

## OS14 **GCA** The steroids put me back on my feet

I am Scottish and live in Northern Italy. I have been diagnosed as having GCA and I would like to share my story with you as I hope it may be of help to someone as the stories of others with GCA have helped me.

I am 65 years old this year. Last year (2011) in October I was washing the dishes after lunch when I felt a pressure in my breast like indigestion. After about ten minutes I had an awful pain in my jaws which eventually went round the back of my head. I just went to bed and hoped that it would soon go away which it did after about an hour. I felt very weak, but pleased that the pain had gone away; I didn't go to the hospital as I was sure they would have told me to go home and not waste their time etc...

Anyway, I did go to my doctor a few days later and she sent me immediately to the hospital for a cardiograph as she thought I had had a heart attack. For the next few months I had different types of tests done for the heart and in the end in December after having a heart scan, the doctor telephoned a cardiologist in another hospital for a second opinion. After having a talk with this other cardiologist it turned out that my heart was in perfect working condition and that the problem was that the aorta was enlarged and making the blood flow too quickly.

I had open heart surgery on the 10th of January 2012 where the aorta was replaced – it was ready to puncture and I would have been a goner. The cardiologist, who fortunately spoke perfect English, explained that I was suffering from GCA, the “silent illness”, and that I was fortunate to be alive - and that was all. I had no idea what GCA was apart from having Giant Cells. Something like a horror film!

When I arrived home from the hospital and Recuperation Centre I just seemed to go downhill instead of getting better. All my energy seemed to be going away. I tried to speak to my doctor and explained how I was feeling but all she said was that I had just had a major operation and now I had to do a lot of walking etc. to get better..... I could have strangled her! Either she wasn't listening to me or she didn't know what GCA was. It took all my energy to crawl out of bed, never mind going for walks!!

My family and friends were always very helpful but I could see that they had their doubts too. One friend even suggested I had a talk with a psychiatrist! I was 'going off my head' but only because I was angry and confused – angry with all doctors because they just didn't want to know what was happening to my body and confused..... my operation was healing well, so why was my body still weak and not getting better? This went on for about two months until I had an appointment with the rheumatologist. She explained very little about GCA but gave me steroids – miracles do happen! The steroids put me back on my feet and now after a month I feel human again.

How do I feel now? I feel happy and sad and have a lump in my throat with the emotion – why? Happy because I have read some of the stories about GCA and this has helped me more than any medicine. I don't feel alone now (That's why I have a lump in my throat; it's nice to share). Sad because doctors just don't understand and don't take time to really listen to their patients – at least the ones I have come across.

Anyway, I am getting on with my life now knowing that I am not alone with GCA. Thank you for sharing your stories – it's life-saving!