June 2012

I was diagnosed with CADASIL in the autumn of 2006 at the same time as going through a separation from a 25-year marriage.

I had started having visual migraines and on one occasion this was accompanied by an episode of difficulty with talking - I knew what I was trying to say but rubbish came out of my mouth!

I went to the GP, as I was aware that my mum (who had died 6 years previously) had had several TIAs, so had her brother also their father obviously years before.
The GP requested a CT head and a Doppler scan on my carotid arteries (just in case) - he fully expected both tests to be normal.

The carotid arteries were perfectly normal and the technician told me to come back in 30 years' time but the CT scan (I am a radiographer myself) was not normal, but no one knew what the problem meant. I was referred to a stroke specialist at the hospital where I work and he suggested an MRI head - he was aware of a very rare condition he had come across in Scotland a few years previously.

The MRI looked like MS but the radiologist said the pattern was 'too symmetrical' and he too had come across this rare genetic condition called CADASIL - it was so rare he doubted it. To rule out MS I had a lumbar puncture, which of course proved negative, and my specialist sent blood samples off to St George's Hospital in London. The DNA testing would took 9 weeks.

The results came back positive, and pieces of the jigsaw started to fit.
The hardest part for me had to talk to my three (grown up) children about how it would affect me, how they had a 50/50 chance of having the condition, and if positive; their children in turn would also have a 50/50 chance of having CADASIL.

6 years later, it doesn't seem so depressing, I have a new very supportive partner who has been a life-saver for me and my children were very philosophical about it all - they too had the upset of their parents' divorce in addition to this medical news. I take medication to keep my blood pressure normal, I do not smoke, and (so far) all is well.

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