

OS05 **GCA** I felt puzzled when diagnosed with GCA

I felt puzzled when diagnosed with GCA. I had been feeling a bit off and suffering from intermittent headaches and toothache, but I put it down to doing too much and so ignored what was going on. The headaches became worse and every bone in my face was aching, I could not chew and wanted to pull the front of my face off.

I decided to visit my GP - I did and he decided to refer to me for a scan. However, I had to go back to him within a week as I was worse than ever. I remembered my mother had had PMR and the symptoms seemed similar. I discussed this with the GP and he ordered a blood test immediately before I left the surgery.

My GP rang at 7.45am and asked me to come in straightaway. By 10.30pm I was on a dose of 60mg prednisolone and within 6 hours all the symptoms had disappeared. I could see again; the headache went away and so did all the other aches and pains. Marvellous. The steroid dosage was reduced very quickly down to 40mg then gradually down to 20mg by November 2007.

I was back at the GPs surgery on the Monday at 9am, first appointment, and it was then that they told me how close I had come to losing my sight and that I had GCA not PMR. I broke down on the Friday - a week on a roller coaster had taken its toll. By the way, I call it Giant Thingy and Polywotsit.

I suppose in a way I was so grateful that my sight had been saved that the complications that have followed pale into insignificance when I imagine what could have happened. I could be blind. There is no reversal.

Problems have arisen with the side effects of the steroids, to the stage where I am unable to walk more than two car lengths because of consistent and sometimes excruciating back pain, now have a Blue Badge Parking Disc, Attendance Allowance, weight gain (which does not help), peach fuzz and triple chins.

My own GP decided after about six weeks - as the back pain got worse and I started to ache in hands and knees that I probably had PMR as well. However the Consultant Rheumatologist disagreed as I have never had the classic problem of stiffness in the morning and the inability to get out of bed. I agree with the Consultant and my GP has agreed that we will only do Blood Tests bi-monthly now as the Consultant says the sed rate can confuse the issue.

My GP insisted that the Rheumatologist sent me for a bone scan (after six months of being on steroids). The result is that I have very good bone density for my age, well within the normal parameters. He has also worked out a programme for the reduction of steroids ongoing until September 2009. This reduction plan depends on the symptoms of GCA not re-occurring. This month I am down to 12.5mg and on the 1st February reduce to 10mg, thereafter it is reduced by 1mg per month until January next year when I should be down to 3mg - then it is a three monthly reduction plan, ending up with 1mg per day. It may be that I shall have to take 1mg per day for the rest of my life - but we are all keeping our fingers crossed on that one.

Every article that I have read insists that a slow reduction of steroids is the best way of coming off them completely. I know people get impatient as they hate the side effects, especially the weight gain - but I don't mind - I do not want to be blind and am willing to put up with every other side effect going.

As far as I can gather, steroids make your own production system of cortisol/cortisone shut down and that is what has caused the back pain. The hope is that as the reduction in the

steroid takes place the glands (adrenal?) will kick in again and as they get working the back pain will reduce and enable me to walk once more.

I see my GP monthly now and the Consultant next May - unless anything untoward happens and have had to promise them that if anything happens at the weekends I will immediately go to the nearest A&E department.

I carry my blue steroid card wherever I go in fact I have three or four in different handbags and one in the car. I still get very, very tired and feel lethargic, some days my head is fuzzy and I just have to retreat - but I realise this is all side-effects and I just have to get on with it as best I can or as another sufferer puts it 'go with the flow'.

I would add that without the people I met on the Internet, I would have been driven up the wall. Self Help/Support Groups are very necessary, even just for a chat on the 'phone', an email with 'how you are at your wits' end' or a cup of tea, coffee, cake, a moan - just someone who understands what you are going through is a blessing.