



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 two years later. Taken to hospital and prescribed high-dose steroids. Returned to gradually decreasing azathioprine and steroid dosages

Challenges of treatment: Struggled with impact of some treatments. Couldn't focus. Highs and lows of adrenaline all day and night. Difficulty sleeping. Suffered panic attacks

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.”

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.”

ANCA, anti-neutrophil cytoplasmic antibody; EGPA, eosinophilic granulomatosis with polyangiitis

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