



Hermann

GPA patient

Primary disease presentation:

ENT (deafness in left ear, Joint pain, Fatigue)

Day-to-day living

- Lives with his wife in Mainz, Germany
- Had to stop working 3 years ago due to the disease
- Leads a patient self-help group at the University Medical Center Mainz (Selbsthilfegruppe Vaskulitis Mainz), organising regular meetings and lectures with specialists

Disease history

First symptoms: When initial symptoms occurred, he saw an ENT physician who thought he was suffering from otitis media (middle ear inflammation). In December 2005, the deafness spread to his right ear and by New Year's Eve he was almost completely deaf

Initial diagnosis: Given very high steroid (glucocorticoid) doses in the hospital and medication to promote blood circulation in both ears. Hearing returned. An MRI scan was carried out and his eyes were examined; various blood tests were performed which showed a positive ANCA test, leading to the diagnosis of ANCA vasculitis

Relapse: In autumn 2006, he was admitted to hospital and given high-dose steroids (glucocorticoids). He then began therapy with cyclophosphamide and stayed in hospital for about a month. Over the next 6 months he was given high doses of steroids which caused bloating and tiredness. When the cumulative dose of cyclophosphamide was reached, he received rituximab in 2007, which led to full remission

Since achieving remission: Takes immunosuppressive medication at regular intervals and every 3 months goes to the doctor to have blood tests

Living with ANCA vasculitis: He leads a self-help group called Vaskulitis Mainz. His wife supports him both with the self-help group and with his health issues

In his own words

Symptoms at relapse:

"I had joint pain, I had night sweats, my eyes were red, I could hardly sleep and I felt extremely tired and worn out in everyday work."

Side effects of treatment:

"Over 6 months, I was given extremely high doses of steroids (glucocorticoids) which caused bloating. I had a moon face. I couldn't sleep well at night and my entire psyche, my entire body was completely messed up."

Feelings after diagnosis:

"In the beginning, the illness was associated with very great uncertainty as well as a lot of fear. I had no contact with other patients at all for many years so I was unable to talk about my experiences. The information I found online wasn't really helpful."

Daily routine:

"I allow myself enough rest and avoid large groups of people due to my very severe immunosuppression. I also avoid contact with people with infections and infectious diseases. I pay attention to hygiene in the world around me and also try to do some sport and eat a reasonably healthy diet."

Patient support groups:

"Together with the group I want to give people with ANCA vasculitis the opportunity to exchange experiences."

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