



# Catherine

EGPA patient

**Primary disease presentation:**  
Lungs, Nerves, Heart, Allergies

## Day-to-day living

- Lives in the UK and works part-time in communications for the Government
- Her cousin has also recently been diagnosed with GPA

## Disease history

**First symptoms:** Flu like symptoms, headaches and tiredness diagnosed as a viral infection. Went back to the GP three more times but was again told it was a viral infection

**Early progression:** Difficulty breathing diagnosed as asthma. Nerve damage in one foot. Lost the ability to walk for a while

**Delay to diagnosis:** One year from first symptoms to ending up in A&E. Diagnosed with EGPA

**Initial treatment:** Prescribed six cycles of cyclophosphamide + high-dose steroids

**Maintenance therapy:** Azathioprine and gradually reduced steroid dose. Experienced a disease relapse 2 years later. Taken to hospital and prescribed high-dose steroids. Returned to gradually decreasing azathioprine and steroid dosages

**Treatment side effects:** Struggled with steroids. Couldn't focus. Highs and lows of adrenaline all day and night. Difficulty sleeping. Suffered panic attacks after each cycle of cyclophosphamide and had to go to the emergency doctors

**October 2019:** Receiving low dose azathioprine. Mobility problems and symptoms are not so severe. She can work part-time and live a balanced life by pacing herself and resting more often (for example, by sleeping during the day if she is going out at night)

## In her own words

### Symptoms:

“So for a year I couldn’t walk....luckily about a year after my diagnosis the nerves started to grow back really slowly so I can now walk.”

### Side effects of treatment:

“I found concentrating and focusing really difficult on high doses of steroids. I was pretty ill after each cycle of cyclophosphamide – a lot of it was panic because it set off all kinds of reactions in my body and it was like suffering from panic attacks.”

### Long-term impact of ANCA vasculitis:

“I have to pace myself and rest more often. I certainly adjust my social activities, if I am going out for the evening I often have to sleep for an hour during the day.”

### Personal advice:

“I think people when they’re newly diagnosed should try and find out as much about the disease as possible and really challenge your clinicians if you’re not getting the answers you want.”

### Patient support groups:

“Make sure that you use the support networks like Vasculitis UK. They have a forum that you can go in and ask questions to lots of people that have got the same symptoms.”

### Personal goal:

“I think my future dream is always to come off medication completely.”

“Make sure that you use the support networks like Vasculitis UK.”