

Wil

GPA patient

Primary disease presentation:
ENT

Day-to-day living

- Lives together with his wife Marleen in the Netherlands
- They have a second home in Austria, where they currently spend around 10 weeks per year, and enjoy taking walks
- Suffers from fatigue affecting his ability to work and socialise

Disease history

First symptoms: Couldn't breathe through his nose, particularly at night. Had to breathe through his mouth and repeatedly woke up feeling thirsty, contributing to fatigue

Delay to diagnosis: Went to the GP but was not diagnosed with GPA at the time. Symptoms stayed the same until diagnosis was made by a specialist in 2001, approximately 18–24 months after he first visited the GP

Treatment: Initially received antibiotics and a nasal spray. Treatment has remained the same ever since, but the dose of antibiotics has been gradually increased over time

Impact on life: The biggest problem has been the disease/treatment induced fatigue, and its impact on his ability to work

Impact on wife: Caring for Wil reduces Marleen's ability to take part in everyday activities. She feels less able to do things such as visiting friends and going for walks. Despite this, Marleen has adapted to the situation and still takes part in a wide range of different activities without Wil



In their own words

Symptoms:

Wil – “I couldn’t breathe through my nose, especially at night. I had to breathe through my mouth all the time and that was almost impossible. I woke up very often. I had to drink something at night. And that was actually the biggest problem, and the fatigue that went along with it.”

Impact of diagnosis:

Marleen – “He had been suffering for so long already, to me it was a real relief in the sense that you knew he was not going to die because of this, but we did not know anything about the disease itself.”

Long-term impact of ANCA vasculitis

Marleen – “Things that you would normally do in the evening are no longer possible because of his fatigue. But my own life does go on. We hope that he remains in such good health that we can continue our walks.”

Disease awareness:

Marleen – “I cannot talk about it with friends and family, because there has never been anybody in the family that has had the disease.”

Personal advice:

Wil – “Always go to a renowned hospital, where there are better educated doctors that really go deep into these kinds of auto-immune diseases.”

Marleen – “Inform yourself about the situation, go to a specialist with it. Ask your questions and do not be afraid to ask because it is unfamiliar to you.”

Patient support groups:

Wil – “For me the most important source of information was the vasculitis.nl website.”



“The biggest problems that I’ve had with it are work and fatigue.”

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

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