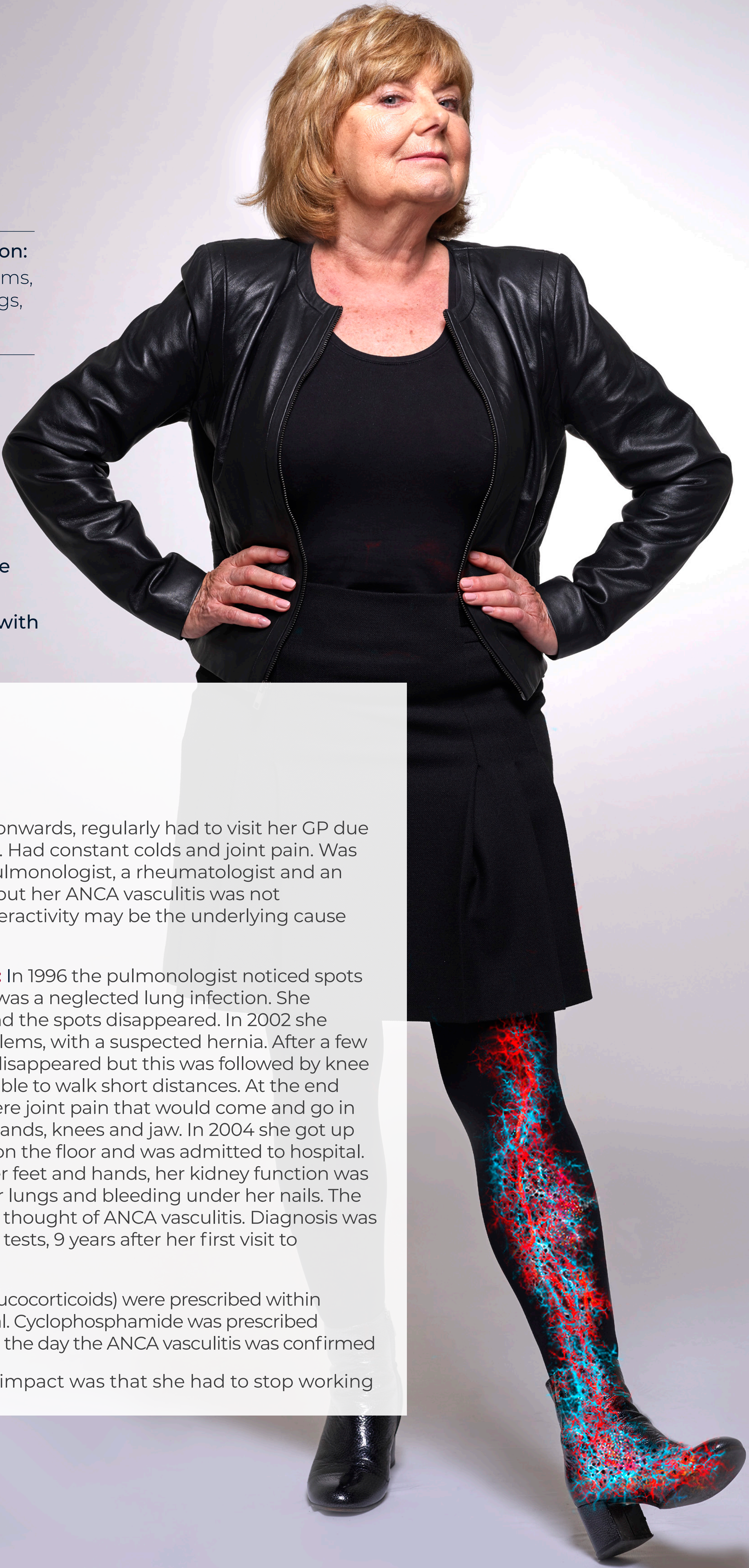
Rina

MPA patient

Primary disease presentation:
Neurological failure symptoms, Joint pain, Spots on the lungs, Bleeding under the nails



Day-to-day living

- Married and has two adult sons
- Diagnosed with MPA in 2004, when her sons were 9 and 13 years old
- Lives in the Netherlands with her husband

Disease history

First symptoms: From 1995 onwards, regularly had to visit her GP due to frequent health problems. Had constant colds and joint pain. Was several times referred to a pulmonologist, a rheumatologist and an ear, nose and throat doctor, but her ANCA vasculitis was not recognised. Was told that overactivity may be the underlying cause of her health problems

Further delays to diagnosis: In 1996 the pulmonologist noticed spots on her lungs, but thought it was a neglected lung infection. She was prescribed antibiotics and the spots disappeared. In 2002 she developed serious back problems, with a suspected hernia. After a few months the back problems disappeared but this was followed by knee problems and she was only able to walk short distances. At the end of 2003 she experienced severe joint pain that would come and go in different places: hips, arms, hands, knees and jaw. In 2004 she got up one morning and collapsed on the floor and was admitted to hospital. In addition to problems in her feet and hands, her kidney function was poor, there were spots on her lungs and bleeding under her nails. The rheumatologist immediately thought of ANCA vasculitis. Diagnosis was finally confirmed after ANCA tests, 9 years after her first visit to the doctor

Initial treatment: Steroids (glucocorticoids) were prescribed within 2 days of admission to hospital. Cyclophosphamide was prescribed 4 days after hospitalisation on the day the ANCA vasculitis was confirmed

Impact on life: The biggest impact was that she had to stop working

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In her own words

Emotions starting treatment:

“When I was hospitalised, I was very afraid I wouldn’t make it. I had two children aged 9 and 13. The thought that I might have to leave them and my husband behind was unbearable… I spent 5 weeks in the hospital and 5 weeks crying. No one could tell me it was going to be okay.”

Long-term impact of ANCA vasculitis:

“I can’t do everything I used to do anymore.”

Personal advice:

“The early period is very annoying and you have to go through that.”

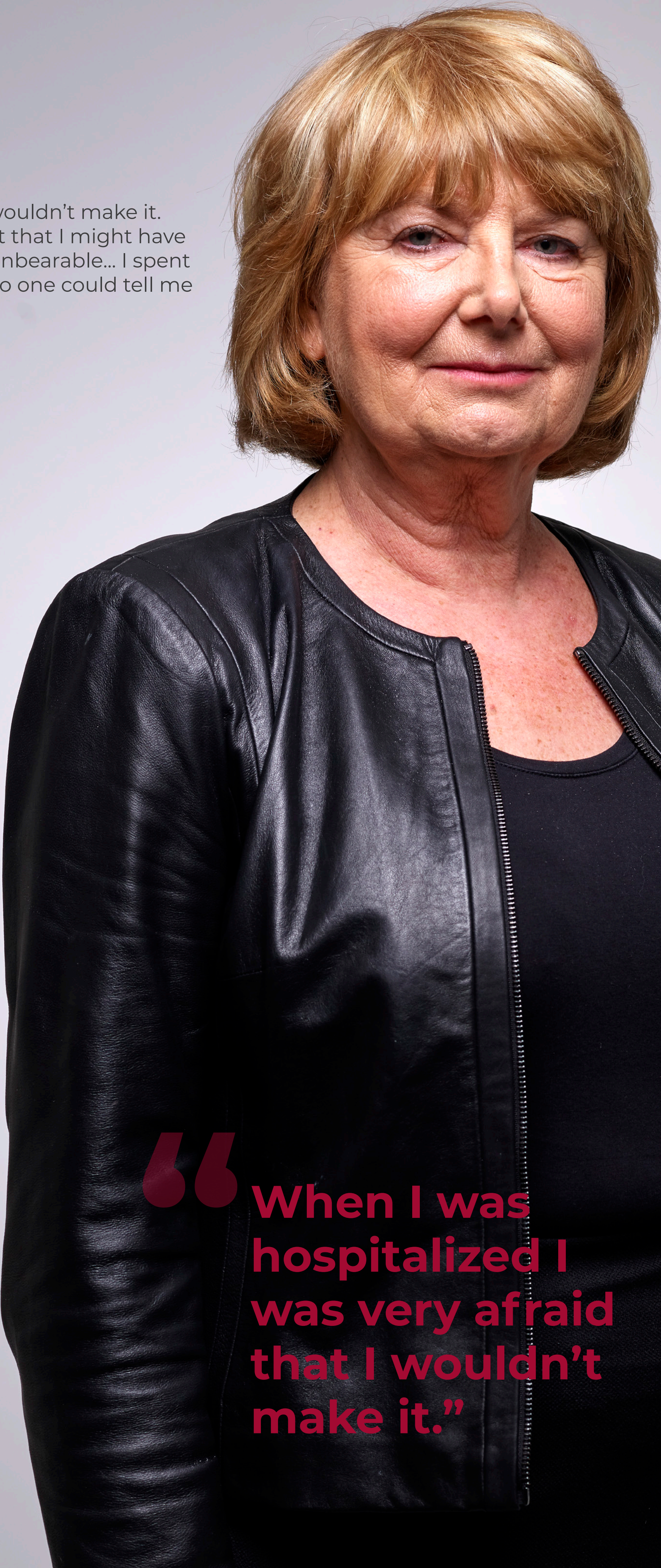
“Look at what you’ve got. And don’t look at what you don’t have.”

Leaving hospital:

“When I was discharged from hospital I suddenly realised I’d made it. That I was still here, and that made me very happy.”

Personal philosophy:

“I live by the day. Of course I hope that I will live for a long time and stay as healthy as possible physically and mentally, and that I can be there for my children and partner for a long time to come. I will do everything I can to achieve that myself. But I also know what damage the disease and treatment can do to your body so I don’t look too far ahead.”



> “When I was hospitalized I was very afraid that I wouldn’t make it.”

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

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