

Elisabeth

GPA patient

Primary disease presentation:
ENT, Lungs

Day-to-day living

- Elisabeth and Peter met when they were both 16, and have been married for the past 53 years
- They live in the Netherlands, where they are from, but previously lived in England for six years
- Peter is chairman of Vasculitis Stichting and a founding member of Vasculitis International

Disease history

Problems before diagnosis: Had problems over a period of two years. Main issues were tiredness and a series of ear infections, eye infections and nose problems

Referral to specialist: Had an ear infection that didn't go away. After two courses of antibiotics, the problem was still not cured. Had to force the doctor to get a referral to an ear, nose and throat specialist for further investigation

Diagnosis and treatment: Was diagnosed with GPA following referral. Received steroids (glucocorticoids) and chemotherapy, was told that if treatment did not work then hope was low. After two weeks, treatment started to make a noticeable difference

Relapses: Has had two flare ups since her initial treatment. These have been managed through further treatment with high dose steroids

Adapting to life with ANCA vasculitis: Goes out less often than she used to but still makes an effort to see friends. Spends a few hours resting each day due to energy levels



In her own words

Daily routine:

Elisabeth – “I get up about eight. Then, before I finish taking a shower and getting dressed, an hour has passed almost – because then I’m dead tired. In between I go and sit for a bit. Because of the tiredness, you cannot do a lot.”

Partner’s perspective:

Peter – “She was so incredibly sick that she couldn’t participate in the process of making choices about her care. I was left with the confusion and the responsibility of solving things. I was very worried because all of a sudden I realised that I could lose my wife and the children could lose their mother.”

Accepting limitations:

Peter – “She has a great talent to accept something very quickly, to accept setbacks, to accept the illness. Accepting your illness is already a very big accomplishment. If the foot doesn’t work anymore, then she just walks on one leg for a while. If the arm doesn’t work anymore, she’ll just use one arm for a while.”

Challenges of treatment:

Elisabeth – “I don’t think I was well educated by my doctor, because you gain weight with some treatments. I was size 34 when I got GPA and I came back home a size 42. I’ve never been fat... I thought it was horrible.”

Advice to others:

Peter – “The most important thing is to make sure that you’re informed. Realise that it’s a rare disease of which we don’t know the origin, and that the doctor doesn’t know everything all the time. No two patients are the same. So whatever you read or hear, it can be slightly different for you.”

Impact on hobbies:

Elisabeth – “Previously, we travelled a lot, to far away countries where hygiene isn’t always like it should be, so we can’t go there anymore. And the tiredness... I’m tired very quickly. So there’s a whole lot of things you cannot do anymore and you have to live with that.”

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

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“The most important thing is to make sure that you’re informed.”

