

Anne



GPA patient

Primary disease presentation:
ENT, Lungs, Joints

Day-to-day living

- Anne lives on her own in an apartment in the Netherlands
- Hobbies include painting and drawing
- Originally a full-time graphic designer, but currently works 18 hours/week because of ANCA vasculitis. Hoping to increase her hours in the future

Disease history

First symptoms: In March/April 2015, flu like symptoms, sinusitis inflammation, inner ear inflammation, crusts inside the nose

Early progression: Coughing got worse and ear started to hurt. Joint pain in fingers, wrists, knees and ankles, and later on, swelling around the joints made it painful to move. Doctor prescribed antibiotics, but they did not work. When she almost lost all hearing in one ear, she went to hospital. Sent home with painkillers and nose drops

During national holiday: Woke up unable to move one side of her face. Searched the internet and suspected a link with her ear infection. Hospital emergency department prescribed a high-dose steroid (glucocorticoid) to relieve pressure and get mouth working. Felt better after 1 week, but no real effect on ear or face

Operation: Scans showed infected ear. Operation to clear ear did not improve hearing. When steroid (glucocorticoid) stopped, she started feeling worse again, could barely move because of joint pain, lost sense of taste, had complete loss of voice, two broken ribs due to coughing

Diagnosis: After a few weeks of being sick and not leaving home, she attended a pre-booked doctor's appointment. Admitted to hospital. Doctor recognised the initial symptoms and suspected vasculitis. They did some tests including a biopsy from the nasal mucous membrane. Diagnosis of ANCA vasculitis received in June 2015

Treatment flow: Prescribed cyclophosphamide + high-dose steroid (glucocorticoid) + plasmapheresis (to replace unhealthy plasma with healthy plasma). Stayed in hospital for 2 weeks before feeling better and going home

Relapse: After a change of medicine 3 months into the treatment, a flare caused narrowing of the windpipe. Windpipe had to be stretched and rituximab was added to treatment

October 2019: Had what is believed to be the last dose of medication. Own immune system is starting to work again. Bit scared of becoming sick again

In her own words

Diagnosis:

"I feel quite lucky that they found it so quickly (2 - 3 months) and that my doctor wasn't really new to the disease. He had other patients that had it, so he knew it was a possibility."

Initial side effects of treatment:

"Not in the beginning because you start feeling better and my voice started to come back. I was really happy that they found what I had and had a treatment that worked."

Long-term impact of ANCA vasculitis:

"I get tired more quickly, but it's not that bad."

Personal advice:

"I really like to focus on the positive things."


Patient support groups:

"My mum really got a lot of information from Vasculitis Stichting [the Dutch vasculitis patient support group]. After a year or so, I was open to going to the meetings and now I help them with their design work."

Personal goal:

"I just want to live a normal life as far as I can."

"I really try not to let ANCA vasculitis hold me down."



“I really like to focus on the positive things and try not to let ANCA vasculitis hold me down.”