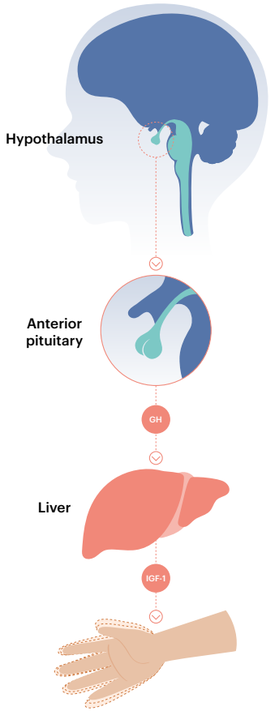
Living with acromegaly

camurus®

Understanding your condition

Acromegaly is a rare condition caused by your body producing too much growth hormone (GH), usually from a small, benign tumour in the pituitary gland.[1]

When too much GH is made, the liver responds by producing more insulin-like growth factor 1 (IGF-1). Over time, this extra hormone can slowly increase the size of your hands, feet, and face, and it may also affect some internal organs.[1]



It's natural to feel concerned about these changes, but the good news is that effective treatments are available. With proper care, most people with acromegaly can live a healthy, normal life.[2] Without treatment, the condition can increase the risk of developing diabetes, high blood pressure, heart problems, and shorten life expectancy.[3]

- Glucose metabolism disorders, including type 2 diabetes
- Cardiovascular disease, including high blood pressure and cardiomyopathy
- Arthritis
- Colon polyps, which can turn into colon cancer

Acromegaly can affect anyone, men or women, and is usually diagnosed between the ages of 40 and 50. Although it is rare, many people worldwide live a full life with the condition.

Median age at diagnosis:

Fifth decade of life[4]

Sex:

Approximately **50%** women, **50%** men[5]

Worldwide prevalence:

5.9

per **100,000** persons[6]

Worldwide incidence:

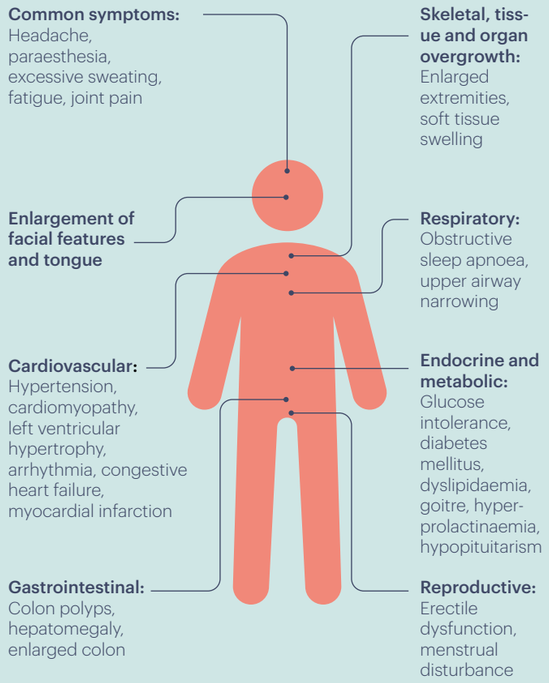
0.38

per **100,000** person-years[6]

Recognizing changes in your body

Acromegaly develops slowly, so changes may not be obvious at first.[1,3] Sometimes, family and friends notice differences before you do.

You may see subtle changes in your face, such as a more prominent chin, forehead, or nose. Your hands and feet might become larger, and rings, shoes, or gloves may feel tighter. Teeth can shift slightly as the jaw changes. You may experience headache, tiredness and joint pain.[3,7,8] Because acromegaly develops slowly, it can take many years before it is diagnosed.[1] Many people first attribute symptoms to normal ageing or everyday stress. **If you have recently been diagnosed, you may have already experienced a long journey. This is very common, and you are not alone.**



Tests and screenings

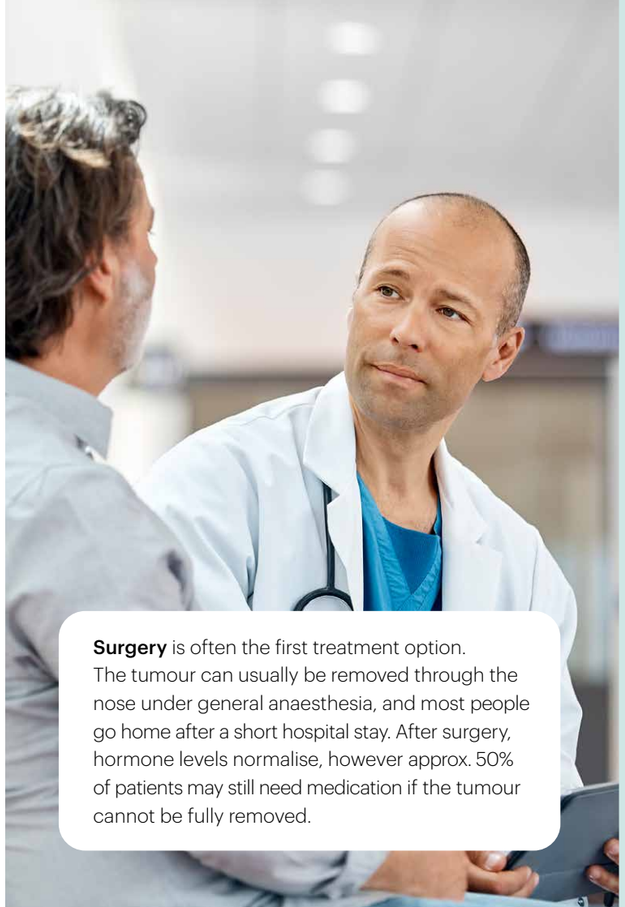
Before being diagnosed with acromegaly, your doctor will usually ask you to take some tests. The most common are[9]:

- **IGF-1:** A blood test that, if elevated, indicates that your body produces too much growth hormone.
- **GH:** Shows how much growth hormone is being produced in the body.
- **Oral glucose tolerance test (OGTT):** Shows how well the body handles sugar.
- **Magnetic resonance imaging (MRI):** Shows the pituitary gland and helps identify and characterise the tumour causing excess growth hormone.

Depending on your test results, your doctor may order additional tests to check for complications of acromegaly.[9]

Treatment

Treatment may help to control hormone levels and manage symptoms. Some symptoms, such as soft tissue swelling or fatigue, may improve over time, while physical changes (for example in bones) may not fully reverse. Your experience will depend on your individual situation. Your doctor can help you set realistic expectations based on your individual situation and will assess which treatment is best for you.



Surgery is often the first treatment option. The tumour can usually be removed through the nose under general anaesthesia, and most people go home after a short hospital stay. After surgery, hormone levels normalise, however approx. 50% of patients may still need medication if the tumour cannot be fully removed.

Medications work in different ways. Some reduce hormone production, while others block its effects. These can be injections given at home every few weeks or in hospital, or daily tablets. Your doctor will guide you to the treatment that suits you best. The different medications are:

Somatostatin receptor ligands (SRL) are synthetic analogs of the naturally occurring hormone somatostatin, which is produced in the hypothalamus just above the pituitary gland. Somatostatin's job is to inhibit the production of growth hormone. SRLs are typically administered as long-acting depot injections, either by a healthcare professional, or by yourself at home. In some countries, the treatment is also available as a once-daily tablet.

Dopamine agonists are taken orally and work by suppressing the secretion of both growth hormone and prolactin from the pituitary gland. Their effect is generally modest compared to other available treatments, making them most suitable for patients with mildly elevated hormone levels or tumours that co-secrete both prolactin and growth hormone. They may also be used in combination with other treatments if hormone levels remain inadequately controlled on other treatments alone. However, these treatments have not been approved by regulatory authorities for the treatment of acromegaly.

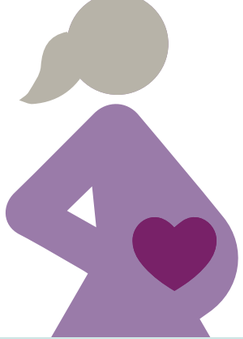
Growth hormone receptor antagonists
When growth hormone is released from the pituitary gland into the bloodstream, it triggers IGF-1 production in the liver. Growth hormone receptor antagonists block this effect, lowering IGF-1 production which regulates cell growth, bone development, and muscle mass without changing growth hormone levels. The medication is self-injected daily and suitable for patients that do not respond to surgery or SRLs. Starting dose should be administered by a healthcare professional.

Radiation therapy is reserved generally for third line treatment of patients with persistent disease or tumour growth despite surgery and medication, or for patients who are not suitable candidates for surgery.

Long-term follow-up: Acromegaly usually requires long-term follow-up. Even after treatment, regular check-ups and blood tests are important to monitor hormone levels and manage any ongoing symptoms or complications.

Pregnancy and fertility

If you are pregnant or planning a pregnancy (both men and women), consult your doctor to discuss whether it's necessary to change your medical treatment.



Living well with acromegaly

It's normal to feel worried or unsure about living with a rare condition. Talking openly with your healthcare team can help you feel informed and supported.

Family and friends may also need guidance. You are welcome to bring them to appointments, ask questions, and share your experience. Being supported and staying informed can make daily life easier and less stressful.

Living with acromegaly can affect more than physical health. Some people may experience emotional changes such as anxiety, low mood, frustration, or reduced self-confidence, particularly before or during treatment.

If you are finding things difficult, speak to your healthcare team – support is available. Remember, you are not alone. With treatment, guidance, and support, it is possible to live well with acromegaly. Patient organisations, such as the World Alliance of Pituitary Organizations (WAPO), can provide information, support, and connect you with others living with acromegaly.

The website acromegalyandme.com offers condition-specific resources and patient stories.

Contact your doctor or health-care team if you:

- Still experience symptoms.
- Have side effects or discomfort that may be linked to disease or treatment.
- Have issues or problems with medication or injections.
- Have travel plans.
- Want to discuss fertility and pregnancy.
- Have questions or concerns regarding your treatment.

For relatives

If you have a family member with a chronic illness, you might feel helpless and grieve over your family's circumstances. Concerns about finances due to decreased ability to work, side effects, pain, frequent visits to the hospital, unfulfilled dreams and uncertainty about the future may all add to your worries. It may also feel burdensome with all practical responsibilities involved, like assisting and/or monitoring with medication.

As a relative, you are always welcome to accompany the patient to examinations, treatments and consultations at the hospital and ask questions from your perspective to the healthcare team.

Bjørn's story

I'm Bjørn, 55, from Oslo. I used to be active and healthy, but about 15 years ago I started experiencing joint aches. I dismissed them as normal ageing, and tests showed nothing unusual, so I continued with life despite ongoing discomfort.

Over time, I developed unusual symptoms like excessive night sweating that often required changing drenched sheets. After my child was born, I spent less time at the gym. When I returned to spinning classes, my cycling shoes no longer fit, which I attributed to ageing or overthinking.

During a routine visit, I told my GP about joint pain and tight shoes. He advised softer shoes, indicating it was nothing serious. Despite accepting his explanation, I became increasingly exhausted and irritable, struggling through workdays and nearly falling asleep at dinner. The changes in my body and mood persisted without answers.

The diagnosis happened by chance when I saw an old friend with acromegaly at a birthday party. He noticed my hands looked swollen just like his own and recommended I see a doctor about acromegaly.

I followed his advice, but since my GP was away, I saw a substitute doctor. Though unfamiliar with

acromegaly, she took me seriously, researched it, ran tests, and referred me to a specialist. After hospital tests, I was diagnosed with acromegaly.

The diagnosis brought relief by explaining my symptoms. It meant my struggles weren't just in my head – there was a reason for everything I'd been experiencing.

Notes:

INT-NPR-2600069 June 2026

References: **1.** Fleseriu M et al. Lancet Diabetes Endocrinol. 2022;10(11):804-826. **2.** Bolfi F et al. European Journal of Endocrinology. 2018;179(1):59–71. **3.** Gadelha MR et al. Endocr Rev. 2019;40(1):268-332. **4.** Lavrentaki A, Paluzzi A, et al. Pituitary 2017; 20:4-9. **5.** Dal J, et al. Clin Endocrinol (Oxf) 2021; 94(4):625–635. **6.** Crisafulli S, et al. Eur J Endocrinol 2021 Jul 1;185(2):251-263. **7.** Colao A, et al. Nat Rev Dis Primers 2019;5:20. **8.** Melmed S. J Clin Invest 2009;119:3189–202. **9.** Giustina A, et al. Pituitary 2024; 27(1):7-22.

This brochure does not substitute HCP visits. It has been developed by Camurus, in collaboration with Rigshospitalet in Denmark.

camurus®

Camurus AB
Rydbergs torg 4 | SE-224 84 Lund, Sweden
medicalinfo@camurus.com

For more information, visit:

acromegalyandme.com

www.wapo.org