Barnabas
Patient
Voices

The Patient Group of
Barnabas Medical Centre

Patient Experience Hints & Tips

Macular Degeneration (1)

Age-related Macular Degeneration (AMD) is a painless eye condition which causes loss of central vision, mainly in both eyes. In AMD central vision becomes increasingly blurred.

Reading becomes difficult and in the later stages people's faces are difficult to recognise and bus numbers are impossible to read. This happens mainly in people over the age of 50.

There are genetic factors and smoking also plays a role.

It is due to damage of the macula (essentially the central area) of the retina at the back of the eye. Diagnosis is by a thorough eye examination. The severity is divided into early, intermediate or late onset.

Dry AMD makes up around 90% of the cases. The late stage is additionally divided into "dry" and "wet" but wet AMD can occur at any time.

There is no cure at present for dry AMD but treatment of "wet" AMD by anti-VEGF drugs injected into the eye(s) can arrest the progression of this disease.

Dry AMD rarely leads to total blindness, some vision remains, mainly peripheral and this is known as eccentric viewing.

I have worn glasses since I was a child because in those days I could not see the blackboard.

A few years after I had retired I noticed that my eyesight was becoming worse so I went to see my optician. Neither he nor I knew much about AMD but immediately he gave me a letter for my GP and because of the urgency I was seen swiftly. My GP referred me to Moorfields at City Road but I waited many weeks for an appointment because they are overwhelmed with patients.

I had many tests done there and dry AMD was diagnosed. I was devastated because I had done some reading of AMD and knew that the outcome was not good. It was not helped by the fact that a young registrar gave me this news, swinging in a chair with his hands behind his back, telling me that nothing could be done, goodbye.

Since then I have been seeing my optician annually and visiting the eye clinic at Northwick Park Hospital also annually. I have tried to keep these sessions six months apart. I am still driving legally but I am aware that those days are numbered.

For at least 4 years I have not been able to drive in dusk and dark because one night when I was out for a meal very locally, temporarily there appeared to be a wall fall in front of my face – not good when driving in traffic. I got home safely but since then I have only driven locally and preferably on roads I know well and in daylight.

I had one scare a few months ago when I thought my left eye had deteriorated overnight so I went immediately to Moorfields City Road; but after many tests, I had not developed wet AMD.

I have never smoked but I have been a heavy passive smoker – both parents smoked heavily and work colleagues all smoked (this was in the days when one could smoke indoors in public places).

I discovered that two of my mother's sisters had similar symptoms to myself; although I have no medical proof, it may possibly be genetic in my case.

What have I done at home to help myself? I have problems reading a newspaper so on the odd occasions when I buy one I direct one of my many lamps on to the script.

I could not read the heating control so I used white Tippex to put a blob on 20°C. I can no longer read kitchen timers so I have bought an Amazon Echo and I give a command, *eg*. "timer in 25 minutes" and that works out well. My alarm clock has large numerals so that is helpful.

Problems can be door locks which to me are very small. I can cope if the light is good but in the dark I do struggle.

I enjoy reading especially in bed so my bedside lamp is directed on to the print. I now use reading glasses most nights.

My cat has suffered – she is mainly black with white paws. She was lying outside the bathroom one night when I was going to the loo. I did not see her, stepped on her and she is wary now when she sees me approach in the dark.

What would I do differently? I would go immediately from my optician to City Road because they run a 24 hour A&E there. There was too long a wait from GP letter going to City Road to me actually receiving an appointment – nobody's fault, just too many patients. From memory it was six weeks, and had I had wet AMD I could have lost my sight.

This is a devastating disease but there is help available. I am a member of the Macular Society and also help to run the local group. Also when I lose my driving licence and become registered partially sighted there will be help available if needed from my local council.

Macular Degeneration (2) : a Drug Trial

I have Macular Degeneration, the dry type for which there is no cure at present and the wet type which is treated with a monthly eye injection.

To give an idea of my sight, when I have an eye test I cannot read a single letter on the chart with my left eye; and reading a newspaper is a distant memory.

Three years ago I agreed to take part in an eye trial led by and paid for by an American pharmaceutical company called Apellis. At that time I did not know if I would receive the trial drug or a placebo. I was aware it was to be injected in one eye only, the one with the worst sight loss. I also knew if it worked it would stop the progress of the disease and my sight would stay the same in that eye.

I went to a local hospital once a month, had various tests throughout the day, and then I was given an injection into my eye. To do this I was lying on a trolley, my eye was anaesthetised, the eye and surrounding area were cleansed, and an instrument fitted to keep the eye open and eyelashes out of the way.

The syringe and needle used for the injection were tiny because only a minute amount of drug was being injected. I lay still as instructed and I felt nothing due to the anaesthetic. I had to wait for 30 minutes afterwards and then the eye pressure was checked. Nothing touched my eye. The eye pressure was usually normal, which meant I could be discharged.

I was lucky that because this was part of the trial I was picked up and taken home by minicab. This was needed as, because of the Macular Degeneration, all the eye drops I need, and the injection, my sight was cloudy in the injected eye; I would have had difficulty recognising a bus number or even finding my way to a tube platform. You should perhaps ask a friend to accompany you, at least until you get used to the temporary loss of even more sight than your normal.

I find this cloudiness lasts for around eight hours, so I made sure my supper those evenings was easy and microwavable. I also find it difficult to watch TV until around 9pm.

After about six months, I worked out for myself that I was receiving the drug because the eye being treated was not deteriorating – and I was told officially two years after the start of the trial that I was indeed receiving the drug.

Apellis stopped the trial because the drug was working so well worldwide with many thousands receiving it. However my local hospital has decided to continue the trial on its own for five years; this month I start year four.

As a thank you for taking part in the trial I will receive the eye injections free for the rest of my life. I am hoping the drug will become available to all those affected in a few months time but, as so often, money is the key factor.

If you are offered an injection for wet or dry Macular Degeneration it is not a decision to be taken lightly. You must attend every month for maximum effect. For three years I have visited the clinic monthly, come hail, rain or shine and throughout Covid.

As I live on my own, and before saying I would join the trial, I had to work out what to do if for any reason my sight deteriorated because of the trial. I decided I would be no worse off if something went wrong.