

The killer headache no one's heard of

Each year about 3,000 people in the UK lose their sight needlessly as a result of – literally – blinding headaches. Some even lose their lives. So which symptoms should be sounding alarm bells?

Words **Eric Clark**

AFTER MORE THAN TWO MONTHS of excruciating headaches that reduced my sleep to two hours a night, treatment from two GPs and a pain specialist, a brain scan and day surgery, it was finally a friend who came up with the correct diagnosis. 'I knew someone with symptoms like yours,' she said. 'It sounds to me like **giant cell arteritis**.'

I'd never heard of it – and neither, to terrible cost, have most people, including far too many doctors. But she was right. And she probably saved my sight, perhaps even my life.

Although giant cell arteritis (GCA) can strike out of the blue, there is often a build-up of symptoms. In my case it began with a mild flu-like feeling I attributed to overwork. Next, pains developed in my neck and head. My GP prescribed ibuprofen, then more potent painkillers as it worsened. The pain settled over my right temple, a symptom that should have been a giveaway.

A second GP thought it was a nerve disorder and prescribed a third, more targeted drug. A pain consultant organised a brain scan (in case of a tumour), prescribed a fourth drug, then decided the nerves should be anaesthetised to allow them to calm down. The pain vanished – then returned with a vengeance. I was exhausted and lost more than half a stone. Next came blurred and double vision. Then – thankfully – my friend's observation.

I repeated her thoughts to the specialist: 'Ah,' he said, 'I was wondering about that,' quickly

referring me to a rheumatologist who ordered blood tests. Within three hours, he phoned: the results were 'grossly abnormal' and in line with GCA. Treatment had to start immediately. The tests detect inflammation and, if high, are strong indicators of GCA. The potential consequences of delay are so great – blindness and, more rarely, stroke – that treatment should begin even before the diagnosis is confirmed.

GIANT CELL ARTERITIS refers to abnormal cells that develop in the walls of the arteries, blocking off blood flow. Little is known about the condition. Infection and genetic factors may play a part. It strikes about 13,500 people in the UK every year, most over 50 and two-thirds women. About 3,000 become blind needlessly.

Consultant rheumatologist Professor Bhaskar Dasgupta of Southend University Hospital says victims could be spared if only their doctors acted promptly and accurately, treating the condition as the emergency it is. Most exhibit clear symptoms before blindness strikes: 'The problem is that public and professional awareness are very low.'

While there is no cure, the condition can be controlled – and sight saved – with fast treatment with the potent corticosteroid prednisolone. My first mega-dose was the start of a long regime. The high dose continues for a month,

and is then slowly tapered down. This inexact procedure balances two risks – the GCA and the side effects of the drug. It usually takes one to three years to recover completely, though some patients have to take prednisolone for ever.

The effect of the first high doses is spectacular – all outward signs of GCA vanish within two to three days. As the first users found 60 years ago, it is a 'miracle drug'. As they also learned, it is too good to be true. 'It makes you feel better, but it's poison as well,' says Dr Kate Gilbert, a university lecturer hit by a related condition, polymyalgia rheumatica (PMR), in her mid-50s. The side effects of prednisolone cover pages; weight gain is especially unpleasant as fat is redistributed to the stomach area and the face. Drugs must be taken to reduce the risk of osteoporosis and protect the stomach lining.

Then there are the psychological effects. The drugs can produce feelings of Godlike invincibility: once, when some lout refused

to move down a bus to let on passengers, I screamed at him to shift. He was a third my age and could have torn me in two, but he moved.

PMRGCA-UK is a new



Victims could be spared if only their doctors acted promptly and accurately, treating the condition as the emergency it is

charity that aims to raise awareness of GCA, offer support and encourage research. New guidelines for doctors have been produced by the British Society of Rheumatology. But it's not only doctors who must adapt. Many sufferers were brought up 'not to cause a fuss'. All too often they ignore their sight-threatening symptoms, dismissing them as signs of getting older – until it's too late. ♦ For more details, visit pmrgcauk.com or call its helpline: 0300 111 5090