



Hellen

GPA patient

Primary disease presentation:
Lungs

Day-to-day living

- Lives in the Netherlands with her husband, Frank, and their three children
- Volunteers at Vasculitis Stichting in her spare time
- Has found a lot of support in her faith which helped her cope with the disease

Disease history

First symptoms: Woke up in the morning struggling to breathe. Felt as though she had no air in her lungs and found it a struggle to walk upstairs

Early investigation: Visited her doctor, who was startled by her symptoms. Referred immediately to hospital where they checked to see if she had a pulmonary embolism

Journey to diagnosis: After confirming that she did not have a pulmonary embolism, doctors continued trying to identify her condition over the next few months. Diagnosis was finally confirmed following a biopsy, around 5–6 months after her first visit to the doctor

Symptoms prior to diagnosis: Experienced multiple headaches, joint pain and fatigue

Treatment: Received a steroid (glucocorticoid) and methotrexate first

Specialist support: Has seen multiple specialists over the years including a lung specialist, an internist, an ear, nose and throat specialist, a rheumatologist, and an ophthalmologist

Impact on life: Had to stop working and has not worked since. Social life has been affected and feels less cheerful

In her own words

Symptoms:

"I had a lot of headaches, joint pain, and I was very terribly tired."

Feelings after diagnosis:

"At first I was really upset, because I did not know what it was and what it meant."

Impact on daily life:

"In the beginning it was difficult, slowly I could do more and more things again. But still not enough to go to work or things like that. Then you adapt, so going out less often, now the day is actually calm and I do a bit of volunteer work."

Personal advice:


"Look for people that know what they're talking about, who can tell you more about your condition, like support organizations. Search for peers, to be able to talk about it. Don't internalize it. And just try to get joy out of all the small things."

Patient support groups:

"To find out about my condition, I received a brochure from the hospital, and then I called the Vasculitis Stichting who understood exactly what it was like, and sent me a whole bunch of information."

ANCA, anti-neutrophil cytoplasmic antibody; GPA, granulomatosis with polyangiitis

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