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## Hidden Disabilities

# Macular Degeneration

### Macular Degeneration (Andrew) – Case Study

Andrew is married and has two young children. He has worked within the finance industry for about 30 years.

Andrew has Best disease or vitelliform macular degeneration, which is a genetic form macular Dystrophy. It is what is known as a dry form of macular degeneration. The condition is hereditary. Andrew's father had it, and Andrew has also passed it on to his daughter.

There are various forms of the condition. For Andrew fluid doesn't break through at the back of the eye the way it can with other forms of MD, but he does have areas of scar tissue which affect his central vision. He therefore relies on his peripheral vision to get around. Andrew describes the impact on his central vision as being a bit like having a big blob of Vaseline on his glasses and trying to look through that.

Andrew's condition was first picked up when he was about 9 or 10. Up until the last two or three years it didn't have a huge impact on his day to day life.

When Andrew was attending school in the 1980s there wasn't the same level of SEN support as there is now, or the kind of assistance programmes that are now available. He had difficulty reading the blackboard, either close up or far away, and he used a pair of opera glasses, which caused some amusement for his peers. He also used a magnifying glass to read print and was provided with enlarged print exam papers.

Andrew attended Moorfields Eye Hospital, where Professor Jay suggested he learnt touch-typing as in the future everyone would be using computers. This has proved to be a useful skill for Andrew to have. Andrew's employers have provided him with a dual screen on his computer and paid for a specialist application that helps him to read text

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on screen. Andrew is aware that there also similar applications already in many computers and these can magnify text (for example: on a PC, using the 'Windows' key and the letter 'U' will bring up applications that will magnify text and screen size).

Andrew has a second standard screen which he needs when showing colleagues things on the computer, as the magnified text isn't so comfortable for them to read and sight make some people feel 'sea sick';. These adaptations have allowed Andrew to continue doing the work he has done all of his life.

Andrew describes how when we speed read or scan read we are usually looking at the first two and last two letters of each word. His condition means that he has to almost spell out the words bit by bit, so he cannot speed or scan read without enlarged font size. With the computer applications Andrew can read much better and more quickly that he could without that assistance. There is also a technique known as eccentric reading, where you don't look directly at the print, but look slightly above or below it.

Andrew's condition has had a more dramatic impact on his life over the past few years. He drove a car for 34 years, but has now stopped driving as he can no longer read the number plates. Following a routine eye examination a couple of years ago, Andrew took it upon himself to take himself off the roads.

Andrew now cycles everywhere. He feels there are many positives to this. He gets to work in 20 minutes, whatever the weather. He feels healthier and fitter. In order to be able to help his wife with the school run, Andrew bought a tag-along for his bike.

As Andrew's condition began to have a greater impact he did start feeling concerned about how he was coming across to others, and about the potential embarrassment for them. He now tries to alert people to his difficulties to avoid awkwardness. These days Andrew is more open about his difficulties. If required to read a document, he explains that it is easy to get around this by photographing it on his SmartPhone and enlarging the text. This is something Andrew also uses in shops to assist him in reading small print on labels. He says that, whilst it may look at bit odd to other people, it is a very useful tool. When Andrew first acquired his SmartPhone it seemed that it wouldn't actually be useful for him, but then he discovered the zoom which allows him to magnify

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the icons and see everything. Siri is also a valuable tool. He describes another incident where he used his camera phone and magnification facility in order to locate his daughter in the park after she had rode off on her bike and he couldn't see where she was.



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Facial recognition is a big issue for Andrew. He has a tendency to walk past people he knows simply because he cannot recognise faces, and he does worry that some people might think he is being rude and ignoring them. He humorously describes even walking past his wife, but goes on to say that she does change her hairstyle a lot! Andrew describes trying to recognise people by their general profile as being rather like using aircraft recognition silhouettes.

Age related macular degeneration can occur overnight, which is a complete shock and absolutely life changing. Andrew feels that there are positives about having a condition that begins earlier in life as he has learnt to adapt and found ways to deal with it. He doesn't know what it is like to have perfect vision, but his condition has not stopped him from having some tremendous experiences. There are things he can no longer do, but he is willing to give anything a go.

Currently there is no cure, but lots of research into macular degeneration is being done. Although Best disease isn't as common, it is in the same area so Andrew hopes that any new treatments discovered for macular degeneration will also benefit those with Best disease. It is not yet known how or why people develop macular degeneration, but Andrew feels that having a healthy lifestyle could help to reduce risk.

Andrew says that in order for others to help him and make his life easier, it basically comes down to general awareness and consideration.

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