

Questions to ask your healthcare team

A guide developed by patients for patients

The questions below were developed from a patient perspective to support open conversations with your healthcare team. Because every person's experience of acromegaly is different, your healthcare team is best placed to guide you on what applies to you.

After every question, you can write down any additional questions you might have around that specific topic.

Section 1: Newly Diagnosed

Finding out you have acromegaly can feel overwhelming. These simple questions will help you understand what's happening and what comes next – there are no wrong questions to ask your healthcare team.

1. Can you explain what acromegaly is, in simple terms?

WHY ASK?

It's completely normal not to have heard of acromegaly before. Hearing a clear, plain-language explanation from your healthcare team helps it sink in – and means you can explain it to family and friends too.

2. What is causing my acromegaly, and where exactly is it?

WHY ASK?

Most cases are caused by a small, benign growth (called adenoma) on the pituitary gland (a tiny gland at the base of the brain). Knowing the cause helps you understand the treatment options ahead.

3. What does the pituitary gland actually do?

WHY ASK?

The pituitary gland is a pea-sized gland at the base of the brain that acts as the body's master control centre for hormones. Some hormones released by the pituitary gland cause direct effect on other tissues and organs. Other hormones signals to other glands and organs to regulate things like growth, energy, metabolism, and stress responses. Understanding its role makes it much easier to follow why acromegaly affects so many different parts of the body.

4. I look different and others have commented on this. What has caused this change – and will I return to 'normal'?

WHY ASK?

The physical changes that acromegaly can cause – such as changes to facial features, hands, or feet – can affect how you feel about yourself, sometimes long before a diagnosis is even made. It is completely understandable to want to know what has changed and why.

Your healthcare team can explain which changes are caused by excess growth hormone, and be honest with you about which may improve with treatment and which may not. Having that conversation early helps you to set realistic expectations – and to know that these changes are a symptom of your condition, not something to feel ashamed of.

5. What are my treatment options, and what do you recommend for me?

WHY ASK?

Treatment is different for everyone – it might be surgery, injections, tablets, or a mix. Asking this early means you go into treatment feeling informed and involved in the decision, not just along for the ride.

6. Are there any side effects I should expect from treatment, how long might they last, and could they be affected by any other health conditions I have?

WHY ASK?

Treatment side effects can feel worrying, especially if you're already managing other health conditions. Asking this helps you know what to expect, which side effects may settle over time, and when something might need extra attention or a different approach.

7. Could acromegaly or its treatment affect my hormones, sex life, or fertility?

WHY ASK?

Acromegaly and some of its treatments can affect hormones in different ways, which may have an impact on things like periods, sexual wellbeing, or fertility. These can feel like difficult topics to bring up, but they matter – and it's completely okay to ask about them, especially if you are younger or thinking about having children in the future.

8. Will my care involve a specialist pituitary team with experience in acromegaly, and if surgery is needed, how experienced is the surgeon?

WHY ASK?

Acromegaly is rare, and experience really matters – both in medical care and in surgery. It is completely okay to ask whether your endocrinologist works closely with a specialist pituitary team, how often they treat people with acromegaly, and which centres or surgeons they work with. If surgery is being considered, knowing your surgeon has strong pituitary experience can make a real difference.

9. Are there other parts of my health that need to be checked because of acromegaly?

WHY ASK?

Acromegaly can affect the heart, blood sugar levels, joints, and more – often quietly, with no obvious symptoms. Early checks mean early action, and catching things promptly makes a real difference.

10. How will we know if treatment is working?

WHY ASK?

There are straightforward blood tests that show whether the condition is being controlled. Knowing what success looks like – and what the target numbers are – gives you something to track and feel positive about.

11. What symptoms should make me contact you between appointments, and who should I contact if I have concerns?

WHY ASK?

It's reassuring to know exactly what to look out for so you're not left guessing. Symptoms like new headaches, vision changes, or unusual tiredness are worth flagging – and it helps to know the best way to get in touch quickly if needed. It also helps to know who to contact if something comes up between appointments – whether that's your endocrinologist, endocrine nurse team, or another member of the team – so you don't feel you have to wait until your next clinic visit.

12. I've heard about something called IGF-1 – what is it, and why does it matter?

WHY ASK?

IGF-1 stands for Insulin-like Growth Factor 1 – it's a hormone produced by the liver in response to growth hormone. In acromegaly, levels of IGF-1 are usually too high, and bringing them back to a normal range is one of the main goals of treatment. You'll hear this term a lot at appointments, so asking your healthcare team to explain it in plain language – and to tell you what your own result means – helps you feel in control of your care rather than confused by the numbers.

13. Are there any symptoms or changes that will get better with treatment?

WHY ASK?

Living with acromegaly can involve symptoms like joint pain, sweating, or tiredness. Knowing that many of these can improve with treatment gives a realistic but encouraging picture of what life may look like further down the line.

14. Are there patient groups or support organisations in Europe I can connect with?

WHY ASK?

Connecting with others who understand what you're going through can make a huge difference. Across Europe, patient organisations – including groups linked to WAPO (World Alliance of Pituitary Organizations) – support people living with acromegaly and can offer practical advice and reassurance.

Your healthcare team may also be able to recommend national or local patient groups you can connect with in your area.

Write down your own questions:

Section 2: Follow-Up Appointments

Once you're settled into treatment, your check-ups are a chance to make sure everything is on track. These questions can help you get the most from each visit.

1. Are my blood test results showing the condition is under control?

WHY ASK?

There are two key markers in the blood (IGF-1 and growth hormone) that show whether acromegaly is well managed. Asking directly means you leave the appointment knowing where you stand, rather than wondering.

2. Are there any lifestyle changes or extra support that could help me manage symptoms, treatment, or things like weight, joints, or blood sugar?

WHY ASK?

Acromegaly is not caused by lifestyle, but things like movement, diet, symptom support, and treatment routines can still make day-to-day life easier for some people. There is also a lot of advice online – especially around weight, fasting, and blood sugar – and not all of it is reliable. Asking your clinical team means you can get advice that is right for you, rather than having to work it out alone.

3. Is my current treatment still the right one for me, or does anything need adjusting?

WHY ASK?

Treatment can sometimes need a tweak as time goes on – a dose change, a different medication, or an added therapy. Asking this keeps the conversation open and makes sure your treatment is always working as hard as it can for you.

4. When is my next scan, and what will it be looking for?

WHY ASK?

Regular MRI scans check whether the size of the pituitary adenoma causing acromegaly remains the same or increases/shrinks. Knowing when your next one is due – and what a good result looks like – helps you stay on top of your care.

5. Is my heart health being kept an eye on?

WHY ASK?

Acromegaly can affect the heart over time, even when you feel fine. A periodic heart check is a straightforward precaution that many patients don't think to ask about but really should.

6. Should I have a bowel check for polyps this year?

WHY ASK?

People with acromegaly have a slightly higher chance of developing bowel polyps. Asking this helps you find out whether you are due for a bowel check now, based on your previous results, your age, and how often your doctor recommends screening.

7. Has my blood sugar been checked recently, and is it normal?

WHY ASK?

Acromegaly can make it harder for the body to manage blood sugar, increasing the risk of diabetes. It's an easy thing to screen for, and knowing your status means you can take action early if needed.

8. How are my bones doing – am I at risk of any problems there?

WHY ASK?

Acromegaly and some of its treatments can affect bone strength over time. A bone density check is painless and quick, and if there's any concern, there are good ways to protect your bones going forward.

**9. I've been experiencing (symptom)
– is that related to my acromegaly or my treatment?**

WHY ASK?

Joint aches, tiredness, sweating, or mood changes are common symptoms, but it's easy to dismiss them as 'just life'. Your healthcare team can help work out whether they're connected, and whether anything can be done to help.

10. Is there any support available for how this condition affects me day to day – emotionally as well as physically?

WHY ASK?

Living with a long-term condition takes its toll in ways that go beyond the physical. Many specialist centres can refer to counselling, psychological support, or peer groups – but patients often don't ask, and doctors don't always think to offer.

11. Have all available treatment options, including clinical trials, been considered for my situation?

WHY ASK?

Your healthcare team is best placed to advise on whether all available treatment options have been considered for your individual situation. This is a good opportunity to ensure your care plan reflects the most current clinical thinking.

Write down your own questions:
