

OS09 **PMR & GCA** I couldn't raise my arms above waist level

3 years ago I was diagnosed with PMR at the age of 56. It was only affecting my arms & shoulders but was very painful & I couldn't raise my arms above waist level. After many months the Prednisolone was down to a maintenance level of 2mg but I could never get below that as the symptoms would come back.

In May of this year I suddenly found the PMR was affecting my whole body from feet to shoulders so the steroids were increased & the symptoms gradually got less.

By July I was down to 15mg then found the pains were going through my head making the scalp very tender & my temples throbbing with the pain & my neck was stiff.

My GP diagnosed Temporal Arteritis & the prednisolone was put up to 50mg for a week then lowered by 10mg on a weekly basis when I saw my GP.

I got as far as 15mg but found my tongue swollen as well as the neck making swallowing a nightmare as was eating since the jaw ached so much.

At first it was thought I had an allergy so was put on a course of antihistamine which did take a little of the swelling down on the tongue but everything else remained the same.

The steroids were put back up to 20mg then it happened again last weekend (September) with the tongue & being unable to swallow, but also when I tried to lie down I wanted to pass out.

I was sent to A&E where a doctor told me it was a PMR attack & to take an extra 5mg. My GP agreed with the diagnosis so I am back to 25mg.

I thought by now I should be getting better not going backwards.

Now I have a balloon face with swollen eyelids, a neck that is almost double in size making it difficult to move up, down or side to side, the occasional swollen tongue, tingling in lower face, sensitive hearing, throbbing coming from the side of my face somewhere, swollen feet & hands, hands that tingle & shake from time to time, occasional cramp but have found drinking Indian Tonic Water helps with that (I think that just about covers it). My emotions are all over the place too.

I find that drinking anything hot makes the symptoms worse for a while & ice lollies helps with the swelling.

I have tried to be positive throughout as we are supposed to be going to Australia mid November but the closer we get the more it may be cancelled, the way I feel at the moment I couldn't contemplate getting on a plane.

My concern is that I have never heard my GP mention having a check done on my Aorta which I now think may be a good idea.