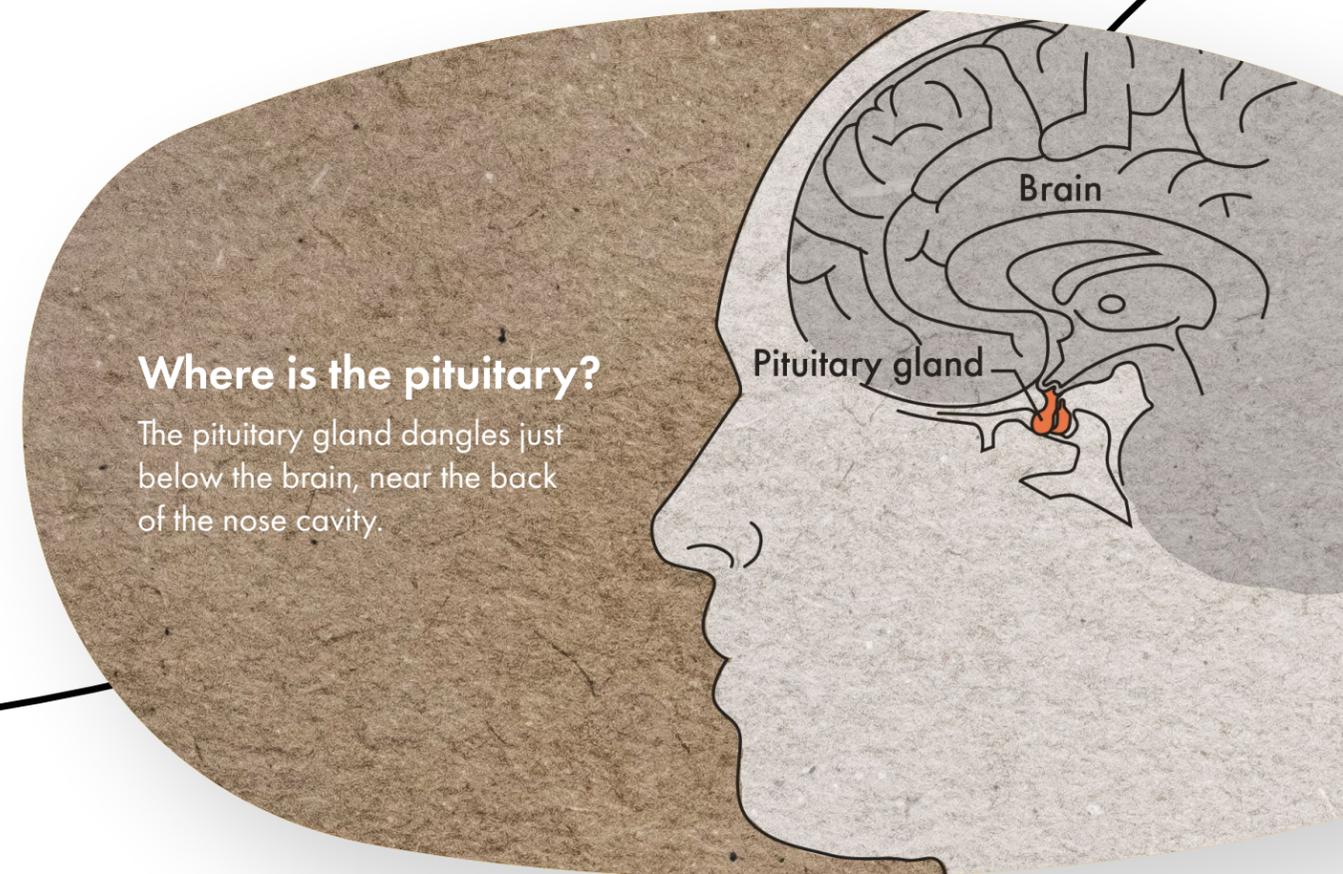
In most patients diagnosed with acromegaly, this excess of growth hormone is caused by an overgrowth of tissue in the pituitary gland.



This **tissue overgrowth** is known as a pituitary adenoma (a kind of benign tumor that causes acromegaly but doesn't spread to other parts of the body).

Where is the pituitary?

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



What impact can acromegaly have?

Acromegaly can cause signs and symptoms due to 2 things:

1. Having too much growth hormone
2. Having a tissue overgrowth near the brain and optic nerve (that sends signals from the eye to the brain)

1. What too much growth hormone does to the body

Growth hormone travels around the body and causes it to make a substance called IGF-I (short for insulin-like growth factor I).

Growth hormone causes IGF-I to be made

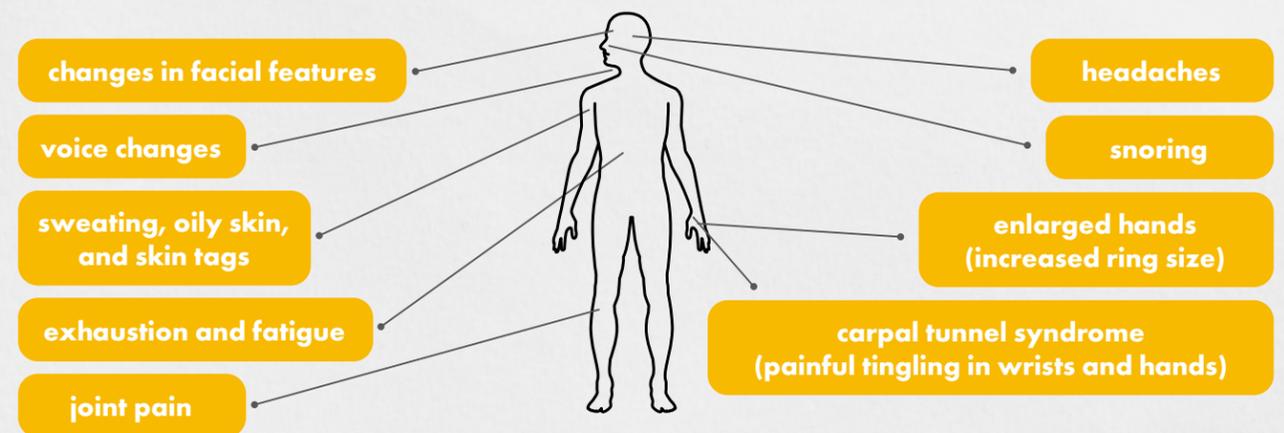
Growth hormone



IGF-I



In someone without acromegaly, IGF-I helps with growth, influencing how your body uses and stores proteins, carbohydrates, and fats. But when there's too much of it, it can cause many body changes and symptoms:



Please note: The symptoms of acromegaly can vary from person to person and the list shown here is not complete.

What is IGF-I?

Pronounced eye-gee-eff one, IGF-I is the short name for a hormone called insulin-like growth factor I. It can be measured with a blood test. Blood tests for IGF-I 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-I remains fairly constant throughout the day.

2. What a pituitary adenoma tissue overgrowth does

Because the pituitary gland sits right under the brain and next to the optic nerve, a pituitary adenoma can cause:



Headaches

- ▶ These can vary in intensity and duration and may be much more severe than regular headaches



Vision loss

- ▶ The mass of the pituitary adenoma can sometimes grow around the nerve connecting the eyes to the brain, causing loss of vision that may be reversible with treatment



Changes in normal levels of other hormones

- ▶ As well as producing growth hormone, the pituitary gland is also needed to help maintain appropriate levels of other hormones in your body
- ▶ These have roles in supporting the thyroid (and rate of metabolism), sex drive, and fertility, among other things

How long will acromegaly last?

Although a high proportion of people with acromegaly can achieve stable control of the pituitary adenoma with treatment, the condition is considered lifelong.

It will likely be recommended that you get periodic checkups throughout your life.

Please note: Coming to terms with the long-term nature of acromegaly, its treatment, and impact on your life can be tough. Please speak with your healthcare team if you are concerned in any way about how you will cope. They may be able to refer you to a health or clinical psychologist who can work with you to help talk through and manage your concerns.

Checkup overview

A summary of the variety of different regular and periodic checkups you might need to help you manage your acromegaly and any related conditions you might get as a result of it. You'll find more detailed information about each of these in the rest of the guide

Important note: Your body's response to acromegaly will be 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.

Sleep check

- ▶ Questionnaire about any daytime sleepiness, or undergo an overnight sleep study, at diagnosis or before surgery if your healthcare team thinks you might have sleep apnea (see page 32 for more information)

Blood tests

- ▶ IGF-I check: At diagnosis, throughout treatment, and periodically thereafter
- ▶ Glucose check: Blood test for glucose every 6 months if your IGF-I levels are above normal, you're having certain types of acromegaly treatment, or you have diabetes (see page 12 for more information)
- ▶ Sex drive/fertility/thyroid hormone check: Every year (see page 30 for more information)
- ▶ Cortisol check: You might need a blood test if your healthcare team thinks you might have an insufficiency of cortisol-stimulating hormone (see page 30 for more information)

Eye test

- ▶ To check your vision if your healthcare team thinks your pituitary adenoma might be affecting it (see page 34 for more information)

Blood pressure check

- ▶ At diagnosis (see page 24 for more information)
- ▶ Every 6 months
- ▶ When any antihypertensive (treatment for high blood pressure) is changed

Echocardiogram (echo) + Electrocardiogram (ECG) checks for heart health

- ▶ Cardiac evaluation may be needed (see page 24 for more information)
- ▶ Every year, if abnormal

Quality of life check

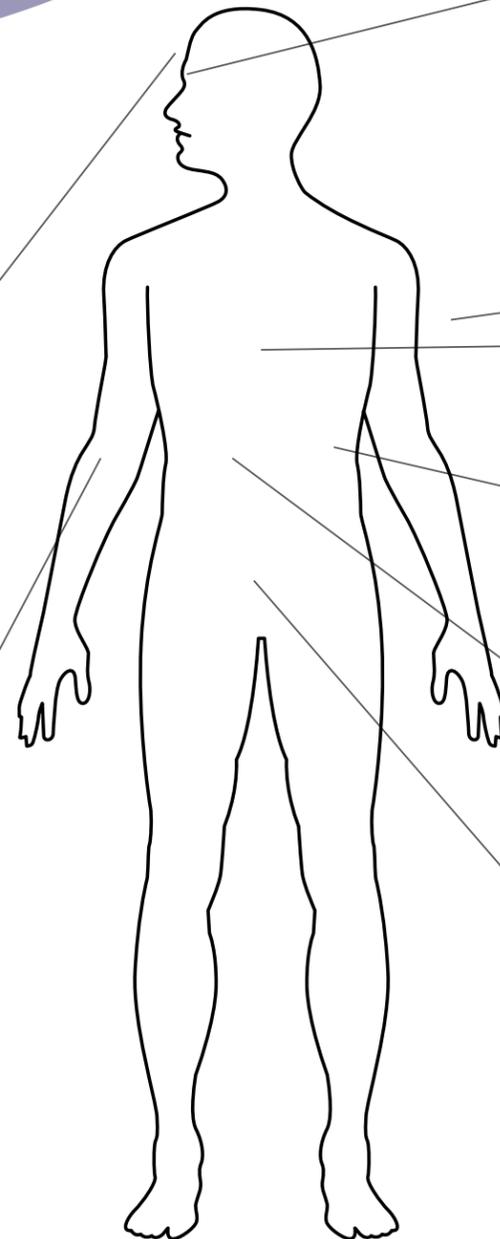
- ▶ Regular checkups with your doctor (see page 28 for more information)

Scans

- ▶ MRI/CT scan at diagnosis, around surgery, and periodically as needed to check pituitary adenoma

Bowel check

- ▶ Colonoscopy: Every 5 or 10 years, depending on IGF-I levels and presence of polyps (see page 20 for more information)



How can acromegaly impact health?

A detailed look into how acromegaly can impact your body and health in general, and what you can do about it.

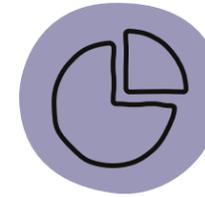
Blood sugar levels

Monitoring the way your body responds to and processes sugar



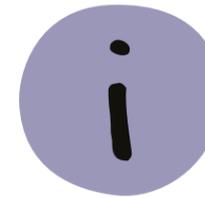
What are the possible problems?

Impaired ability to effectively process the glucose in the food and drinks you consume, usually because your body has developed a resistance to the hormone insulin.



How common are these problems?

Of every 10 people diagnosed with acromegaly, 3 to 5 will also have insulin resistance at a level that leads to diabetes.

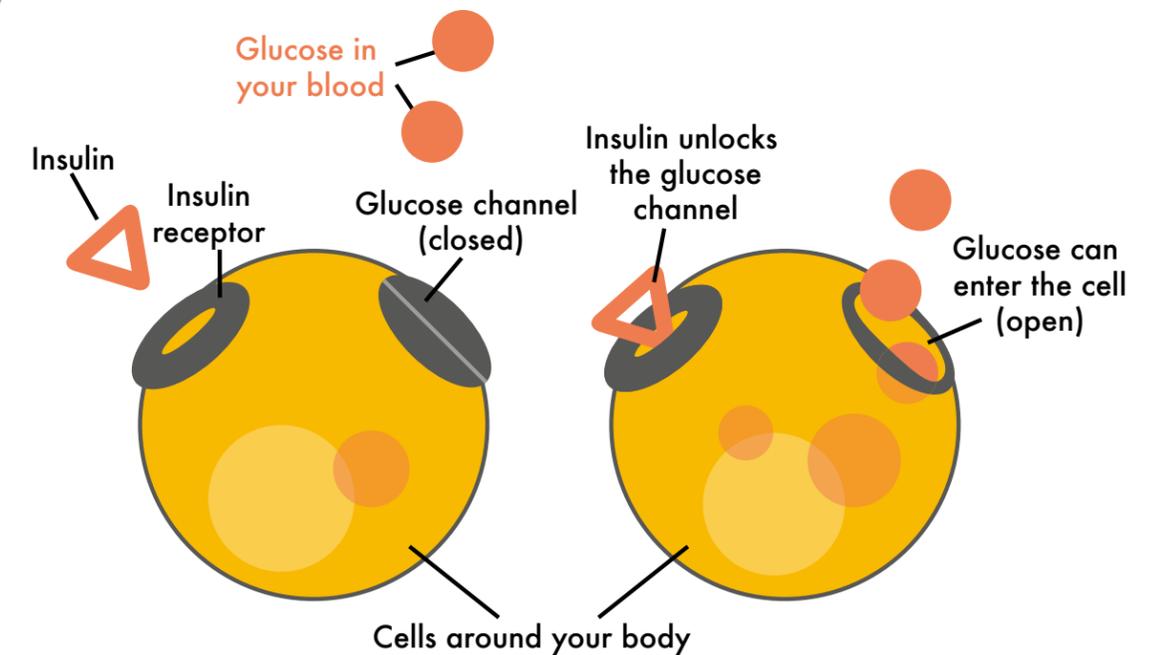


What is insulin resistance?

Insulin is a chemical messenger that tells parts of your body to absorb glucose. If you have insulin resistance, your body doesn't respond to insulin well enough, and so some glucose remains in your blood ([see page 24](#)).



How does insulin work?





Why can this happen?

An excess of growth hormone can be responsible for insulin resistance. Furthermore, some medical treatments for acromegaly can influence the way your body processes sugar.



How is it monitored?

If you might be at risk of insulin resistance and diabetes, or you experience symptoms of hyperglycemia, you'll have regular blood tests. These might test for fasting blood glucose, in which you'll need to avoid food or sugary drinks for 8 to 10 hours before the test, or HbA_{1c}, a marker in your blood that can show if your glucose levels have been high over time.



What can be done about it?

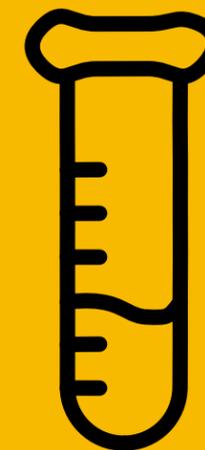
There are several ways to treat insulin resistance and diabetes. You and your healthcare team will discuss the best approach for you to take.



What are the symptoms?

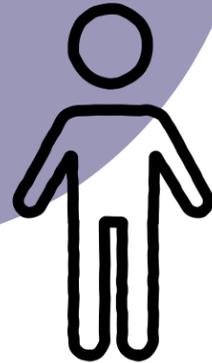
You might not experience any symptoms, though some common signs of too much glucose in the blood (hyperglycemia) are:

- ▶ Increased thirst
- ▶ A dry mouth
- ▶ Needing to pee frequently
- ▶ Feeling tired
- ▶ Blurry vision
- ▶ Losing weight unintentionally
- ▶ Getting infections again and again (such as thrush, cystitis, and skin infections)
- ▶ Stomach pain
- ▶ Feeling nauseous
- ▶ Breath that smells fruity



Body changes

Assessing the ways your body might have changed, and whether these changes may be short- or long-term



What are the possible problems?

Acromegaly can cause your body to change shape, particularly around your hands, feet, nose, cheekbones, forehead, and lips. Your skin may also become more sweaty (especially at night), oily, and thicker, and you might frequently grow skin tags. You might also develop Raynaud's disease, a condition that causes your fingers, toes, ears, nose, lips, and/or nipples to feel painful, numb, or difficult to move when you're feeling cold or anxious.



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.



Why can this happen?

An excess of growth hormone in your blood can, over time, act on the tissues around your body to cause abnormal growth. This often starts with soft tissue swelling in your hands and feet.



What are the symptoms?

As changes are gradual, you might not notice them. Swelling of soft body tissues may affect how you use your joints ([see page 18](#)).



How is it monitored?

You may be asked periodically to complete an acromegaly-specific questionnaire, which asks questions about body shape and swelling, among other things.



What can be done about it?

Swelling of soft tissues may decrease with acromegaly treatment. Getting your IGF-I levels into the normal range for your age and gender gives you the best chance of achieving this. It's important to note that some body changes may be more permanent, especially if you have had them for a long time.



Changes to your body can impact the way you feel about yourself, and may be especially difficult to come to terms with if they are permanent. Find practical tips and support in the **Self-image guide**, another booklet in the Acroline™ series.

Bones and joints

Looking after your bone and joint function and health



What are the possible problems?

Your bones and joints may grow and change composition in a way that makes them more vulnerable to pain or fracture. If this happens, it may affect your jaw, fingers, spine, rib cage, legs, and/or arms. Furthermore, the nerve signals to and from your limbs may be affected.



How common are bone and joint problems?

Out of every 10 people with acromegaly:

- ▶ Around 3 to 7 experience joint and/or muscle pain
- ▶ About 4 to 5 have back pain
- ▶ Around 6 have upper back fractures
- ▶ 2 to 8 have carpal tunnel syndrome (painful tingling in wrists and hands)



Why can this happen?

Acromegaly and hypopituitarism (underproduction of some hormones produced by the pituitary gland) can cause a change in the composition of your bones, making them more fragile. Increased levels of growth hormone and IGF-I contribute to swelling around joints and nerves, which can contribute to joint pain and carpal tunnel syndrome, respectively.



What are the symptoms?

You might notice changes in your body shape, or experience joint and/or muscle pain, particularly around the knees, shoulders, hands, wrists, and/or hips. If your nerves are affected, you might notice tingling sensations or pain in your extremities.



How is it monitored?

Bone imaging methods may be used, usually x-rays. These will either be of a single part of your body and/or a DEXA scan to measure bone mineral density of a larger area.

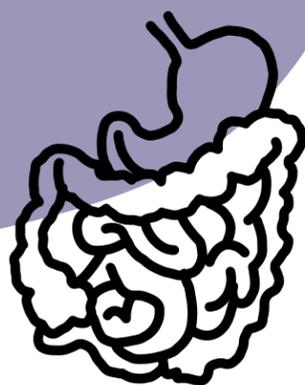


What can be done about it?

Carpal tunnel syndrome generally improves with treatment and normalization of IGF-I levels. There are several ways to treat joint and muscle pain and to support and protect your bones. Please ask your healthcare team for further information about these.

Gut and colon health

Checking for signs of more serious problems



What are the possible problems?

You might develop small growths in the lining of your large intestine, called bowel or colonic polyps. For most people these are harmless and not something to be concerned about. However, in a small number of cases, colonic polyps can grow further and become cancerous, so they need to be monitored periodically.



How common are gut problems?

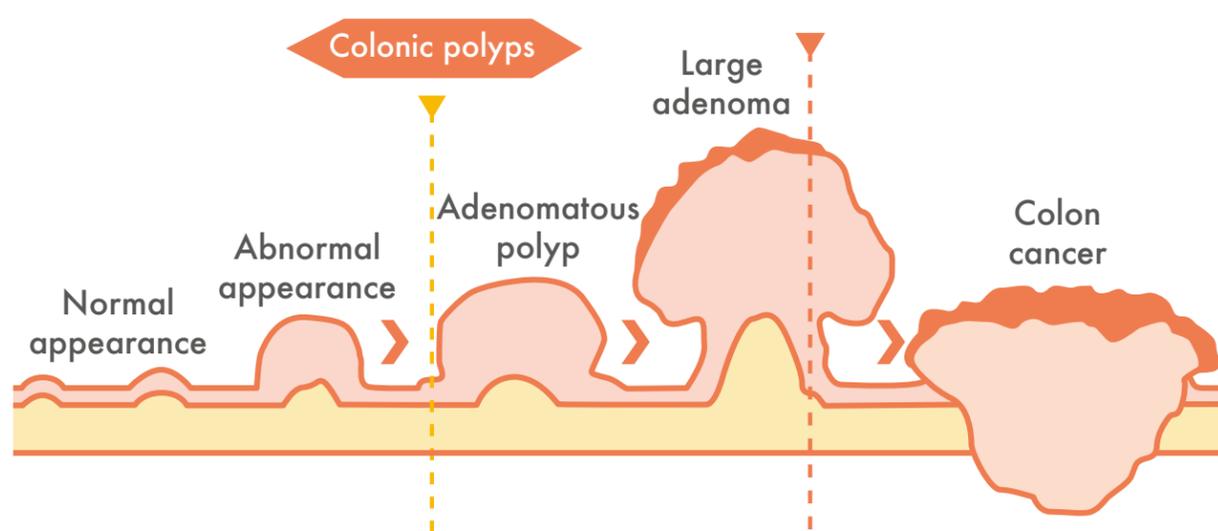
Up to 5 out of every 10 people with acromegaly have colonic polyps, of which less than a quarter will become adenomatous (that is, polyps that have a chance of turning into cancer, [see illustration opposite](#)).



Why can this happen?

It's not known for certain, but it might be that a higher-than-normal growth hormone level may make it more likely for colonic polyps to develop.

Possible progression of a colonic polyp into colon cancer





What are the symptoms?

Often, colonic polyps don't cause any symptoms and are only found during the monitoring process. Some people may experience:

- ▶ A small amount of mucus in the stool
- ▶ Blood in the stool
- ▶ Diarrhea or constipation
- ▶ Stomach pain or cramps



How is it monitored?

Most people with acromegaly will be offered a colonoscopy soon after they are diagnosed. If you're over 40, you may have a colonoscopy at diagnosis. After treatment, repeat colonoscopy is suggested every 5 years in those who have a polyp or persistently elevated IGF-I, and every 10 years in those without a polyp and with normal IGF-I.



What does a colonoscopy involve?

This is a procedure that is usually performed in the hospital, under sedation or with painkillers. A long, narrow, flexible tube containing a light and camera is passed up through your rectum and around your colon (large intestine). You'll also need to undergo what's known as "bowel prep"—a process of clearing your bowels using special foods and/or laxatives beforehand.



What can be done about it?

Sometimes your healthcare team may recommend removal of your polyps. This could be by burning or cutting them off during a colonoscopy, or you may be offered surgery to remove the affected part of the bowel, for example. Your healthcare team will discuss your options with you and the best approach to take.

Heart health

Checking your heart and blood system



What are the possible problems?

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



How common are heart problems?

Of every 10 people with acromegaly, 3 to 6 have high blood pressure and around half have an abnormal heartbeat; 3 in every 100 people with acromegaly may get heart failure.



Why can this happen?

The increased levels of growth hormone in your blood are generally the cause of an enlarged heart. They also contribute to insulin resistance ([see page 12](#) for additional information), which itself can cause your blood to retain increased salts and water, making your blood pressure go up.



What are the symptoms?

You might not have symptoms, or you could start to feel out of breath during light exercise, or experience chest pain, among other things.



How is it monitored?

Blood pressure is monitored with a cuff around your arm that inflates and then deflates. You may have a single measurement, or you may need to wear a monitor that takes repeat measurements over a 24-hour period (you can still carry on with your activities as usual). Your blood pressure will be measured periodically and/or if you change any blood pressure treatment that might be prescribed for you.

There are 2 main further investigations for heart conditions:

- ▶ Echocardiogram (echo)
 - ~ Looks at your heart shape and structure
 - ~ Uses an ultrasound device and some sticky sensor pads that are usually placed on your chest
- ▶ Electrocardiogram (ECG or EKG)
 - ~ Looks at the way your heart beats
 - ~ Generally uses a number of small sticky sensor pads attached to your arms, legs, and chest

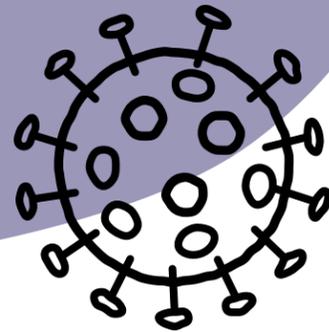


What can be done about it?

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 IGF-I levels. Your GP/family doctor and your cardiology and acromegaly healthcare teams will discuss this with you and any further treatment you may need, for example, to help bring your blood pressure down.

Immune system, infections, and COVID-19

Protecting against the consequences of getting an infection



What are the possible problems?

If you catch an infection such as COVID-19, you might have an increased risk of more severe health complications and consequences. If you are taking any medications for COVID-19 or any infections, check with your doctor to see if they interact with your current medication.



How common are infection complications?

Complications of the COVID-19 infection are linked with other health problems associated with acromegaly. Of every 10 people from around the world who develop severe complications from COVID-19, roughly 3 have high blood pressure and 3 to 5 have heart problems, for example.



Why can this happen?

Having acromegaly can impact your immune system and cause inflammation. This can make you less able to fight infections that enter your body. However, the main causes of infection complications in people with acromegaly are because of related health conditions, especially heart problems, high blood pressure, diabetes, and sleep apnea.



What are the symptoms?

Symptoms of complications from a COVID-19 infection include severe shortness of breath; rapid, shallow breathing; tiredness; drowsiness or confusion; or feeling faint.



What can be done about it?

You may be advised to take extra precautions, such as staying at home or discussing your vaccination options with your doctor. Furthermore, working with your healthcare team to manage any other health conditions you may have that could increase your risk of severe consequences of COVID-19 could help to minimize the extra risk that these conditions can pose.

Mental health

Supporting your emotional well-being



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 feel overwhelming. Many people may suffer from mental health problems such as depression, anxiety, and low self-esteem.



Why can this happen?

Acromegaly and managing it can cause considerable emotional strain; furthermore the changes in hormones caused by the condition and its treatment may impact thinking ability, personality, and behavior.



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 thoughts of self-harm.



How is it monitored?

Your healthcare team may ask you to complete a questionnaire when you are diagnosed, and each year thereafter. This acromegaly-specific questionnaire asks about the impact of both physical symptoms and psychological symptoms on quality of life day to day.

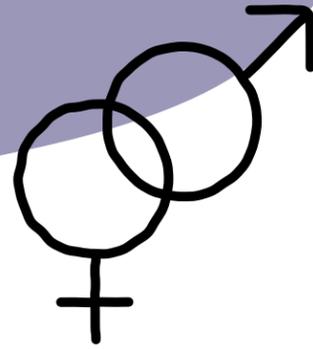


What can be done about it?

If you feel your mental well-being 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 behavior therapies.

Sex drive, metabolism, fertility, and pregnancy

Tracking and supporting your hormone balance



What are the possible symptoms?

You may feel unaccountably tired, sensitive to cold, or experience weight gain. You may feel a lower than usual desire or interest in sex. Women may have irregular or no periods. If you are trying for a baby, you may experience difficulty in conceiving.



How common are problems with hormone levels?

About half of people with acromegaly may experience lower than normal levels of sex and fertility hormones (known as hypogonadism); others experience lower than normal levels of hormones involved in metabolism—thyroid and cortisol stimulation hormones (known as hypothyroidism and hypoadrenalism, respectively); some people experience insufficiencies across all these hormones (known as panhypopituitarism).



Why can this happen?

A number of hormones impacting metabolism, sex, and fertility are made by the pituitary gland. Reduced levels of these hormones may be the result of:

- ▶ The pituitary adenoma pressing against surrounding healthy tissue
- ▶ The pituitary adenoma overproducing the hormone prolactin
- ▶ Radiotherapy to remove the adenoma, which may damage healthy tissue



How is it monitored?

This will generally fall under the care of your endocrinology healthcare team and/or gynecologist. You may have to take periodic blood tests to assess for levels of the various hormones in your body.

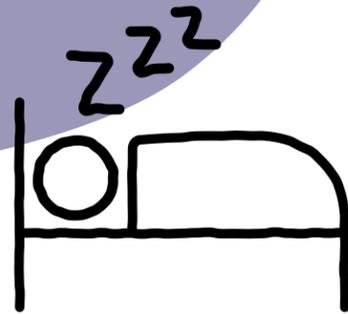


What can be done about it?

The effect of the adenoma on hormone production may resolve after treatment. If necessary, replacements for each of the hormones can be taken. These often come in a variety of forms, such as tablets or gels.

Sleep and sleep apnea

Ensuring your sleep is effective for you



What are the possible problems?

Snoring and sleep apnea, a condition in which your breathing stops momentarily during sleep, cause your body to be aroused multiple times an hour during the night (even if you do not notice waking up). This condition can impact the health of your heart and blood system, leading to several possible heart problems and disorders.



How common is sleep apnea?

Up to 8 of every 10 people diagnosed with acromegaly also have sleep apnea.



Why can this happen?

Increased growth hormone and IGF-I levels can cause swelling of the tongue and soft tissues around the back of the throat, which then collapse during sleep. This can cause harmless snoring but can also lead to sleep apnea, a more serious condition.



What are the symptoms?

You might notice frequent night awakenings, where you seem to choke or gasp for air. You may also feel excessively sleepy during the day due to a lack of quality sleep.



How is it monitored?

Your healthcare team may ask questions about your sleep when you are diagnosed and ask you to complete a questionnaire about it. If your healthcare team thinks you might have sleep apnea, you may be asked to undertake a sleep study, or polysomnography, where you stay in a hospital overnight while many aspects of your sleep and breathing are monitored.



What can be done about it?

As with many other conditions commonly linked to acromegaly, sleep apnea generally improves with treatment and normalization of IGF-I levels, though it can persist despite successful acromegaly treatment, and can be treated with a specially fitted mask that blows a continuous stream of air through your nose and throat while you sleep.

Vision

Monitoring for pituitary adenoma pressure on the optic nerve



What are the possible problems?

Changes in what you can see that can potentially lead to permanent sight loss if untreated.



Why can this happen?

The pituitary adenoma can sometimes press on the optic nerve, affecting its ability to send signals from your eyes to your brain.

Please remember: 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 are the symptoms?

Most usually, the midperipheral vision is affected initially. Over time, more of the outer peripheral vision may be lost.



Normal appearance



Midperiphery affected



Outer periphery affected

This can cause you to struggle with walking in the dark, to trip up, or see a curtain or spiderweb off to the sides of your line of sight. Some people do not notice any changes in their sight and these are only identified with testing.



How is it monitored?

Tracking visual field (how much you can see) and visual acuity (how clearly you can see) with regular eye tests by an optometrist or ophthalmologist.



What can be done about it?

Acromegaly treatments that remove or reduce the size of the pituitary adenoma can help you regain your vision if you have lost it. Eye test results can help to give an indication of treatment progress and can also check for possible regrowth of the adenoma.



Helping you live well with acromegaly

Created in collaboration with an international panel of people with acromegaly, acromegaly support groups, and health psychologists, Acroline™ is a series of supportive guides and tools designed to help you keep your life on track and live well with acromegaly.

Related titles include:

- ▶ Self-image
- ▶ Looking after your well-being
- ▶ Supporting people with acromegaly

To view related brochures for more information, please [click here](#) or visit acromegaly.pfizerpro.com.