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Why a stiff neck could leave you blind

The debilitating muscle condition polymyalgia rheumatica causes pain and stiffness and can even lead to sight loss – yet many GPs have never heard of it. LAURA MILNE reports

WHEN Janice Maddock began suffering from crippling pains and stiffness in her neck, shoulders and back four years ago, she presumed her aches were down to the stress of caring for her elderly mother, who had passed away earlier that year. Yet very soon, everyday life became almost impossible to manage for the 59-year-old child care development adviser from Ruislip, west London. Her neck became so stiff that she could not turn her head, which affected her ability to drive safely. “I had to park away from other cars as I had so much difficulty getting in and out of the car,” says Janice, who is married to Steve, also 59.

She struggled getting in and out of bed and says she came to dread going to sleep at night because of the pain she would suffer.

The swiftness and severity of her physical deterioration eventually forced Janice to take early retirement from her job.

“The final straw was when I couldn’t even bend down to put my shoes on and my husband

had to do it for me. He said that I needed to go to the doctor as something wasn’t right.”

When she sought help, Janice was diagnosed with polymyalgia rheumatica (PMR), a rheumatic condition that causes pain, the tenderness and stiffness in large muscles around the shoulders, hips and back. It can cause disability and severely affect quality of life.

PMR is linked to another rheumatic condition called giant cell arteritis (GCA), which causes the arteries in the head and neck to become inflamed. It is called “giant cell” because abnormally large cells accumulate in the artery walls.

One of the arteries that is commonly affected provides blood to the optic nerve and if the optic nerve is starved of blood it can lead to

irreversible sight loss. Both are autoimmune illnesses and with GCA the main symptoms are headaches and tenderness which can lead to blindness if untreated. Both conditions usually affect the over-50s but it is most common in those over the age of 75.

Consultant rheumatologist Professor Bhaskar Dasgupta, who is an expert in the illnesses, says: “In many ways PMR and GCA should really be seen as the same condition, we do see a significant number of patients who have PMR symptoms but also have giant cell arteritis.”

An estimated 250,000 people in the UK have PMR and GCA, although there may be many undiagnosed sufferers as awareness among GPs and the public is so low. Each year, about 3,000 people are thought to lose sight as a result of late diagnosis of GCA. Janice says: “I was lucky

that I had a doctor who knew what PMR was but I’ve heard many stories of people who have been misdiagnosed or when they have eventually been diagnosed, they’ve just been left to get on with it.

“More GPs need to know about these conditions so quicker diagnosis can be made.”

For both PMR and GCA, the main treatment is steroids, which can be associated with serious side effects such as diabetes and osteoporosis. Janice, who

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is stepmother
to Lauren, 28,
and Paul, 24,

says: "When I was diagnosed I was put on a high dose of steroids which reduced the pain and stiffness but they had side effects. I was very tired and put on weight because they made me so hungry.

"I reduced my steroids but did it too quickly and my symptoms started to come back. I had a bit of a meltdown as I thought I was never going to get better."

Janice then discovered the charity Polymyalgia Rheumatica and Giant Cell Arteritis UK (PMRGCAuk), which was able to offer advice and support on managing the condition. "Many PMR sufferers reduce their steroids too quickly without listening to their body and end up with the symptoms returning," she says.

However new effective treatments that have fewer side effects are being developed including tocilizumab, a common arthritis drug.

An international trial involving more than 250 patients in 14 countries, including the UK, found that 56 per cent achieved steroid-free remission after a year on tocilizumab.

Professor Dasgupta says: "About 40-50 per cent of patients in the

tocilizumab study had PMR as well as GCA and their PMR symptoms improved as a result of taking the drug. Tocilizumab is a significant breakthrough in the treatment of PMR and GCA.

"It is particularly effective in those patients who do not respond well to steroids, which often fail to control the disease in the long term."

It is hoped that the drug will become available to patients later this year.

● Visit pmrgca.org.uk to find out more about PMR and GCA

AGONY:
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was in
so
much
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every
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Picture: ALAMY

SHOULDER ACHE: The rheumatic condition can lead to disability if undiagnosed