

Acromegaly Reality

Real stories, real
support, real life
with acromegaly

Wendy,
living with
acromegaly.

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Going beyond



the numbers

“My IGF-1 levels were normal—
but I still didn’t feel like myself.”

—Wendy, living with acromegaly

Sound familiar? You’re not alone. **True acromegaly control takes 2 things: managing IGF-1 (insulin-like growth factor 1) levels and symptom control.** While IGF-1 levels are a critical part of monitoring acromegaly, they don’t always tell the whole story. That’s where symptom control comes in. Even if your IGF-1 level is in the normal range, you might still be experiencing:

- Joint pain
- Leg weakness
- Difficulty sleeping
- Sweating
- Headaches
- Numbness or tingling
- Fatigue
- Swelling
- Short-term memory difficulty



Biochemical control

Keeping IGF-1 levels in normal range means you’ve achieved biochemical control. This is how your doctor assesses how well your acromegaly is managed. Elevated IGF-1 levels may mean your acromegaly isn’t under control—putting you at risk for serious complications. But that’s only half of the equation.



Symptom control

If symptoms are still negatively impacting your life, they need attention too. **Real success comes from managing the things you feel, like headaches and joint pain, in addition to your IGF-1 levels.** That’s why your voice matters just as much as your lab results. If you’re still dealing with symptoms, talk to your doctor.

Are you still struggling with acromegaly symptoms?

Take the acromegaly reality check to assess how well your acromegaly is really managed.

FINDING MY WAY WITH ACROMEGALY

Tony's story of facing acromegaly—and learning what it really means to manage it

It all started when Tony's hands and feet began to grow irreversibly, but he chalked it up to weight gain or building muscle since he had been working out regularly. When his hip pain became severe, his doctor suspected something and ordered a brain scan—and told him he had acromegaly.

When Tony was diagnosed, he didn't know what to expect. Despite his symptoms, he didn't think there was an urgent need for treatment and hadn't considered the long-term impact of some symptoms. He stayed active, kept working out, and tried to push through the changes he was feeling.

“I've always believed I could beat anything. I thought I could fight this without medication.”

Tony remained resistant to treatment. The idea of monthly injections didn't sit well with him. But over time, something shifted. He wasn't just worried about how acromegaly would affect him—he was worried about how it would affect his wife and kids too.

“I didn't want to take the injections. But I had to make it bigger than myself. I had to think about my family. If I didn't get treated, what would happen to them?”

Telling his kids he had acromegaly was one of his hardest moments. As a hands-on dad and basketball coach, he didn't know how acromegaly might change the way he showed up for them. Today, Tony takes an injection every month to help keep his IGF-1 levels in normal range—but symptoms still linger.

“I still deal with memory fog. I forget things all the time. It's why I stopped coaching basketball. I just couldn't remember the plays anymore...I won a city championship with a bad memory. But I think a lot about what I could've done if I had a better memory.”

Despite the challenges, Tony stays on top of managing his acromegaly, but he's honest about what “managed” really means. It isn't just about numbers; it's about how he feels.

“There's a mental side to this that you can't put on paper. You can have good numbers and still not feel good.”

Looking back, Tony wishes he'd started treatment earlier. But today, he's focused on moving forward.

“If I could talk to someone who thinks they can manage this on their own, I'd say, don't wait. Talk to your doctor. Talk to your family. It's not just about you. It's about the people who love you.”

Tony now knows the importance of advocating for himself and how being part of an acromegaly community has a positive impact on his treatment journey.

“Get more involved. What's helped me is having someone who understands what you're going through and being able to share experiences.”

Tony, living with acromegaly.

Sign up now to get helpful information and resources on living with acromegaly.

Inside IGF-1

What IGF-1 means and why it matters

IGF-1 plays a role in many body functions, including cell growth and repair, blood sugar control, and metabolism.

A high IGF-1 level means that you have too much growth hormone, which can lead to complications. Keeping your IGF-1 level in check is key to achieving biochemical control.



Understanding lab results

Normal ranges for IGF-1 levels can differ from person to person. First, they depend on your age and sex. Second, there's no one-size-fits-all "normal" for IGF-1 levels because labs use different tests.

Each test has its own way of measuring and defining a normal IGF-1 level range.

Frustratingly, not all IGF-1 tests give the same results. Some tests may say that your level is normal, while others may say that it's too high. That's why your results should always be checked against the specific normal range of the test you received.



Numbers matter. But so do you

Remember, even if your IGF-1 level looks "normal," you might still deal with acromegaly symptoms that impact your overall quality of life. This could mean your acromegaly isn't fully controlled. Your approach to managing acromegaly should look at both IGF-1 levels *and* symptom control, so you can feel your best.

Take *control* of your care

Find out what to ask, what to track, and how to stay on course

Managing acromegaly can be challenging—between dosing schedules, side effects, and breakthrough symptoms, staying on track with treatment isn't easy. Here are some tips on getting the support you need.



Speak up

Side effects from treatment, breakthrough symptoms, and symptoms of acromegaly can happen—but you don't have to keep suffering.

You know your symptoms best and it's important to share what you're feeling with your doctor. Make your next visit count by talking about how you feel. You can even use your results from the Acromegaly Reality Check quiz to help guide the conversation. **Go to acromegalyreality.com to take the quiz!**



You are *not* alone

For additional acromegaly support, our dedicated services are here to help.

- **Chat one-on-one with a nurse** who understands acromegaly
- **Find a doctor** who specializes in acromegaly
- **Connect with** the acromegaly **community**

Call **844-CRN-HELP** or visit crineticare.com to get started.

Track your side effects and symptoms in a notebook or app. Be specific—when, how often, and how intense they are.

Talk about it at your next appointment. Your doctor can only help you if they know about your experience.

Ask about other options for treatment.



BATTLING BREAK- THROUGH

Breakthrough symptoms—symptoms that continue or pop up when on treatment—can be a frustrating reality for people living with acromegaly. They can even occur when IGF-1 levels are considered stable.

SYMPTOMS

You're on treatment and taking your medication. You've had a few good weeks. Maybe you've even gotten back to a routine. You're feeling...normal. Then suddenly your joints start aching. Perhaps you're feeling more fatigued than usual. What previously felt like an everyday stress headache suddenly hits new levels of discomfort. And the sweating—it might feel like it's never going to stop.



“No one looks forward to being jabbed with a 21-gauge needle, so sometimes I put it off. I’m not great about having it exactly on a schedule, but it just gets to a point where I’m just feeling worse and worse. It’s never the right time. It’s never a great time to get an injection.”

—Ellen, living with acromegaly

The mental burden

The impact of breakthrough symptoms is not just physical. There is an emotional and psychological toll as well.

“If you ask my husband about the breakthrough symptoms, he would say emotional side effects,” said Ellen, a person living with acromegaly. “And I would agree with that. Like, why does everything feel like the end of the world?”

When sticking to it becomes a struggle

Breakthrough symptoms can be so painful and debilitating that you might end up self-adjusting your own treatment or even stopping treatment altogether.

50% of people on the most commonly used acromegaly treatments occasionally skipped or reduced doses*

From a survey of adults with acromegaly treated at 2 hospitals.*

Is it time for a closer look?

If the thought of your symptoms coming back before your next injection hangs over you like a cloud, or if you find yourself getting frustrated with your current treatment and wondering whether there may be other approaches, you are not alone. Talk to your doctor, advocate for yourself, and consider taking a closer look at your acromegaly.

*Siegel S et al. *Pituitary*. 2024;27(4):403-415.



Ellen, living with acromegaly.

Living with acromegaly

can affect many aspects of life, including your physical well-being, sleep, and mental health. It can also lead to related conditions such as diabetes and heart disease. While healthy routines and habits may not impact acromegaly itself, they may improve your overall quality of life and help you feel your best.

LIFE IN BALANCE

Support for



Your Body

Consider starting a light fitness routine. But make sure to talk to your doctor about what is appropriate for you.

Low-impact favorites like walking, swimming, cycling, or yoga might be a good place to start.

Consider asking if light resistance and body-weight exercises for strength are appropriate.

Avoid doing high-impact workouts unless you've discussed it with your doctor.



Your Nutrition

What you eat may make a difference. Food is fuel—and it's a way to support your general health.

Consult your doctor about which foods might impact related conditions such as diabetes and heart disease.

Discuss incorporating more whole foods, like fruits and veggies, lean proteins, and whole grains.

Ask if certain anti-inflammatory foods, like berries, leafy greens, and omega 3-rich fish, might help.



Your Rest

Quality sleep can improve your overall physical well-being and mood. Try to keep a consistent sleep schedule.

Wind down by turning off screens 30 minutes before bed.

Keep your room dark, quiet, and cool.

Avoid heavy meals too close to bedtime.



Your Mind

Taking care of your mental health is an important part of feeling your best, and even simple adjustments may help.

Consider mindfulness, breathing exercises, or meditation.

Move your body—even a few days a week may be beneficial.

Have you tried writing things down? A journal may help track both symptoms and emotions.



Your Care

Your healthcare plan is a team effort, but remember, you know your body best. Don't be afraid to advocate for yourself.

Keep up with regular appointments and lab monitoring.

Talk to your doctor before trying new workouts or diets.

Report any new or lingering symptoms—even if your numbers look good.

The lifestyle tips provided on this page are intended to support overall health and well-being. While these practices may help improve your health, they are not proven to impact the underlying progression or symptoms of acromegaly. Always consult with your doctor to determine what is right for you.

Access valuable acromegaly resources

Sign up today to get exclusive access to resources designed to help you navigate your acromegaly. These resources are available only to those who sign up, so don't miss your chance to take advantage of all we have to offer!

For more information on living with acromegaly and to get resources, visit acromegalyreality.com.

