

Klaus

GPA patient

Primary disease presentation:

Kidneys, Lungs, Limbs

Day-to-day living

- 62 years old, lives in Germany, married to wife Heike, with four grandchildren
- Runs patient association group Selbsthilfe Vaskulitis e.V
- Diagnosed with GPA in 2008 after 3 years of worsening symptoms

Disease history

First symptoms: Bloody cough, followed by pain in the limbs and swollen legs. Liver function was very poor. After 3 weeks symptoms subsided but soon returned with pain in the legs. The general practitioner checked his liver and came to the conclusion that he must be an alcoholic even though he never drank

Diagnosis: In 2008 everything fell apart. His legs were so swollen he couldn't walk. Heike called an ambulance and he was taken to hospital and diagnosed with lung cancer. At the same time his kidneys started failing. He was transferred to a specialist hospital and was diagnosed with GPA within an hour. He was 50 at the time

Treatment history: Haemodialysis did not work so he was given a steroid (glucocorticoid) injection. Then went back on dialysis for 3 days and by the third day was beginning to feel better. Despite the high dose of steroids, he was still in pain. After 11 years of steroids, an MRI revealed an accumulation of fatty tissue behind his sternum. Steroid treatment was discontinued. He now takes mycophenolate and rituximab every 3 months along with painkillers

Relapse: In 2017, he had a relapse and collapsed. The swelling in his legs returned accompanied by severe pain. He was exhausted but couldn't sleep because of the pain. This continued for 4 months. Some pain relief medications can cause him to retain water and when this happens his legs swell again



In his own words

Symptoms:

Klaus – “I had a bloody cough first. Then the pain started in my limbs all over my body. My legs were swollen and I got petechiae. That was in 2005.”

Diagnosis:

Klaus – “The senior doctor said to me ‘You will not be fit again, you will not be healthy. You can forget about your work. You can apply for a pension’. That was at 50.”

Long-term effects of ANCA vasculitis:

Klaus – “I was a bundle of energy and then the disease showed me how far I could actually go. Five metres and I’m done.”

Heike – “Klaus’ quality of life is also very, very limited. He used to walk and hike a lot. Unfortunately, he can’t do that anymore. Today he walks on crutches and it’s slow progress if you want to go somewhere.”

What a typical day looks like:

Klaus – “I have to take 26 drugs a day. On a typical day Heike leaves the house in the morning, I take a shower as best I can with the help of crutches and walking aids. Sometimes I have to crawl up the stairs because my legs just don’t work.”

Heike – “There are also days when Klaus is very moody. As carers for GPA sufferers, it’s not as easy as it may look. We have to endure the changing moods of our partners. There are phases when they’re in pain and they’ll blame other people.”

Personal advice:

Klaus – “My advice for new patients or new sufferers is that they have to accept their illness. New patients are practically facing a brick wall, and you need to break through that wall – I give them help and advice on where to turn.”

“I was a bundle of energy and then the disease showed me how far I can actually go.”



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

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