

Maresa

GPA patient

Primary disease presentation:
Kidneys, Lungs

Day-to-day living

- Maresa, aged 20, and her boyfriend and carer, Kai, are from Germany
- Passed police force entrance exam at age 19, but after being diagnosed with ANCA vasculitis just one month later, she had to give up her dream job

Disease history

First symptoms: Flu like symptoms over and over again, was constantly sick for 2–3 years, caught a cold, had tonsillitis, liver pain, fever then eventually started coughing up blood

Diagnosis: 5 days after being hospitalised her lung collapsed, rushed to a specialist hospital to identify the cause. Was in an induced coma whilst she was examined by specialists from each department and diagnosed with GPA

Treatment: Started with high-dose steroids (glucocorticoids) and two doses of chemotherapy, then continued with steroid treatment

Standard of care side effects: Significant change of appearance caused by treatment; heavy psychological and physical burden; fatigue

Ongoing monitoring: Blood is taken and checked by physician every 4 weeks; sees a specialist physician regularly

Adapting to life with ANCA vasculitis : Goes to bed earlier and sleeps more often. While she still suffers from fatigue, thanks to the support of her doctors, Maresa has been able to start studying again

Help: Gets more information from web/social media interactions with other ANCA vasculitis patients, she has met Martina, another patient case study profile, through her social media blog



In their own words



Feelings after diagnosis:

Maresa – “You realise that you are seriously ill. I had been accepted into the police academy, which then was off the table of course. That was a big shock.”

Initial side effects of treatment:

Maresa – “When I got home, we removed all the mirrors, because after the steroids I felt so disgusting that I couldn’t look at myself anymore.”



Daily routine:

Maresa – “I have a little dog now and he is active. He really keeps me busy, so I have something to do and someone who needs me. I take care of him and I also meet up with friends.”

Personal advice:

Kai – “You have to set new goals. It is also quite normal to feel sad.

But little by little, it will even out again. Then the sad moments become fewer and the beautiful moments more.”

Patient support groups:

Kai – “I think it’s good that Maresa also has contact with others, because that helps, and then nobody is alone. Then you always have a contact person if you don’t want to confront your family and friends with it.”



Future goals:

Maresa – “That I can live a normal life with Kai and maybe later be able to have children.”



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