Personal Experience with Macular Degeneration and Types of Macular Degeneration

By
Robert Simmons, O.D.

Submitted to the Iowa Department for the Blind on March 31, 2011

I was born in 1925 and was an intensely visual person, who enjoyed an active lifestyle. My life occupation was as a Doctor of Optometry. I practiced my profession for fifty years.

In 2001, at the age of seventy-six, I developed macular degeneration in one eye. For six months I was fine, until the loss was followed swiftly by the loss of my vision in my other eye from full-blown wet macular degeneration. Laser treatments could not stop the progression of the condition, and I was forced to give up driving, a significant disadvantage. My low vision was a tremendous blow to me. I struggled with managing my business affairs, and struggled with depression.

Today, at eighty-five, I am into late stage macular degeneration, with 20/800 in one eye, and 20/400 in the other. Yet my outlook is brighter than it was several years ago. Since I am still alive and healthy, I believe I am meant to be happy, and so I've decided to do so. I am a full-time care-giver to my wife, and we live independently. I take long walks in the neighborhood, regularly crossing intersections of every size, shop for groceries, and use the local buses. I volunteer at charities, helping other seniors. I bowled and play cards, attend a morning coffee group, dine out often and write my own checks. I particularly enjoy books on tape, and have become an avid listener. I read more now with my ears than I used to with my eyes.

What enables me to survive, to be happy? How do I manage to meet the enormous challenge of vision loss, combined with being a full-time care-giver? How did I manage to turn a larger-than-life lemon into lemonade? I do have some important advantages.

First, as an optometrist, I knew about optics and how magnifiers work, and could experiment with different models, finding the right one to maximize my sight. Just as I used to solve vision problems through careful testing. Secondly, I am quite straightforward about my vision loss, and I do not hesitate to ask acquaintances to identify

themselves or waiters to help with menus. I believe low vision is nothing to be embarrassed about. Finally, my son is a Doctor of Optometry and has access to rehabilitation services, a support group, and a full range of optical aids.

But what about the1.5 million other Americans who have vision loss from macular degeneration and may not have these advantages? There may not be another medical condition in this country that is so common, that impacts daily living as profoundly, and yet is so little publicized. Many with macular degeneration are frustrated that there aren't better treatments, and they want to know exactly what is known about macular degeneration, and the status of current research.

Macular degeneration does not blind. It leaves peripheral vision intact, and this remaining vision is a saving grace. You can learn to maximize your remaining sight through optic aids and rehabilitation, and it will take you a long way to maintaining a lifestyle you enjoy.

<u>What is ARMD?</u>

Age-Related Macular Degeneration is the leading cause of adult vision loss in the United States. It affects more people than all of the better known eye diseases combined; glaucoma, cataracts, and diabetic retinopathy. One out of twenty-five Americans over sixty-five suffers significant vision loss from advanced macular degeneration. Clearly, if you have ARMD, you are not alone.

Macular Degeneration dismantles central vision painlessly and silently, leaving peripheral vision intact. As a result, people with advanced macular degeneration do not feel any change in their eyes, nor do they appear any different to their friends or family, but their experience of the world and of their own capacities change radically. Because macular degeneration leaves peripheral vision intact, people with ARMD can see whatever rests at the edges of their vision, but cannot see clearly whatever they look at directly. It takes away what we most want to see, and leaves visible what appears to be irrelevant. You can't read or drive or recognize faces, but you can pick up a piece of thread off the carpet, but that is not high on my list of activities.

<u>Why has macular degeneration been a big secret?</u>

Unlike cataracts, which can be easily seen, or glaucoma, which can easily be measured, macular degeneration is more difficult to analyze and to treat, so it wound up a bit lower on the research priority list.

Secondly, declining vision was simply accepted as the result of " just growing old". People now days are living longer and more healthy than their parents and grandparents; a sixty-five-year-old may have twenty to forty more years of reading, entertaining, traveling, and sports ahead of them, and may not be ready to retire. This is why insurance companies do not cover visual aids or therapy for low vision. The truth is that macular degeneration is complicated: there is no easy answer to its cure.

<u>Macular Degeneration isn't just about your eyes.</u>
Most people say that they would rather lose a limb than an eye. Surveys have shown that vision loss is among the most feared afflictions, among with cancer. Why? Because eyesight affects every aspect of life: mobility, physical activity, communication, appearance, psychological health and so on. Macular Degeneration is tailor-made to push every button we have. It can raise feelings of grief, helplessness, depression, fear, anxiety and anger.

<u>Macular Degeneration explained.</u>
Our eyes are like cameras. Light enters our eye through the pupil, is focused by the lens, and falls on the retina at the back of our eye. The retina picks up light and converts into nerve signals. The retina sends the nerve signals through the optic nerve to the brain, which "develops" into the images we actually see.

<u>The Macula</u>
The retina has two types of photoreceptor cells that convert light into electrical messages for the optic nerve to transmit: rod cells and cone cells, so named for their shapes. There are many more rod cells that are responsible for peripheral vision. Cone cells are concentrated in the center of the retina – and are responsible for central vision, color perception and sharp images (acute vision). The capacity of cones to distinguish detail is one hundred times greater than rods. We need them to tell the difference between forest green and black, and to see precise detail. The fovea is the very center of the macula, and contains only cone cells. This tiny area is responsible for so much of what we see. In macular degeneration, the rods and cones in the macula begin to die, reducing the number of cells to transmit visual signals to the brain. In addition to the rods and cones, there are three other key players (membranes) in macular degeneration. They supply

a delivery line for nutrition (oxygen) to the macula and whisking away waste. Dying from lack of oxygen and clogged with refuse is what causes macular degeneration.

Two types of ARMD

There are two types of macular degeneration, commonly called dry and wet. All cases are thought to start with the dry form. Between 10 percent and 15 percent of the people who show signs of dry macular degeneration eventually develop the wet form. Dry macular degeneration develops slowly and silently. They gradually lose visual acuity, while wet loses vision. Dry type can usually continue to drive and read, but blurred.

Wet macular degeneration

Wet ARMD is called "wet" because it is characterized by abnormal, leaky blood vessels that grow underneath the retina in the choroid layer. Ninety percent of the people who develop wet macular degeneration become legally blind.

Risk Factors of acquiring ARMD

Sex: Women over the age of seventy-five have twice the incidence of early macular degeneration and over seven times the incidence of developing wet macular degeneration.
Race: Caucasian, rarely seen in African-Americans
Genetic factor: Familial affect
Blue and light colored eyes
Cigarette smoking
Cardio-Vascular disease
UV exposure

Antioxidants and Vitamins for delaying ARMD:

Vitamins A, C, E
Zinc
Dark leafy vegetables
Lutein
Zeaxanthin
Low fat diet
Beta-carotene

Selenium
Copper
O.T.C. vitamins:
Bausch & Lomb Preserv-a-vision
I-Caps

<u>Making Things Bigger</u>

There are sophisticated devices constantly being made available to us to help in daily living.

Magnifiers are fantastic tools. But magnifiers are also tricky. Thoughtful people give people with low vision a perfectly good magnifier as a gift, and it doesn't work at all. Technically, magnifiers always work. Their job is to magnify and they always do, but magnifiers are made in different strengths and styles, and they magnify clearly only when they are held at the correct distance. You have to choose magnifiers with the right strength (power) for your visual acuity, you have to choose the right styles for your needs, you have to use your magnifier correctly, and you have to have adequate lighting. Since magnifiers are rarely sold with instructions or users manuals, it's very easy to get the wrong one if you're choosing on your own. And it's true that the wrong magnifier will not work for you.

There are two broad categories of magnifiers: magnifiers for seeing up close, and telescopes for seeing things at a distance. To get the right one you need to know what you want it to do, and what the magnifier you are considering actually does.

There are five types of magnifiers for close viewing. 1. Hand-held magnifiers; 2.Magnifiers in non-adjustable holders that sit directly on the page; 3.Magnifiers on an adjustable support (goose neck); 4.Electronic magnifiers (closed circuit television, CCTV), computer software and hardware; and 5.Magnifiers that fit on you nose or hear.