

Living with ACROMEGALY

Reset the Balance
Improve Your Outlook



Acromegaly Isn't a Life Sentence

Acromegaly is a condition that physicians recognize infrequently. The signs and symptoms develop so gradually that diagnosis may be missed for up to 15 years or more. Without proper diagnosis and treatment, you could have complications from this pituitary disorder. Your heart could fail. You could get **diabetes** or high blood pressure.

First, remember you are not alone—millions of people worldwide have acromegaly. Second, acromegaly can be a serious, life-shortening disease, but it should not be thought of as a life sentence. If you have acromegaly, there are many things you can do to feel better, look better, and live longer. Acromegaly isn't a life sentence—it's a wake-up call to care for yourself.

"I now lead a very active life, which wasn't possible before my treatment."

Did I Always Look this Way?

The signs and symptoms of acromegaly (see below) often take years to develop and to diagnose. Acromegaly may be suspected by a keen physician who recognizes the physical changes. This is not typical because the physical changes occur very slowly. Most often, laboratory tests are needed to confirm acromegaly. These tests measure your levels of growth hormone and IGF-I and help confirm your diagnosis. An oral glucose tolerance test can also help. You may need pictures of your brain taken with an MRI machine or a CT scanner to see if you have a pituitary tumor.

- Acne
- Barrel chest
- Breast milk (women)
- Carpal tunnel syndrome
- Coarsening body hair and thickening or darkening skin
- Coarsening facial features as bones grow
- Deepening voice
- Enlarged heart, lips, nose, and tongue
- Fatigue and weakness
- Headaches
- Impotence (men)
- Increased perspiration and body odor
- Irregular menstrual periods (women)
- Joint pain
- Loss of vision
- Protruding jaw
- Snoring
- Strange sensations and weakness in arms and legs
- Swelling of the hands and feet

"It took years from the start of symptoms until my diagnosis."

Don't Put Your Head in the Sand

If you ignore your disease, your health will not improve. Excess growth hormone will make you look different and feel worse. You might also get complications such as:

- Colon cancer
- Diabetes
- Growths in your bowel
- Headaches
- Heart disease
- High blood pressure
- Loss of vision
- Osteoporosis
- Sleep problems
- Stroke

These complications could cause an early death. The good news is that treatment can often stop, reverse, or minimize the symptoms you already have. Headaches may go away. Your hands and feet may stop swelling. You may sweat less. Your acne may subside. Your joints may stop aching. You may sleep better and have more energy.

"Be an assertive patient. Always ask questions..."

Stick with It

Acromegaly is a chronic illness. This means it will be with you for a long time. Your doctors can help you stick with a program to keep you healthy. Here is some advice from a treated patient with acromegaly:

- Keep regular appointments with your doctor
- Note changes in your ring and shoe size and facial appearance
- Have your hormone levels checked regularly
- Read the latest information about acromegaly
- Keep on top of the latest treatment advances
- Monitor your health
- Tell your doctor if you still have symptoms; there may be other treatment options

Too Much of a Good Thing

Acromegaly is a Greek word meaning enlargement and enlargement. You may have noticed your rings not fitting or your shoe size getting larger. The extra growth happens when a **tumor** on your **pituitary gland** makes too much growth hormone. Most often the tumor is an **adenoma**, which is not cancerous.

A Leaky Faucet

Hormones control many functions of your body. When they are not properly balanced, your body begins to show signs and symptoms, and things go wrong. When you have acromegaly, 3 hormones are unbalanced. They are:

- 1) Growth hormone: made in the pituitary gland
- 2) IGF-I (insulin-like growth factor I): made in the liver when growth hormone tells it to be produced
- 3) Somatostatin: made in the brain; can stop growth hormone from being produced

Your pituitary gland is like a faucet. A certain hormone in your brain causes growth hormone to be released from the pituitary gland. Growth hormone then turns on IGF-I. It takes somatostatin to turn off the faucet and stop the release of growth hormone. When you have acromegaly, the faucet doesn't always work right and tends to leak too much growth hormone.

Stopping the Leak

Treatment for acromegaly is aimed at stopping the leak of growth hormone and returning hormone levels to normal. Signs and symptoms you experience will often be reversed or managed. Treatment will help keep your pituitary gland functioning normally.

Acromegaly is treated in 3 ways: surgery, radiotherapy, and medication. You and your doctor can decide what's best.

Surgery is used to remove the pituitary tumor. A surgeon usually performs an operation called transphenoidal surgery. This operation reaches the pituitary gland through the nose and/or mouth, not through the brain. Occasionally a craniotomy (a surgical opening through the skull) may be needed.

Radiotherapy involves the use of x-rays to the pituitary gland. Radiation kills off tumor cells and is used generally in patients when surgery fails and medications no longer work or are tolerated.

Medications are used to restore the balance of growth hormone and IGF-I. Several drugs are available to decrease growth hormone or block its effects. Your doctor may prescribe one or more of the drugs listed here.

Drugs Commonly Used to Treat Acromegaly

Trade Name	Generic Name
Parlodel®	Bromocriptine
Dostinex®	Cabergoline*
Sandostatin®	Octreotide
Sandostatin LAR®	Octreotide (long acting)
Somavert®	Pegvisomant

*Used for treating acromegaly but not approved by the FDA for this use.

Follow-up Monitoring

- Keep your family physician aware of your condition and status
- Have your vision checked regularly
- Have your blood glucose levels and blood pressure checked regularly
- Eat healthily and exercise regularly
- Schedule a colonoscopy to screen for colon cancer
- Schedule an MRI to monitor your tumor
- Consider getting counseling or psychological support

Most patients learn to take an active role in their treatment and recovery. You can too. Work with an **endocrinologist** and other health care professionals until you feel good every day. Don't let acromegaly be a life sentence, let it be a life experience.

Glossary

adenoma - A noncancerous tumor made up of cells that form glands.

diabetes - A disease in which the body does not properly control the amount of glucose in the blood.

endocrinologist - A doctor specializing in diseases of the endocrine glands and their hormones.

hormones - "Chemical messengers" that are made and released by endocrine glands and that target one or more parts of the body.

pituitary gland - Master gland of the endocrine system that produces several hormones, including growth hormone.

tumor - An abnormal growth that may be cancerous or noncancerous depending on the cell type. It may cause visual impairment or may be life-threatening depending on the location.

For More Information

American Association of Clinical Endocrinologists

(www.aace.com)
Provides information about endocrine disorders and helps you locate an endocrinologist in your area.

The Hormone Foundation (www.hormone.org)

Answers general questions about various pituitary tumors, medical treatments, and hormone replacement therapy.

MEDLINEplus® Health Information

(www.medlineplus.gov)
Has a medical encyclopedia that contains facts about acromegaly and pituitary disorders in general.

National Institute of Child Health and Human Development (NICHD) (www.nichd.nih.gov)

Conducts research on the various processes that determine and maintain the health of individuals, families, and populations.

National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) (www.niddk.nih.gov)

Provides links to national organizations serving patients concerned about endocrine and metabolic diseases.

Pituitary Network Association (www.pituitary.org)

Provides information about ongoing clinical trials, medical resources and terminology, and links to other organizations.



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