

## OS07 PMR & GCA My advice is not to try to reduce too fast

After a week's trip to Athens the first week in April 2005, I felt very strange and had a dry cough. After two weeks I went to the doctor. After blood work, he couldn't tell what was wrong but made a plan where he step by step eliminated possible diseases. After some months without a real diagnosis, I was sent to the medical department of a main hospital. I had some new blood work, and then they told me that I had better have a biopsy in a temple. The problem was that I had two trips coming up. They put me in after the first one and the biopsy showed that I had what they had expected. I was told I had PMR but they didn't tell me I also had GCA, so I heard about that later.

I was put on 20 mg Prednisone and the next day I flew to the USA to participate in a class reunion after 50 years from graduation as an exchange student in a small town in Minnesota. My wife covered my white band aid in the temple with skin-coloured surgical tape, so it shouldn't show so much, especially not on the class picture. After about a week, while travelling in California by rented car, my wife used the scissors of a Swiss army knife to cut the strings that they had sewn at the biopsy. She dipped the scissors in gin from a miniature bottle we had got on the Atlantic flight – to sterilize it. Due to the prednisolone, I felt great and on the national day of the USA, 4th of July, we walked downtown without problems. The brochure said the motel was in midtown, near downtown. I think we had to walk 20 blocks and then back – but I felt great even if my wife got tired despite being in better condition than I.

I reduced the pred. by 2.5 mg every 3-4 weeks until I reached 10 mg. Then I reduced by 1 mg every month until I reached 5 mg. I tried to reduce during a whole year, but every time I had to go back to 5 mg due to fatigue. I thought it was no idea to go around being tired all the time when I didn't have to. Unlike most persons with PMR, I had fairly little pain. When I had slight pain, it could be anywhere in legs or arms. After a year, I thought I would test a new regime. I took the lower dose 1 day, the old dose 2 days and repeated this once more. After about a week I took the step and lowered the dose each day. By doing this, my body reacted positively and I could start going down below 5 mg but only about 0.5 mg at a time. I had 2.5 mg tablets and cut them by hand in four parts, so it really was 0.6 mg at a time. If there was a problem, I just continued 1 day low dose, 2 days old dose for another week or so.

After 3 ½ years – in the middle of December 2008 – I got down to zero and I haven't had any problems after that. I have done some travelling this summer – we were for instance a week in Scotland (Glasgow, Edinburgh and a short trip to the Highlands). I just take it easy when we walk and when we visit a museum I just sit down to have a rest while my wife does it more thoroughly. I have just had my 72nd birthday, so I guess age also makes me a bit tired. Taking care of a friend's golden retriever keeps me busy and also makes me walk a bit more than I would otherwise do.

I had reduced my weight about 6 kg before I had the diagnose and now I am up to the same weight as before, which I of course am sad about. I had a moon face for some time, but for a man it probably isn't as bad as for a woman. My advice is not to try to reduce too fast, especially not below 5 mg when every 1 mg reduction is a very high percentage reduction. My belief is that it is better to feel well and take the disadvantages a bit longer, especially when reaching doses of 5 mg and under. I am of course grateful that I haven't been in pain so badly as most of fellow PMR-sufferers have.