MY ACROMEGALY REFLECTION SHEET

NOTICE HOW YOU FEEL. SPOT CHANGES EARLY. KNOW WHEN TO ACT.

This sheet is for you. It is a simple way to notice how acromegaly is affecting you between appointments, and to spot changes worth mentioning to your healthcare team. There are no right or wrong answers, and you do not have to fill in every box.

Helpful tip.
Bring this sheet to your appointments. It can help you and your healthcare team have a more focused conversation about your care.

The symptoms here are drawn from two recognised acromegaly questionnaires — the Acromegaly Symptom Diary and the Acromegaly Quality of Life questionnaire (AcroQoL) — with a few additions that people often find matter after diagnosis.



ASSESS
Check in on how your symptoms have been.



CONSIDER
Look for patterns, and how they affect your daily life.



TAKE ACTION
Contact your healthcare team if something changes.

YOUR CURRENT ACROMEGALY TREATMENT

MONTH / DATES THIS SHEET COVERS

WAPO
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PART 1 · YOUR WEEKLY CHECK-IN 

Once a week, think back over the past seven days and give each symptom a number from 0 to 3.
Use the same day each week if you can.

0 = none | 1 = mild | 2 = moderate | 3 = severe | leave blank if you would rather not answer

Over the past week	Week 1	Week 2	Week 3	Week 4
Headache				
Joint pain				
Fatigue (feeling tired)				
Muscle weakness				
Sweating				
Swelling				
Numbness or tingling				
Sleep difficulty				
Memory or concentration changes				
Vision changes — blurring, double vision, bumping into things				
Digestive symptoms — feeling sick, abdominal discomfort, diarrhoea or constipation				
Low mood, anxiety or mood swings				
Snoring, or feeling sleepy during the day				

Anything else you want to track:

PART 2 · SLOWER CHANGES · ONCE A MONTH

Some acromegaly changes happen gradually, so they are easier to spot month to month than day to day.

Compared with last month	No change	Some change	Not sure
Changes in how rings, shoes, gloves or hats fit			
Changes in your face, jaw, tongue or the way your teeth meet			
Changes in your skin — thicker, oilier, or new skin tags			
Changes in your weight			
Changes in your sex drive			
Changes in your menstrual cycle			
Changes in how thirsty you feel or how often you need to pass urine			

PART 3 · LOOKING AT THE PATTERN



Since your last dose, have you noticed any of these?

- ◯ Discomfort where you take your treatment
- ◯ Nausea or an upset stomach
- ◯ Changes to your bowels
- ◯ None of these

How much are your symptoms affecting your daily life?

For example: work, energy, sleep, hobbies, time with other people.

- ◯ Not at all
- ◯ A little
- ◯ Quite a lot
- ◯ A lot

How much is your treatment affecting your daily life?

This includes side effects, appointments, and fitting treatment around your routine.

- ◯ Not at all
- ◯ A little
- ◯ Quite a lot
- ◯ A lot

Looking back over the whole month, overall my symptoms are:

Compare how you feel now with how you felt at the start of the month.

- ◯ Improving
- ◯ About the same
- ◯ Getting worse
- ◯ Hard to say

PART 4 · ANYTHING ELSE ON YOUR MIND

Use this space however you like — how you have been feeling physically or emotionally, questions for your team, or anything that might explain a change (a missed dose, an illness, a stressful few weeks, travel).

QUESTIONS FOR MY NEXT APPOINTMENT

Things you would like to ask, or symptoms you want to be sure you mention.

WHEN TO CONTACT YOUR TEAM

Seek urgent medical help immediatly

Do not wait for your next appointment. Contact your healthcare team straight away. If you cannot reach them, seek emergency medical care.

- A sudden, severe headache — especially with vision changes, being sick, or feeling faint
- A sudden change in your eyesight
- **If you have adrenal insufficiency:** being sick and unable to keep your hydrocortisone tablets down
- **If you have AVP deficiency (AVP-D, also called diabetes insipidus):** being unable to take or keep down your desmopressin, or to drink enough to replace the fluids you are losing

Contact your healthcare team soon

- Your symptoms have been getting worse over two weeks or more
- You notice a new or unusual symptom
- Your symptoms are getting in the way of everyday activities
- You feel your condition is not well controlled
- Your treatment is causing side effects you are finding difficult
- You feel worried or unsure about any change

HEALTHCARE TEAM — NAME

PHONE NUMBER — INCLUDING OUT OF HOURS

This is a personal reflection tool to support conversations with your healthcare team. It is not a validated questionnaire, it is not scored, and it cannot diagnose or assess how well your acromegaly is controlled. Always speak to your healthcare team about any concerns.

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