

# Supporting a Diagnosis of Acromegaly

## Rare condition brings new roles, terms, and concerns

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For many people who live with acromegaly, the road to a diagnosis can be long.<sup>1</sup> Receiving a diagnosis can be validating and a relief, but it also comes with questions about how to cope with the new aspects of managing a rare condition and integrating them into one's day-to-day and family life.

### Affecting the Family

Having a rare condition, like acromegaly, can bring complex emotions and new roles to everyone in the family. Family members of those with rare conditions may step in as advocates and caregivers. People who live with acromegaly may also experience anxiety and depression.<sup>2</sup> Talking with others who are living with acromegaly and who truly understand the day-to-day challenges may help. Patient advocacy groups can connect patients and their families to support groups, both online and offline.

### Disclosing an Acromegaly Diagnosis

When and how to discuss acromegaly with friends, family, and co-workers is an individualized decision and a new consideration for the recently diagnosed. There are several ideas to keep in mind when discussing a diagnosis:

- Information on how day-to-day life is affected and if assistance is needed
- Any potential risks to disclosing (such as employment discrimination)
- The potential benefits to disclosing (such as advocacy and support)

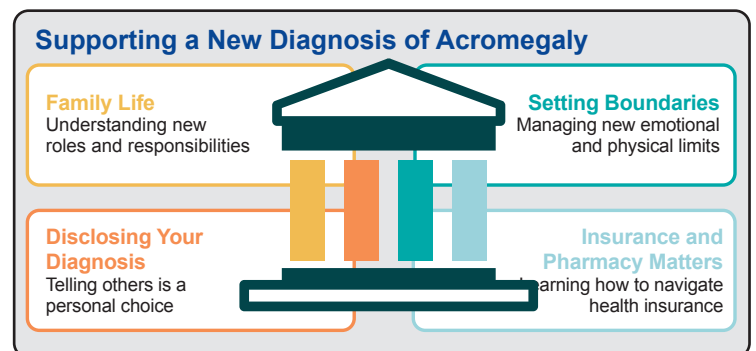
Disclosure isn't always needed, and for some situations, nondisclosure is a valid choice. However, it's important to keep in mind that while talking about rare conditions may have some drawbacks, it is also a way to find support and to educate others. The choice about who to tell, when, where, and how is ultimately up to the person living with acromegaly.

### A New Diagnosis May Bring Limits

People who live with acromegaly report that they have increased fatigue, anxiety, and depression, as well as decreased general well-being.<sup>2</sup> Working with a care team can be important in understanding how these challenges may be managed as well as how to adjust in everyday life. Connecting with other people who live with acromegaly through advocacy and support groups can help in learning tips and tools for living better with the condition.

### Adjustment Takes Time

Learning to live with a new diagnosis can bring successes and challenges. Receiving support for the physical, emotional, and administrative parts of the rare condition journey can help with adapting. Friends, family, co-workers, and a health care team can all be good sources of support, as can other people who live with acromegaly. Creating bonds within one's circle and in the acromegaly community can help make the adjustment easier.



**References:** 1. Adelman DT, Liebert KJ, Nachtigall LB, Lamerson M, Bakker B. Acromegaly: the disease, its impact on patients, and managing the burden of long-term treatment. *Int J Gen Med.* 2013;6:31-38. doi:10.2147/IJGM.S38594 2. Biermasz NR, van Thiel SW, Pereira AM, et al. Decreased quality of life in patients with acromegaly despite long-term cure of growth hormone excess. *J Clin Endocrinol Metab.* 2004;89(11):5369-5376. doi:10.1210/jc.2004-0669



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