

## WHAT ARE ACROMEGALY AND GIGANTISM?

Acromegaly is a rare medical condition that is generally caused by a benign (non-cancerous) tumour that is secreting growth hormone (GH). The tumour is typically located inside or attached to the pituitary gland, but there have been some very rare cases where the tumour is located on an organ.

The pituitary gland is considered the master gland—it controls and regulates all our other glands and organs. It is a pea-sized gland located in the frontal part of our brain, about an inch back from the centre of our eyes.

Acromegaly is a condition that happens after puberty ends, but this condition can also happen in children and teens—it is then called gigantism.

To confirm a diagnosis, a medical professional may suggest magnetic resonance imaging (MRI) and/or an oral glucose tolerance test (OGTT). The first determines whether there is a pituitary tumour present and the second measures how quickly glucose is cleared from the blood. To help with the diagnosis, a doctor will request bloodwork for various hormones, including the growth hormone and insulin-like growth factor 1 (IGF-1).

If a tumour is visible on the MRI, the first line of treatment is usually surgery to remove or reduce the tumour. This surgery is generally transsphenoidal: through the nasal cavities or, less often, through the gums.

If there is no visible tumour or the surgery does not reduce IGF-1 levels, there are several drugs that can help suppress IGF-1 and improve symptoms.

If surgery and drug therapy are not effective, radiation may be considered. This may be one dose or a series of doses. This decision will be made between you and your medical team and will depend on the size and location of the tumour.

## SIGNS AND SYMPTOMS

Acromegaly can cause the following symptoms, whether due to the extra growth hormone or because of the tumour itself. If you are experiencing two or three of these, please reach out to your doctor and ask about GH or IGF-1 bloodwork or an oral glucose tolerance test.

- Headaches/migraines
- Profuse sweating
- Snoring/sleep apnea
- Joint pain
- Carpal tunnel syndrome
- Fatigue
- Breast leakage (when not pregnant; can also happen to males)
- Infertility, amenorrhea, impotence, decreased sex drive
- Growth in hands and feet (increased ring, shoe, and hat size)
- Swelling and growth of facial features, especially nose, chin, and brow
- Thicker hair and faster growing hair and nails
- Weight gain
- Weakness
- Skin tags
- Increased spacing of the teeth, overbite, underbite
- Difficulty concentrating
- Difficulty recalling words
- Difficulty speaking due to tongue swelling
- Difficulty controlling emotions and increase in angry reactions
- Loss of sight or double vision, blurriness
- Colon polyps
- Diabetes
- High blood pressure
- Stroke
- Enlargement of the internal organs, potentially leading to heart issues

## Acromegaly Canada



## Acromégalie Canada

Our mission: to raise awareness of acromegaly and gigantism through education while providing a network of support for patients and their families across Canada.

[contact@acromegalycanada.ca](mailto:contact@acromegalycanada.ca)

[www.acromegalycanada.ca](http://www.acromegalycanada.ca)

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## FACTS AND FIGURES

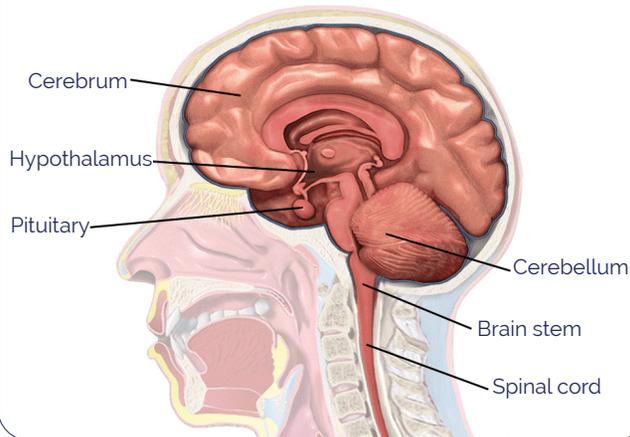
50-70 individuals  
per million have acromegaly

6-10 people  
diagnosed each year

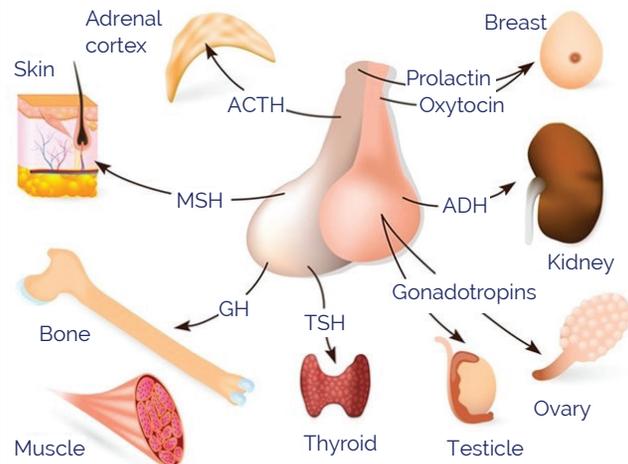
50-50  
affects men and women equally

8-10 years  
to get diagnosed

### BRAIN



### PITUITARY GLAND



## CAREGIVERS

The circle of caregivers and loved ones that supports a person diagnosed with acromegaly or gigantism can be diverse, and may include friends, spouses, partners, children, parents and grandparents. They are also impacted by the disease, because they want to offer the most useful support to the one they love who is facing a diagnosis, its treatment and its symptoms. For patients and their families, the people who provide thoughtful companionship can make a real and very positive difference. Whether newly diagnosed or coping with challenges in the years that follow, some common issues and concerns arise for acromegaly and gigantism patients as well as those who care for and support them.

Patient needs will vary, particularly depending upon their age and the fluctuation of their health status. Acromegaly patients are adults whereas those diagnosed with gigantism can be children and youth. Support can mean different things, to different people, at different times. As an advocate, a caregiver's first priority is to respond to what a loved one needs, and then to support them in ways that are beneficial but not intrusive.

## NOTES

How can caregivers be supportive?

- Help to book and to remember medical appointments, tests, and procedure dates and times.
- Attend appointments and procedures, if allowed.
- Remind about taking medication.
- Notice when they are feeling off, or seem different, and ask whether they took their medications that day or need to reach out to a member of their medical team.

What can caregivers do to help?

- Be beside them, present when they want to talk, or just a passive second set of ears.
- Help them shop for clothes, shoes, hats and gloves as their bodies change.
- Look for appropriate furniture and bedding for their weight and height with them.
- Contribute to them eating healthily and getting enough quality sleep.
- Be aware of any food and drug interactions.
- Encourage them to exercise daily and help them find ways to move that work for them.
- Notice when they might be in pain or uncomfortable and help them find ways to manage it.

Reach out for advice, support, and more:

[facebook.com/groups/acrocanadafamilyandcaregivers](https://www.facebook.com/groups/acrocanadafamilyandcaregivers)

Acromegaly Canada thanks these organizations for their support: