

How Family and Friends Can Help

Acromegaly is a rare disease caused by too much growth hormone in the body. It affects many body parts and causes physical and emotional changes. You want to help but might feel overwhelmed and not sure where to start. That is not surprising, but your support and help can be very important. This document will explain what you need to know and give you some ideas about how to help.

Things to Know

- Acromegaly is a treatable but lifelong condition that requires a commitment to seek and accept ongoing medical care.
- Living with acromegaly can be overwhelming and challenging at first. It takes time to learn about acromegaly and adjust to the diagnosis.
- The person with acromegaly will need your help. How much and what kind of help you can give will depend on the acromegaly symptoms and what they want help with.
- Acromegaly may cause them to act in ways you are not used to. Remember, they are dealing with lots of different emotions adjusting to life with acromegaly. Try to be patient!

What You Can Do

- Learn about acromegaly and the specific treatment plan.
- Let them talk about their condition when they are ready.
- Be a good listener and try not to ask too many questions. They may just need to vent.
- Respect their privacy and don't share their personal information with others.
- Help them keep a positive attitude – acromegaly is treatable and has good outcomes.
- Help them not feel overwhelmed, take one day at a time.
- They will have good and bad days, and tomorrow will probably be a better day.
- Ask how you can help. Encourage them to be specific so you do the right thing.
- Help them make the most of doctor appointments. Offer to go with them. Encourage them to make a list of things they want to tell the doctor and questions they want to ask. Refer to the list during the doctor appointment. You can help by taking notes. Make and record follow up appointments.

More You Can Do

- Encourage them to join a community support group and attend meetings so they can meet and talk with others who have acromegaly. If there are none close by, consider joining a closed/members only Facebook group. Facebook groups provide a way to “talk” to others and share feelings and resources. It is not necessary to participate and share personal information if you don't want to – just join and read other members posts. It can be comforting to know others have acromegaly with similar symptoms and you can learn a lot about available resources.
- Offer transportation to doctor visits, lab tests, radiation treatments, surgeries.
- Offer to pick up medications; help with shopping, household chores, and running errands.
- Make and deliver a meal once in a while – be sure to follow their specific dietary restrictions.
- Some fun activities to do together:
 - Go out for coffee and conversation.
 - Go on a car ride to see something interesting.
 - Go to a good movie at a movie theater.



Acromegaly West: www.acromegalywest.com

Facebook Group: [Acromegaly Canada - Family & Friends Support Group](#)

Facebook Group for Patients: [Canadian National Acromegaly](#)