

Martina

MPA patient

Primary disease presentation: Kidneys

Day-to-day living

- Lives in Germany and is a single mother with two young children (3 and 9 years old)
- Is a kindergarten teacher, but had to quit her job due to infection risks and now works part-time as a physiotherapy studio receptionist
- Believes that connecting with patient support groups gives her a sense of belonging and provides emotional support

Disease history

First symptoms: Flu like symptoms, headaches and tiredness diagnosed as a viral infection. Went back to the GP several times but was repeatedly told it was a viral infection. One day it got so bad she had to go to hospital

Family history: Her brother died a year before she was hospitalised. The doctor told the family it was related to organ failure. Due to her brother, she had the courage to speak up and seek better support

Delay to diagnosis: Several years from first symptoms to ending up in A&E. Fortunately, a rheumatologist was present in the hospital and diagnosed MPA. Tests showed her kidney function was very poor. Nephrologists took good care of her and prevented her from needing dialysis

First treatment: Double dose of rituximab + high dose of glucocorticoids (steroids). Rituximab did not appear to be effective at first, so cyclophosphamide was administered between doses. After 12 weeks of rituximab, efficacy occurred

Maintenance therapy: Rituximab keeps her in remission currently, although after each dose she needs to sleep for two days, feels nauseous and experiences mood swings. Her work life was also affected as she was recommended to stop working as a kindergarten teacher

Help: Connecting with other ANCA vasculitis patients via social media helps her cope with the situation. Although she has fewer friends since being diagnosed, those who remain are reliable and often look after her and get her away from her everyday life

Today: Glad about the alternative job offer she received – being able to work part-time and having a boss and colleagues that understand her situation and support her



In her own words

Symptoms:

"I was sent back home from the doctors many times and told 'This is a flu – be patient it will be better'."

Challenges of treatment:

"I had to stop my intial treatment because it affected my kidneys negatively."

"I can no longer work as a kindergarden teacher, because under immunosuppressants I simply don't have an immune system."

"I had to look for a job where I was less exposed to infection and could work part-time."

Personal advice:

"If you feel sick and it is not getting better, don't let them send you home. Ensure they check you over properly."

Patient support groups:

"There are local patient support groups available. I like to use social media such as Instagram and Facebook. I connect with the patient support group Selbsthilfe Vaskulitis e.V. The connection with others helps me to cope with my disease better."

Personal goal:

"I am a young mother – I want to take care of my boys and see them grow up."

If you feel sick and it is not getting better, don't let them send you home."

ANCA, anti-neutrophil cytoplasmic antibody; MPA, microscopic polyangiitis

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