

GLIC
HE



**TREATING
ACROMEGALY
MEANS MORE
THAN JUST
HORMONE
LEVELS**

Charles, living with acromegaly

Treating acromegaly means finding a treatment that also helps manage symptoms and considers your total health.

This summary of treatment options and recommendations is from:

- American Association of Clinical Endocrinology
- Acromegaly Consensus Group
- Endocrine Society
- The Pituitary Society

Use them to learn how to talk with your doctor about your treatment options, speak up about any concerns, and stay informed about your care.



Goals of Acromegaly Treatment

There are many treatment options for acromegaly. Your treatment plan may change based on your hormone levels or symptoms, or after you try certain options. Data show that about 50% of people who have had surgery will need medical treatment. It is important to talk openly with your healthcare team about how you are feeling and what is important to you. Together, you can build the best treatment and management plan.

Goals of acromegaly treatment

- 1 **Bring hormone levels back to normal**
- 2 **Control symptoms**
- 3 **Lower the risk for other health conditions**
- 4 **Control the tumor**

“
Creating patient-friendly guidelines is one of the most important things we can do. Education is a powerful thing.
”

—Jill Sisco, President,
Acromegaly Community



Understanding Current Treatment Guidelines

When discussing your treatment options, your doctor may refer to current treatment guidelines.





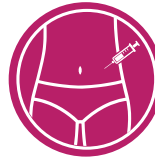


**Acromegaly Consensus Group,
American Association of Clinical Endocrinology,
Endocrine Society, and The Pituitary Society**

**In the 2021
Pituitary Society
update to the acromegaly
treatment guidelines,
oral therapies were
included.**



Acromegaly Treatment Options

Work together with your doctor to decide which treatment is right for you.

Type of treatment	Important points to know			
 <p>Surgery</p>	<ul style="list-style-type: none"> • Transsphenoidal surgery is often the first treatment doctors recommend; it attempts to remove as much of the tumor as possible from the pituitary gland through the nose • About 50% of people with acromegaly will require ongoing medical treatment after surgery 			
 <p>Medical Therapy</p>	Somatostatin Analog (SSA) Treatments			
	 <p>Intramuscular</p> <ul style="list-style-type: none"> • Octreotide LAR Sandostatin® LAR Depot (octreotide acetate) for injectable suspension <ul style="list-style-type: none"> o Given monthly by the healthcare team • Pasireotide LAR Signifor® LAR (pasireotide) for injectable suspension <ul style="list-style-type: none"> o Given monthly by the healthcare team 	 <p>Deep Subcutaneous</p> <ul style="list-style-type: none"> • Lanreotide Somatuline® Depot (lanreotide) injection <ul style="list-style-type: none"> o Given every 4-8 weeks by the healthcare team 	 <p>Subcutaneous</p> <ul style="list-style-type: none"> • Octreotide Sandostatin® (octreotide acetate) injection <ul style="list-style-type: none"> o Self-administered 3 times daily 	 <p>Oral</p> <ul style="list-style-type: none"> • Octreotide Mycapssa® (octreotide) capsules <ul style="list-style-type: none"> o Taken orally twice a day
 <p>Radiation</p>	<ul style="list-style-type: none"> • May be used if surgery or medications are not sufficient • Uses high-energy beams, usually x-rays, to kill tumor cells inside the body and reduce growth hormone (GH) levels • Different types (conventional, stereotactic radiosurgery) may be used • May take 5 to 10 years to see full effectiveness • Can impact other hormones, so follow-up is needed to track those hormones levels 			

Other Treatments

- **Pegvisomant**
Somavert® (pegvisomant) for injection, subcutaneous use
 - o Self-administered once daily

- **Cabergoline***
Dostinex® (cabergoline) tablets
 - o Taken orally each week

*Not indicated for the treatment of acromegaly.

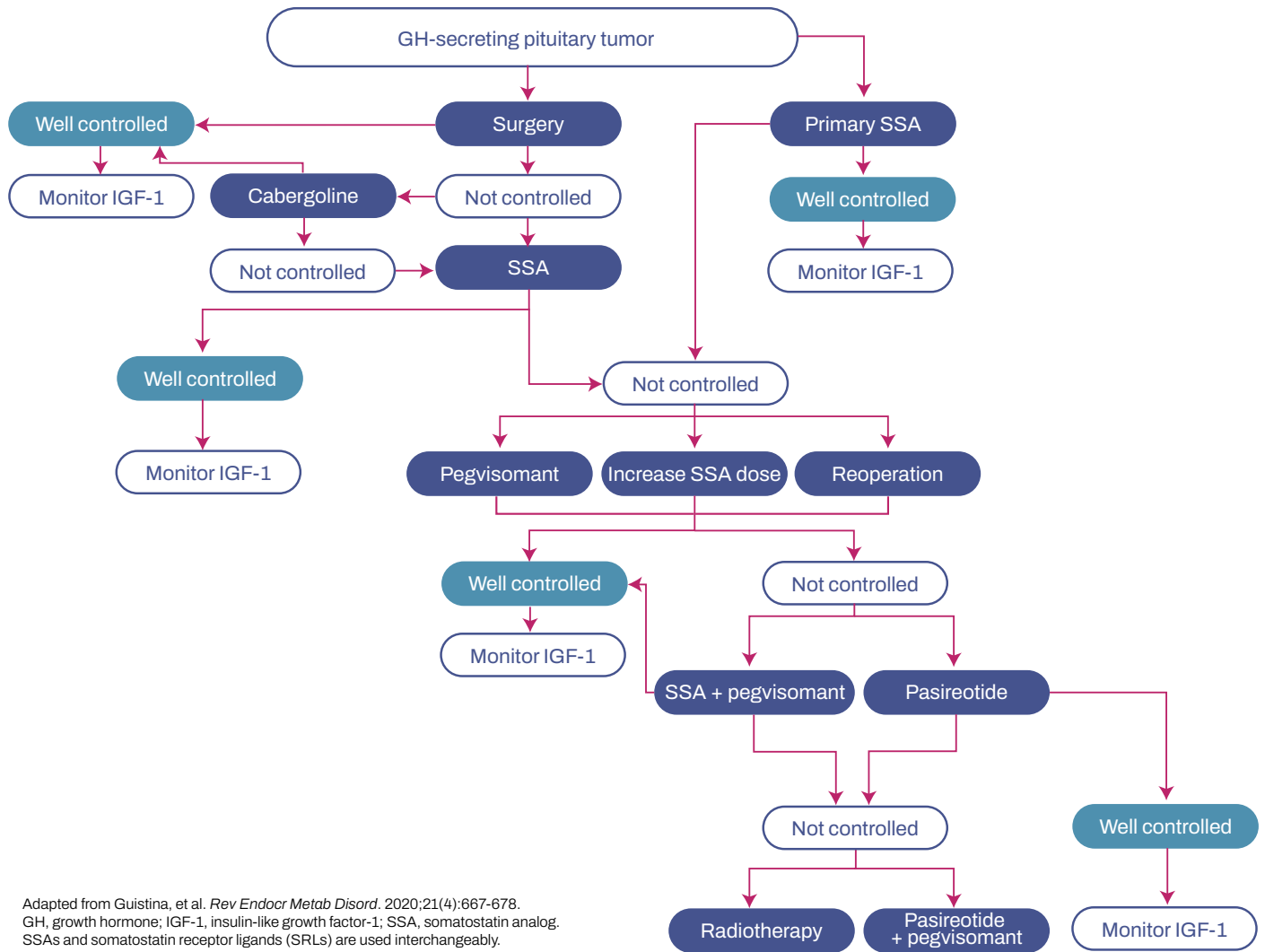
Trademarks are the property of their respective owners.



How Is a Medical Treatment Selected?

With about 50% of people with acromegaly requiring ongoing medical treatment after surgery, your doctor may use the guidelines below to determine your next treatment option.

Medical treatment guidelines for acromegaly



Adapted from Guistina, et al. *Rev Endocr Metab Disord.* 2020;21(4):667-678.
 GH, growth hormone; IGF-1, insulin-like growth factor-1; SSA, somatostatin analog.
 SSAs and somatostatin receptor ligands (SRLs) are used interchangeably.



Managing Acromegaly Symptoms

Even if you have had surgery, you may still have symptoms of acromegaly. Symptoms may change over time, so it is important to keep your healthcare team up-to-date on how you are feeling.

Symptoms of acromegaly

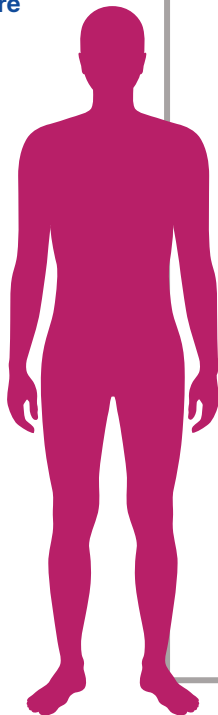
Core acromegaly care team

Endocrinologist

Primary care doctor

Surgeon

Nurse



Respiratory issues

- Sleep apnea
- Snoring

Sweating

Insulin resistance/ type 2 diabetes

Gastrointestinal issues

- Colon polyps
- Stomach pain
- Diarrhea
- Constipation

Fatigue/tiredness

- Daytime sleepiness
- Brain fog (forgetfulness, short-term memory loss)

Headache

Vision problems

Mental health

- Anxiety
- Depression

Heart disease

- High cholesterol
- Heart failure

Skin and bone changes

- Swelling
- Enlarged hands, feet, or jaw
- Gaps in teeth

Joint and muscle issues

- Carpal tunnel
- Osteoarthritis
- Arm, leg, and back pain

Specialists for specific symptoms or conditions

Psychiatrist/
Psychologist/Counselor

Pulmonologist

Cardiologist

Rheumatologist

Gastroenterologist

Sleep specialist




Optometrist/
Ophthalmologist



Managing Other Health Conditions




People with acromegaly often have other health conditions at the same time. It's important to be aware of them so you can talk with your doctor and build a healthcare team of specialists who can help manage your total health.

Health conditions that may happen at the same time as acromegaly

Health condition	Important points to know	Steps you can take
 <p>Hypertension (high blood pressure)</p>	<ul style="list-style-type: none"> • High GH levels can raise blood pressure • A blood pressure level of 130/80 mm Hg or above is considered high 	<ul style="list-style-type: none"> ✔ <i>Monitor your blood pressure often and keep track of your results</i> ✔ <i>Ask if you should be referred to a cardiologist (heart doctor)</i>
 <p>Diabetes</p>	<ul style="list-style-type: none"> • Increased levels of GH and IGF-1 can lead to high blood sugar 	<ul style="list-style-type: none"> ✔ <i>Watch for and talk with your doctor about common symptoms of diabetes:</i> <ul style="list-style-type: none"> o Increased thirst o More frequent urination o Tiredness o Cuts that heal slowly ✔ <i>Ask if you should be referred to an endocrinologist</i>
 <p>Obstructive sleep apnea</p>	<ul style="list-style-type: none"> • Can happen due to thickening of the tongue and tissues in the upper airway • Symptoms include: <ul style="list-style-type: none"> o Repeated waking at night o Disruptions in breathing o Sleepiness during the day 	<ul style="list-style-type: none"> ✔ <i>Ask if you need a sleep study to test for sleep apnea and if treatment may help prevent health conditions caused by sleep apnea</i> ✔ <i>Ask if you should see a specialist, such as an ENT or pulmonologist (lung doctor)</i>

ENT, ear, nose, and throat.

Health conditions that may happen at the same time as acromegaly (continued)

Health condition	Important points to know	Steps you can take
 <p>Vertebral (spine) fractures</p>	<ul style="list-style-type: none"> • May happen because of osteoporosis, a disease that weakens the bones 	<ul style="list-style-type: none"> ✓ <i>Work with your doctor to monitor your bone health</i> ✓ <i>Take any prescribed medicines to improve bone density and prevent fractures</i> ✓ <i>Ask if you should see a physical therapist or orthopedic specialist</i>
 <p>Polyps of the colon</p>	<ul style="list-style-type: none"> • Acromegaly increases the risk for growths on the inner lining of the colon 	<ul style="list-style-type: none"> ✓ <i>Follow your doctor's instructions about getting a colonoscopy, a test that uses a tiny camera to check the colon lining, after your diagnosis and as often as recommended during treatment</i> ✓ <i>Ask if you should see a gastroenterologist (a digestive system doctor)</i>
 <p>Hypopituitarism</p>	<ul style="list-style-type: none"> • A condition caused by enlarging tumors on the pituitary gland that keep it from making enough of certain hormones that keep your body functioning properly • Can impact bone health, sexual function, and fertility 	<ul style="list-style-type: none"> ✓ <i>Take medicines as directed by your doctor to help get your hormones back to a healthy level</i> ✓ <i>Ask if you should see an endocrinologist</i>



Charles, Annie, and Amber, living with acromegaly

Follow-Up and Long-Term Care

Acromegaly is a chronic condition, meaning it never goes away. Together with appropriate treatment and a team of doctors, you can get your acromegaly under control and in remission, and look after your total health.

What may happen during follow-up doctor visits	Why it's important
<ul style="list-style-type: none"> • Do tests to monitor your pituitary gland function and measure hormone levels, particularly IGF-1 and GH • Talk about any new or continuing symptoms and how they are impacting your life • Monitor for symptoms of other health conditions caused by acromegaly and recommend a special doctor, if needed 	<ul style="list-style-type: none"> • Signs and symptoms help your doctor know how well treatment is working and if changes need to be made to your treatment plan • Help detect and manage other health conditions
<ul style="list-style-type: none"> • Check how well your medicines are working • Ask about side effects you might be having • Make any needed changes to dose/type of medicine • Discuss other treatment options if your current plan isn't effective 	<ul style="list-style-type: none"> • Help you find the treatment plan that best manages your acromegaly and the health conditions it may cause
<ul style="list-style-type: none"> • Answer questions you might have about living with acromegaly, such as taking trips and planning for a family 	<ul style="list-style-type: none"> • Help you understand acromegaly and feel in charge of your life

You're at the Center of Your Team

You are the best person to tell your healthcare team how you're feeling and how you're doing. Work together with your doctors to keep them up-to-date, ask any questions you have, and decide on the best treatment plan for you.

Charles, Annie, and Amber, living with acromegaly



Visit
RethinkAcromegaly.com
and sign up for
email updates



Download the
Acromegaly Handbook
to track symptoms,
your healthcare team's
contact information,
notes, and more