

YOUR TURN: START TELLING YOUR ACROMEGALY PATIENT STORY

Below is an outline template to help you create the structure of your story. You may find that not all of these elements play a part in your story, which is fine. Just skip over anything that doesn't feel right and move to the next item.

STORY POINTS	THOUGHT STARTERS	EXAMPLE	YOUR TURN
<p>Story point 1: What is acromegaly?</p>	<p>What causes acromegaly? What happens in your body?</p>	<p><i>I have a rare endocrine disease called acromegaly caused by a benign tumor on the pituitary gland that secretes excess growth hormone. There's only about one new case per 100,000 people.</i></p>	
<p>Story point 2: What are (were) your symptoms?</p>	<p>What physical changes did you experience? Any nonvisible symptoms you had to deal with? How have they affected your day-to-day?</p>	<p><i>The symptoms of acromegaly vary. I have larger hands and feet and a bit of a pronounced jawline from excess growth hormone. I also get fatigued quickly and get frequent headaches, so I need to avoid overcommitting myself.</i></p>	

FEELING STUCK?

If even starting with an outline feels daunting, consider warming up with a bit of freewriting.¹ Freewriting helps you get out of your head and write whatever comes to mind, free of judgment. The only rule is you need to write without stopping for a certain amount of time. Once you've done a free-write for 15 minutes or so, then you can start outlining.

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<p>Story Point 3: What was your path to diagnosis?</p>	<p>How many doctors did you see? How long did it take for you to get a diagnosis? How did you find the doctor who finally "got" you?</p>	<p><i>I went to all kinds of doctors; a foot doctor, internal medicine, and an ENT for my headaches, but no one could tell me what was happening. After about 15 years, I was referred to an endocrinologist and was finally diagnosed with acromegaly. Unfortunately, this delay in diagnosis isn't unusual because this disease is so rare.</i></p>	
<p>Story Point 4: How did all of this affect you at the time?</p>	<p>How did living in the dark about your disease feel? Did your life change? If so, how? How did it affect your job? Your social life? Be as honest and direct as feels appropriate.</p>	<p><i>Getting diagnosed was so frustrating. Sometimes I'd laugh about it; other times, I'd cry. I was too tired to play with my kids for more than ten minutes. I didn't want to go out with my friends, and I gave up hobbies I loved.</i></p>	

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<p>Story Point 5: What treatment did you pursue, and what was the outcome?</p>	<p>Did you have surgery? Do (or did) you take medicine? How effective were these treatments?</p>	<p><i>When the doctor first discovered my tumor, I had to have surgery to remove it. Now I get a monthly injection to help control my growth hormone levels, and I find that acupuncture helps my headaches. My levels mostly stay within normal range, but the shots are painful. Some overgrowth has gone down since I've taken these measures and my energy level is better, for the most part.</i></p>	
<p>Story Point 6: How do you cope today?</p>	<p>How do your symptoms today compare with those before your diagnosis? Where do you get support? How do you take care of yourself?</p>	<p><i>I take it one day at a time, like everyone else, and some days are better than others. However, swimming, watching what I eat, and meditating all seem to help. I've also met some great people on online support sites.</i></p>	

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STORY POINTS	THOUGHT STARTERS	EXAMPLE	YOUR TURN
<p>Story Point 7: What should others understand about living with acromegaly?</p>	<p>What, if anything, do you need from your listener? If you had to boil it all down to one takeaway for them, what would it be?</p>	<p><i>I'd ask that you have a little patience with me. My doctor visits take a big chunk out of my day every month. I also need to lie down for an hour or two most afternoons, so I can't always answer calls and emails right away. Please know I'm not ignoring you.</i></p>	
<p>Story Point 8: How has acromegaly positively influenced your life?</p>	<p>While we don't advocate making up happy endings, they can give people a sense of hope or positivity, making them more empathetic and more receptive to what you're saying.</p>	<p><i>It's been a long road and not something I thought I'd experience. It's definitely made me more apt to speak my mind and not be a doormat—which has been a real asset at the car dealership!</i></p>	

REFERENCES

1. The Writing Process: Freewriting, MIT Global Studies & Languages, <https://writingprocess.mit.edu/process/step-1-generate-ideas/instructions/freewriting>