

Jeremy

MPA patient

Primary disease presentation:

Kidneys, Skin

Day-to-day living

- Retired railway worker from the UK
- Enjoyed excellent health up until late 50s, at which point he had heart trouble and required heart bypass surgery
- After heart surgery he had to attend regular health check-ups to monitor his health

Disease history

First symptoms: A loss of kidney function was found when GP was checking for coronary heart disease. Sent to a kidney specialist

Early progression: Rash developed on his legs around the scar from the heart bypass surgery. Initially ignored the rash as it didn't bother him and he assumed it was related to the bypass, but later found out it was an important sign of ANCA vasculitis

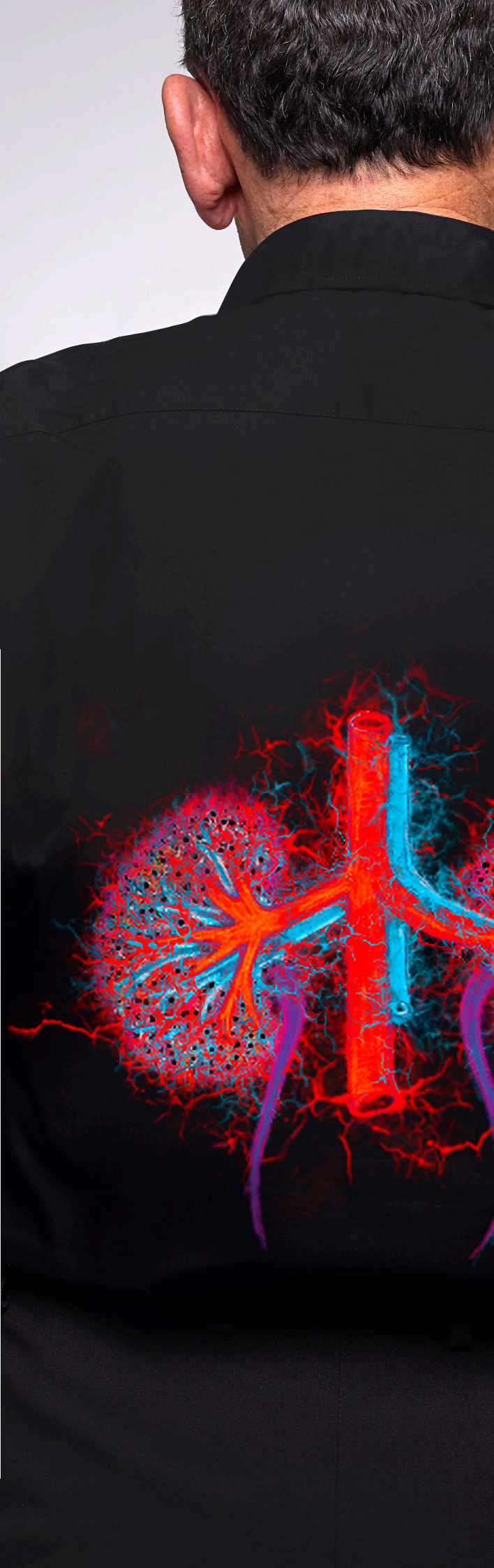
Delay to diagnosis: Not due to diagnostic confusion, but to a delay in seeing the appropriate specialists. 10 months until diagnosed with MPA

Initial treatment: Prescribed cyclophosphamide + enrolled in a clinical trial (unaware of the treatment received)

Maintenance therapy: Azathioprine started 6 weeks after initial treatment. Remained on azathioprine for ~4 years. Experienced flares 1–2x a year. Treated with high-dose steroids (glucocorticoids). Resumed azathioprine treatment each time

Increased flares: 18 months ago experienced five flares within a single year. Switched from azathioprine to rituximab. Helped reduce the frequency of flares but has not enabled him to reach remission. Currently experiences 1–2 flares per year

October 2019: A flare did not clear. Taking high-dose steroids (glucocorticoids) + increased rituximab dose





In his own words

Symptoms:

"I did actually develop a rash on my legs which I paid no attention to because it didn't cause me any difficulty."

How initial treatment works:

"The initial treatment was, as the specialist explained, to hit it hard in order to try and push it into remission. And then after that they would put me on what they called a maintenance therapy to keep it in remission."

Maintenance therapy:

"The specialist recommended switching to something called rituximab. This seemed to work and the flare ups reduced to once or twice a year."

Personal advice:

"Make sure you get the maximum possible information from the specialist... But don't be put off by what they say."

"Whatever the case just keep positive."

Patient support groups:

"There's a very excellent website called Vasculitis UK which is worth looking at, gives you all sorts of reliable information about ANCA vasculitis."

Personal goal:

"I just hope in the next 5 years I'm just the same as I am now."

“Whatever the case just keep positive.”

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

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