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## WHAT YOUR PATIENT IS THINKING

### Looking but not seeing

Michael explains what it is like to experience sudden loss of sight and how he has learnt to cope with age related macular disease (AMD)

Michael Riley

I have AMD, which means I have a hole in each eye that takes away my ability to focus. As soon as I look at something, such as a letter or a number, it disappears. When I look out to sea there is always an approaching tsunami.

#### Forever having to explain

I developed the condition three years ago in my early seventies, and it is relatively mild compared with the experience of others. I can no longer read a book, read music, or drive. Nor can I look people in the eye. To see the full face I focus on the right ear, otherwise I must settle for part of the face being pixilated. I have to bend my head to the left to make a sideways glance in order to get the full picture. Similarly, when crossing a road, half a vehicle appears. I am forever having to explain the sideways glance.

#### Beating the clock

One afternoon I was reading when the letters on the right page seemed to run towards the spine as if in response to an alarm. The phenomenon was accompanied by a moment's brain jar, although I had no floaters or jagged signs, and no headache. Within seconds, a fearful glance through my fingers found the words on the page normal. Putting it out of mind, I made a mental note to get my glasses changed the following week. Later I became aware that the window blinds had become waves. That was when it became scary.

The next day I performed so badly at the optometrist's that he insisted I go straight to my GP practice. The doctor had some difficulty in finding an NHS ophthalmologist appointment. By this time, I sensed I was in a game of beat the clock. So, when a private appointment was offered, I took it. After a scan, the treatment of injections directly into the eyes began immediately: more frightening in concept as there is no pain (this comes with the bill). After 10 weeks I transferred to an NHS facility.

Relieved to get treatment, but anxious to know if I will read again, I am driven towards magnification. Rationally, bigger must be better—however, reading aids and magnifying glasses only serve to enlarge the distortion.

#### Coping with daily life

AMD is a nasty invisible condition that infiltrates daily life. But the treatment does work. I have good contextual sight but must contend with distorted focus. This makes me wary of the encroaching digital world, especially anything “smart.”

It is not all gloom: after all, no one is going to ask me to put up a shelf, fill in a form, or watch a film with subtitles. Best of all is a general improvement in memory, which has come about through memorising the array of financial security numbers salient to daily life. However, battling with daily irritations is one thing, shifting from visual activities towards more social and physical ones is quite another. This is where help is needed, particularly group support. The Macular Society provides such groups and keeps me abreast of the latest research on AMD. It also supplied me with a bright yellow badge, which I find is essential when travelling.

On the hottest day of last year and carrying something heavy, I staggered into a rough looking pub. A pile of menus was on the bar. The barman—black vest and tattoos—beat me to it. “Would you like me to read the menu for you? I noticed your little badge.” It made my day.

#### What you need to know

- A sudden loss of sight is cruel and stressful. Learning to adapt is hard
- Identifying activities that are social or physical can help reduce isolation and frustration
- Organisations like the Macular Society can provide support and advice on learning to live with AMD

#### Education into practice

- How could you best support someone who has been diagnosed with AMD?
- Which activities might you suggest they concentrate on, while they learn to cope?

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