

OS12 **PMR** If you suspect that somebody you know has PMR then get them to a doctor ASAP

In early 2008 I was a fairly fit specimen for my age, male and just turned 61. I had one or two little complaints but nothing too serious and they didn't stop me using my mountain bike in the hilly forests around where I live. It was wonderful getting out in the fresh air with pine scented trees all around and the wonderful views denied to those who stay on the road. I used an exercise bike at home and a rowing machine. I was also an active gardener, lots of digging.

Something curious happened one day about then. I always walked down to the shop to get the Sunday papers. Coming back uphill I felt a pain in my left side and had to stop half way up. Did I go to the doctor about it? Of course not, being a man. I experienced this the next week but not so severely but it would recur now and then, say if I was using the rowing machine, so I stopped using it. Eventually it went away and I thought nothing of it. Some months later, June 2008, I took advantage of a nice day and decided I would walk to the local butcher's shop, continue into town and get the bus back. I realised I had misjudged the time needed and would need to put a spurt on to catch the bus. I was used to walking quickly if I had to but my legs just would not respond. If I tried to speed up my calf muscles felt as if I was to develop cramp. I still have that a bit to this day. I did catch the bus, just!

Within two days or so I had completely stiffened: upper thighs, legs, buttocks, neck, arms, shoulders, and I was unable to raise my arms above shoulder level. I also developed a stabbing pain in my left shoulder as if somebody had stuck a needle in. Around this time I had to drive to Glasgow to see a sick friend and it was the most uncomfortable of experiences having difficulty getting in and out of the car. I had no idea what was wrong with me. There had been no warning. One often reads that PMR is preceded by flu like symptoms but in my case there had been nothing. Talk about out of the blue! I assumed I had been overdoing it and my body was reacting. The feeling was rather as if you had done a 30 mile walk and some weight lifting but this did not improve with rest. I tried analgesics like ibuprofen, but nothing worked. The stiffness was muscular, not in my joints, so it wasn't arthritis or so I thought.

One day I had taken my wife to the doctor's surgery and there were some booklets published by Arthritis Care on display. I took a few away and recognised my symptoms in one of them almost straight away. I should have gone to a doctor immediately but three things put me off: the side effects described for prednisolone, the fact that my experience had been that things eventually get better by themselves and, I kid you not, the dreadful appointments system for my surgery. So I delayed despite the fact that the symptoms were not improving. I was also getting swollen blood vessels in my forehead which could have been related to GCA. Eventually in September I arranged an appointment with one of the doctors in the surgery. When I think that I could have lost my sight as a result of my intransigence my blood runs cold.

The doctor diagnosed PMR at the first appointment as I described my symptoms. I explained that I had come to the same conclusion. He arranged a blood test which among other things included an ESR which was high (65 I think). I was put on 15mg of prednisolone daily and the symptoms vanished within 3 days including the swollen blood vessels in my forehead. Within a month the ESR reading had dropped like a

stone and the dose was gradually reduced, month by month, to 12.5 then 10 then at 1 mg intervals basing the decision on the blood test. The doctor involved me in deciding next month's dose depending on how I felt. However I was never given the option of seeing a rheumatologist nor was the offer of a bone scan ever made.

Each time the dose was reduced there seemed to be withdrawal symptoms as if the condition was returning but these passed by the time of the next appointment. After the initial high doses I continued to feel a little stiffness at all times. Eventually the dose came down to 1 mg per day around February 2010 and I stayed on that for a few months for the symptoms did not totally disappear. We agreed that I should gradually come off the Prednisolone altogether but cutting the dose to 1 mg every two days brought the symptoms back very noticeably. So I hit on my own plan. I would miss out one tablet in 7 days, then one in 6, one in 5 and so on until it was one every 2 days. This worked, so I then took one tablet every three days, then four days and at that point I stopped taking them around end of August 2010.

I still have some stiffness but it is almost at the "twinge" level and I am not back to my original state of fitness by any means though I was able to dig the garden without too much bother this autumn. There seems to be a slight improvement week by week, but it is slow. I take an ibuprofen now and again (400 mg a day max) and it seems to improve things a little. My one regret is that I did not go to the doctor sooner, for I fear that some permanent damage may have been done to my muscles and tendons that will prevent a complete cure. Time will tell. If you suspect that somebody you know has PMR then get them to a doctor ASAP, concerns over side effects of prednisolone or not.