Emotional Wellness With Acromegaly

Living powerfully with a rare condition

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A diagnosis of acromegaly can bring a lot of emotions as well as a long "to-do" list of doctor appointments, tests, and decisions. Maintaining a healthy emotional state can present challenges. Being proactive about signs and symptoms, learning to be an empowered patient, and seeking out support for mental health can all be parts of learning to live well with this rare condition.

What Does Your Body Say?

Listening to the body and providing for its needs can be an important part of living with acromegaly. Part of managing a rare condition includes having the confidence to ask questions of health care providers and being assertive about receiving and understanding the answers. Keeping a log of signs and symptoms may help to stay in tune with one's body in order to communicate these changes to a health care team.

Staying Social

People who live with acromegaly can have full, vibrant lives that can include exercise, travel, and an active social life. Being proactive about health care needs can help in becoming more confident while enjoying these activities. A good practice is to keep a list of medications and physicians in a wallet or on a smartphone should this information be needed. A medical alert bracelet that contains this information is another way to ensure that providers will have much-needed information in the event of an emergency.

Communication Is Key

Managing acromegaly is a team effort, and good communication is key in helping patients engage effectively with health care providers, family, friends, and colleagues. Education about acromegaly is important in understanding how the condition affects the body and quality of life. Finding a community of other patients on social media and working with advocacy groups can help in learning about the disease and in understanding how to have impactful conversations with health care providers.

Caring for Mental Health

Living with acromegaly can impact more than just the physical body. The diagnosis may come as a relief but learning that the condition might need surgery or ongoing maintenance medication can be distressing. People with acromegaly might experience anxiety or depression.¹ For that reason, it's important to recognize depression and anxiety early in its onset. In recent years, a new focus is being placed on helping patients cope with the difficulties of adjusting to an acromegaly diagnosis and its effect on everyday life. Working with a mental health professional can be part of a holistic approach to treating acromegaly. Discuss with your physician whether you need a referral to a mental health professional.

Living With Rare Disease

Life with a visible illness can be challenging but it can be helpful to find the balance between managing signs and symptoms and staying involved in the activities that bring enjoyment. Actively working toward empowerment and getting support to have day-to-day physical and emotional needs met is part of living well with chronic illness.

Surrounding Yourself With Emotional Wellness

Reference: 1. 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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