



# Supporting people with acromegaly

*A guide for friends and family*

# Acromegaly: it's a lot to take in



**Finding out that someone you care about has a serious health condition can be a difficult and confusing thing to deal with,** especially when the condition in question is so rare that you most likely had never heard about it before.

This guide aims to give you enough information about acromegaly to help you understand what your friend or family member is currently going through. It will also explain how their condition and its treatment might impact them in the future. Furthermore, you'll find some suggestions on how you could offer support in a way that's helpful for both of you.

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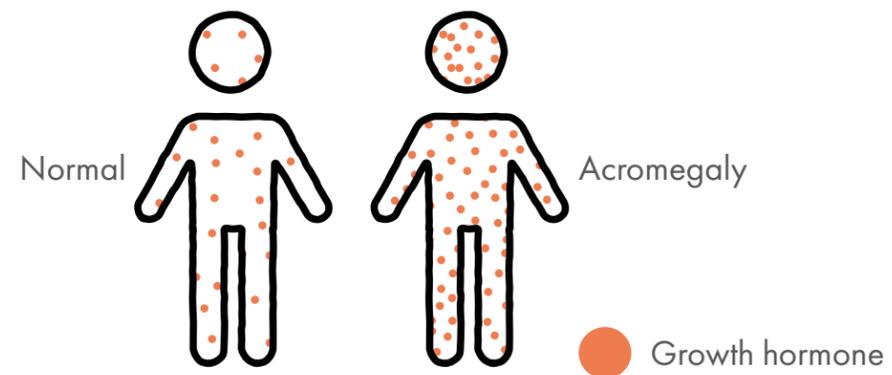
# What is acromegaly?

## Let's look at the cause, signs, and symptoms of the condition

Acromegaly is a rare condition where the body produces too much growth hormone, causing a wide range of potentially harmful effects.

### It's mainly about growth hormone

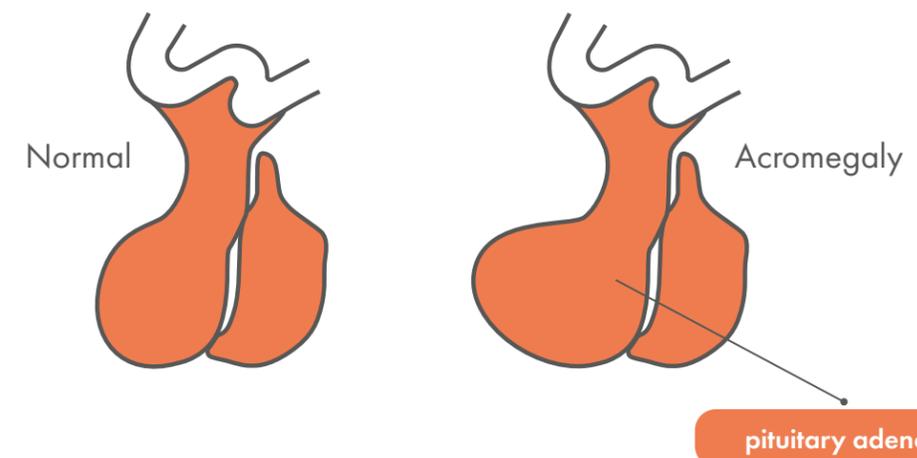
Acromegaly is caused by an excess of growth hormone.



### 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 almost all people with acromegaly, this excess of growth hormone is caused by an overgrowth of tissue in the pituitary gland.

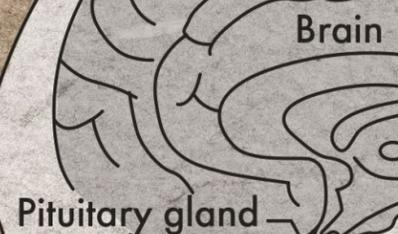


This **tissue overgrowth** is known as a pituitary adenoma (a kind of benign tumor that causes acromegaly but doesn't cause cancer).

### What is the pituitary?

Usually about the size of a pea, the pituitary gland dangles just below the brain, near the back of the nose cavity.

It makes all kinds of hormones that impact things like your metabolism (how quickly your body burns energy) and fertility.



## 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

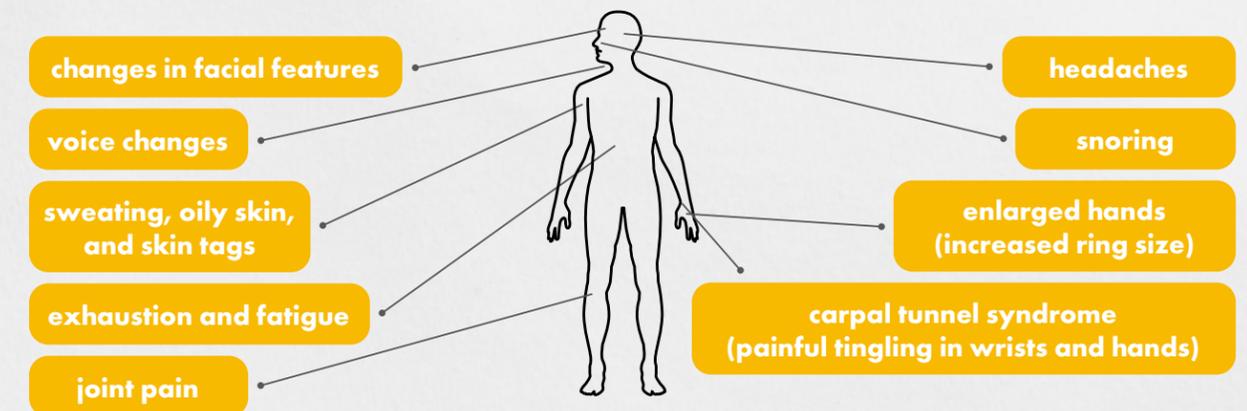


IGF-I

### What is IGF-I?

Pronounced eye-gee-eff one, IGF-I is another hormone and it can be measured with a simple blood test. People with active acromegaly have much higher levels of IGF-I than those without. 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.

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 all sorts of symptoms and changes to your body:



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

### 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



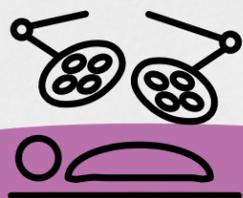
#### Changes in normal levels of other hormones

- ▶ 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 is acromegaly treated?

Here are some treatments that may be used to help manage the condition and its symptoms

**Please note:** This is just a guide—everyone's treatment journey will need to be tailored to their individual situation. The order and types of treatments may vary from person to person.



## Step 1

Removing as much of the adenoma as possible with **surgery**—operations usually take 1 to 2 hours with 3 to 5 days in the hospital, plus a few weeks more for recovery at home.



## Step 2

Shrinking and managing any remaining adenoma with **initial medical therapy** (usually daily or periodic tablets or injections). If successful, these will generally need to be taken for life.



## Step 4

**Radiotherapy** of the adenoma, causing it to shrink and die away over time. This can take months or years to reach full effect (during which time medical therapies may be necessary), after which no further treatment may be necessary, although some hormone replacement therapies may be needed due to damage to healthy tissues.



## How long does treatment take?

As acromegaly is a very complicated condition, it can take several months to years to get it under control. Even with successful treatment, the pituitary adenoma can occasionally grow back—people with acromegaly will likely be recommended to have periodic checkups throughout their lifetime.

## Step 3

Further medical therapy (usually daily or periodic injections) to manage the excess of growth hormone. Again, these may need to be taken for life.

# How can acromegaly impact health and life in general?

## An overview of the many different ways acromegaly might impact day-to-day life now and in the future

As you've seen, acromegaly is quite a complicated condition, and it can have an equally complicated impact on life. Here are just some of the ways it can affect people who've been diagnosed with acromegaly.

### Treatment can be demanding

From surgery through medical treatment to radiotherapy, there may be many different steps involved.



### Symptoms and treatment complications/ side effects can be debilitating

Even with treatment, symptoms such as headaches, joint pain, and exhaustion are common.

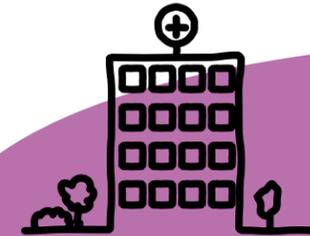
### It can cause other health complications

Sleep apnea (a serious condition that can result in sleep deprivation), diabetes, heart problems, and changes in fertility and sex drive are common in people with acromegaly. These will all need to be monitored and treated in their own way.

Acromegaly can also make the consequences of catching some infections, like COVID-19, more severe.

## There may be frequent hospital visits and healthcare appointments

There are many types of specialist doctors and healthcare providers who may be involved in caring for people with acromegaly.



### It involves regular checkups and scans

Even people who've had successful treatment will need periodic checkups, including blood tests and brain scans.

### It's a lot to go through

The emotional strain caused by all of this can feel immense and overwhelming. Your understanding and support will be invaluable.



### Your role

Please don't underestimate what you can do for your friend or family member. Reading this booklet will help put you in a good place to provide much needed support or reassurance. **See page 12** for some more suggestions on ways you can help.

# How can I help?

Having a friend or family member affected by acromegaly can be tough. Here are some things to consider discussing or doing that can help you both move forward



## Be there to acknowledge their thoughts and feelings

Living with a rare condition that's often unknown and misunderstood can feel very isolating. You might find it difficult to see things from their perspective. Just knowing that you're there to listen, ideally without judgment or trying to give advice, will be a huge help.



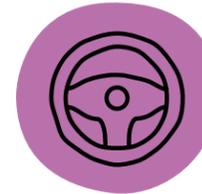
## Consider offering to attend appointments

Having an extra pair of ears to listen, and hands to take notes, could help even more than you'd think. Your support can be invaluable in helping your friend or family member to work with their healthcare team to make informed decisions about treatment choices, for example. (But please remember that they didn't write this guide. This isn't an informal request from them, just a suggestion to consider asking them if they'd like your help in this way, if you think it's appropriate.)



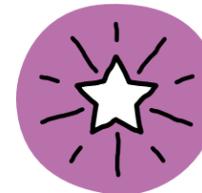
## Try not to add pressure

You might sometimes feel that your friend or family member isn't taking the right approach to their condition or its treatment. And you may also find that talking it through with them hasn't helped to change their approach. Even though your concerns will likely be out of love and wanting the best for them, it can be helpful



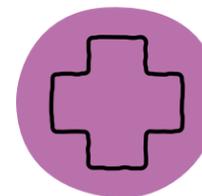
## Respect their responsibility

As long as they are still able, people with chronic conditions such as acromegaly generally achieve the most positive outcomes when they remain in charge of their symptoms, treatment, and day-to-day life. Anything you can do to support their autonomy will help.



## Remember your help can make a huge difference

Each of us loses sight of our self-worth at times. Someone who has been suffering with acromegaly symptoms and/or undergoing treatment for the condition is no different. It will mean a lot if you are able to help remind your friend or family member of their value, and the positive impact they have had and can continue to have on your life. Remember, you don't have to communicate this with words if that's not you. Taking time to be there for them, or helping them feel included in other aspects of your life, can be just as important.



## Try to see the positives

Looking for things to be grateful for (such as a deeper relationship or a changed perspective) can be just as helpful for you as it can for your friend or family member, especially if you are close enough to them to be personally affected by their diagnosis. It can also be helpful to think about times in your life when you have had to deal with difficult situations, for example at work or in family life, and remember how you found the strength to overcome those. That experience puts you in a positive position to face this new challenge.





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 people with acromegaly and their supporters.

**Related titles include:**

- ▶ Self-image
- ▶ Well-being
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