Patient's journey

Living with birdshot

Six years ago, Steve Page was diagnosed with birdshot uveitis, he explains how he coped with the eye disease.

Flashing lights

Typical for the condition, it took three years for the diagnosis. I was 52 at the time.

I was on a boat bobbing on Lake Michigan, close to Chicago, when I thought I was surrounded by thousands of small midges. Within a few minutes I worked out that these were actually dots within my eyes.

A couple of days later, flashing lights in my eyes became visible and resembled what I can only describe as shells, other people refer to this as "shimmering," see box.

Diagnosis

After the usual checks and tests I was referred to the Birmingham and Midland Eye Centre. More tests wrongly concluded that I had a problem in the optic nerve.

Two years later, after thousands of more dots flared up in my eyes. I rang my GP who referred me to a specialist in Birmingham. I was seen by a duty eye specialist in the casualty department. He knew what was wrong and after a second opinion he suggested I had birdshot uveitis, see box and that it could be treated with steroids.

Treatment

I later transferred to Moorfields Eye Hospital in London. On 24 September, 2009, I stood holding 80mg of the steroid prednisolone and was ready to start my treatment. That was a real lump in the throat moment. You only have to read the label for possible side-effects – weight gain, depression, black stools – to know why.

The improvement was remarkable – please don't think I am sad – but I have kept notes of the condition, changes in my eyes and how I felt from the start.

Within two weeks, the problems I had with glaring light had significantly reduced, as had the visibility of the dots in my eyes. The downside was the steroids made my skin very dry, my tongue felt swollen, my face was hot and my lips were sore. For me it was a pretty a good trade off, eyesight for a bit of discomfort.

We all react differently to drugs – there is a long list of stuff I take and I'll spare you the details – but, I seem to do okay on steroids. The specialists are managing the condition and balancing my eyesight against the long term effects of taking the drugs.

I've had three flare ups since I started on the steroids on 10 Dec, 12 April and 12 June. The first one was very distressing, because you think the condition is cracked and literally within a few seconds, it's back with vengeance. I now know the routine – back to Moorfields, an increase in steroids and on we go. The symptoms subside and I hope for the best.

I know I can't see as well as I did. Detailed images are difficult to interpret and certain lighting conditions are definitely better than others. But on the other hand, birdshot is pain free, so that's something to be thankful for. At present the condition is under control again, but I know it's only a matter of time before the next flare up.

I don't usually tell people about the condition, not because of any embarrassment or shame, but hearing about others' ailments can be pretty dull. But, this is where the Birdshot Uveitis Society (B.U.S.) was good for me.

When I attended the inaugural B.U.S. meeting, I met lots of other people with the same condition. It was clear it affected us all similarly, but also differently. I know I don't have it as bad as others and I put that down to luck.

All I can conclude is that I have visual field defects that include bits of retina where I can't see anything, bags of floaters and thousands of black dots. Thankfully, my brain has learned to ignore all these things. Despite having birdshot, there's not a lot I can't do now that I could do before. And, for me, that's a pretty good result.

What is birdshot?

Birdshot chorioretinopathy, also known as birdshot or birdshot uveitis is a rare, auto-immune, potentially blinding and chronic form of posterior uveitis. Uveitis means inflammation of the uvea, part of the eye that is made up of the iris, choroid of the eye and ciliary body.

Common symptoms include floaters blurred vision, night blindness, sensitivity to lights and shimmering vision, this is difficult to describe but some people say imagine looking through a glass or water.

A doctor will be able to see oval shaped spots coloured cream or orange at the back of your eyes, if you have had it for some time. The disease is called birdshot because the spots resemble the pattern seen when you fire birdshot pellets from a shotgun.

Source: BUS

For more information visit **Birdshot.org.uk**