

OS13 **GCA** Finding people with the same condition has meant a lot to me

My story began on 6th November 2007. I had been feeling strange for a while, and felt I had flu but nothing definite. I went to the doctor and some blood tests were taken. Later that week I hobbled into the doctor's with gout, something I had never had before.

On the 27th November I returned to the doctor with severe head pains and my eyes were sensitive. She looked at the bloods and my ESR was 95 so, after an examination, I was sent to the medical emergency day centre for further tests. The conclusion was that I might have a sleep problem and that the raised ESR was due to gout and that I should return later to undergo some tests. The doctor did in all fairness order both a CT scan & an ultrasound scan which did not materialise. Only the CT was done later. The next day the pain was worse, and I was given an antidepressant to help the pain by a locum GP.

After this I suffered pain daily and the pain became worse. It was like fireworks in my head at times and I was worried as I knew this was not normal or just a simple type of pain. I went back again and again and finally asked to pay to see a consultant. I had to fight for this as the GP said I should wait to see the first consultant (a chest man!) in February 2008. I was finally given 20mg of steroids on Christmas Eve as the GP admitted it might be dangerous to wait.

I saw the first consultant in January at my own expense. He prescribed 15mg of steroids to be reduced and within 3 months I would be off them. This was the dose for PMR, although it was agreed that I had GCA. The examination consisted of examining the pulse on my head and looking at the bloods taken in November. Nothing more was done except taking notes. In the letter back to my GP with a copy to me it stated that "she looked well" and not to rush too soon to get off the steroids. Well his instructions only took me until March 2008 just a few weeks after this and he assured me all would get better.

Of course, it did not. and I then asked the GP to refer me for a second opinion, which I also paid for. I finally saw another consultant who said he felt I still had active GCA and put me on to 40mg per day. This is coming down now but I have some hearing, sinus and neck problems, and Cushing's Syndrome with the triple chin and buffalo hump on the back of my neck; also the "not being able to get around the supermarket" syndrome; cramp in my hands and legs and all those nasty side effects of the steroids.

However, I now feel more positive and able to cope with the future, although I am still not happy with some pains running around in my head, but I do think that lots of these problems are drug-related. The loss of one's good health can be a real blow not only to yourself but your husband or family. One year you're running around well and then the next year you have lots of mountains to climb and are in poor health. I feel if only my condition had been recognised earlier, the treatment would have been the same, but I would have been in better health to cope with the steroids and the reduced dose would be much lower by now.

Finding people with the same condition has meant a lot to me as everyone else you tell looks blank when you say what you have. Knowing someone else who can understand the pain and the steroid side effects does help. I have now invested in some Acupuncture for a few weeks to see if this can help, recommended by the GP. We are all game for anything that might improve the illness so it's all worth a try. I don't feel on my own so much now and there is light at the end of the tunnel even if it may be a little way off.

Today may be good and tomorrow not so good, but there isn't an alternative yet so we have to keep positive and I am determined to get better so that the retirement my husband and I looked forward to will come true