

OS19 **PMR & GCA with some sight loss** don't get despondent, there is definitely light at the end of the tunnel.

In 2007 I had just returned from a holiday in Menorca and on the way back I started to experience some really bad pains in my back. Having had back trouble for some considerable time, I naturally thought this was the problem. That was, until I endeavoured to get up from my seat to get off the plane. I couldn't move! I was absolutely terrified, thinking I had somehow slipped a disc. Eventually my husband managed to help me out of the aircraft, but the next problem was getting down the steps. How I managed it, I still can't remember. We crossed the tarmac to get on the obligatory bus and as I mounted the platform, an elderly lady said "You don't look well, would you like my seat?" I was so grateful; I took the seat and somehow managed the onward journey home.

The following day I went to see my chiropractor who treated me and told me to return after two days. This I did and on the second visit he told me he was not happy with my condition and I should consult my doctor. I managed to get an appointment and went to see her. By then I was in pain in both my back and my shoulders and had flu-like symptoms. She took a blood test and I asked her if I could see a specialist as I felt so very ill. The response was "I would send you to one, but I have no idea who to send you to". The following day I had a call from her, telling me I had something called PMR. I had never heard of it. I have now!

My doctor organised for me to see a geriatric specialist the next day. He did more blood tests and told me I did indeed have Polymyalgia Rheumatica but that it was quite common for people of my age to get it. They did not know what caused it, but it was treatable with steroids. I was absolutely horrified, having heard all the awful stories about steroids. But, it seemed, I had no choice. I was reviewed monthly and, as my blood tests were all satisfactory, was referred back to my GP. However, this is where it all started to go horribly wrong. My GP had not the slightest idea of how the reduction of steroids should be carried out and I was (in hindsight) clearly coming off them too quickly.

I had been looking after my elderly mother (who was still in her own home, but very frail) and she had died about six months previously. I was still recovering from that ordeal, which my GP knew about and I think she was putting down the symptoms I was getting to that.

A few months later, my husband and I decided to go on holiday in Majorca and it was there that I started to experience "flashes". I put this down to the excess heat and tried to enjoy our break. When I came back, things did not seem to improve. I started to get very bad headaches, pains in my jaw when chewing and a general feeling of being unwell. I was back and forth to the GP and all I was given was paracetamol. After several visits (and even stronger painkillers) I asked if I could again be referred to a specialist. The Doctor told me he would write to the person concerned. I went back after two weeks (the doctor himself had been on holiday) and asked if he had my referral. He responded by saying that no, he had not had a response as he was too busy to write before he went on holiday!

My headaches became much worse, I felt very ill indeed and I noticed the vision in the lower part of my right eye was not there. I went into see my optician but he told me he was too busy and that I should go back to my GP and asked to be referred!

By chance, I was talking to a neighbour who had been a secretary to an eye specialist and she was very concerned that no one was taking any notice of my condition and advised me to go to the Eye Hospital.

We went and spent three hours waiting to be seen and for a diagnosis to be carried out. Eventually, I was told I had incurred a “stroke” behind the eye and must be admitted immediately and a biopsy carried out there and then. I did not have time to think, but was carried along by the shock of it all. The biopsy was done and I was put onto an intravenous dose of steroids. For two more days I had the same dose and was told that I now had GCA and that I would never recover the sight I had lost. I was totally devastated.

After discharge, I began to take stock of the situation. I was on doses of steroid of 60 mg per day initially so was pretty agitated and could not sleep. I was beside myself, thinking that my precious sight was very much deteriorated and did not know where to turn. The hospital was of little help. Someone (I don't remember who) suggested I contacted the RNIB who were extremely supportive and suggested I had some counselling, which I found very beneficial. Losing some sight may not seem a “big deal”, but it is almost like experiencing a bereavement and you must have time to come to terms with it. The RNIB organise weekend courses for people who have recently become blind or have lost sight (for whatever reason) so my husband and I decided to enrol on such a course. This was definitely the turning point in my case. Things started to become almost “normal” and I began to pick up the pieces. I recovered my confidence.

I started to drive my car on my own again, which does not sound much, but as I had lost a fair amount of vision in my right eye, I was extremely nervous in the car. Although I do still drive, I have to say I am more aware and use my wing mirrors frequently. I have come to terms with the GCA, however, it is always in the back of one's mind; will I have another attack? I am still on steroids, 4.5 and 5 on alternating days. I have regular blood tests. I endeavour to eat healthily and keep active, doing ballroom and Latin American dancing twice a week. I think, above all, this is one thing which has kept me going. Initially, I did have trouble turning in any of the dances but now can do all of them without thinking, including the Viennese Waltz.

I have recently found a new chiropractor who is extremely interested and knowledgeable about Polymyalgia and who is helping me to manage my aches and pains, which are nothing now compared with how they were initially. I do hope one day to come off the steroids totally, but that is for the future.

To anyone who has recently been diagnosed with PMR, don't get despondent, there is definitely light at the end of the tunnel.