You've been diagnosed with

# MACULAR **DEGENERATION** NOW WHAT?



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New England Low Vision

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# INTRODUCTION

#### So, you have been diagnosed with Macular Degeneration, now what?

Many, when being told they have Macular Degeneration, inaccurately hear, "I'm going blind", and that can feel like your whole world is collapsing.

It is extremely rare to go completely blind from Macular Degeneration, whether you have either the wet or dry type. If someone tells you that nothing more can be done, that can be very depressing and is often not completely correct. What matters is a better understanding of how to navigate the landscape of the professionals who can assist you with adapting to a world of vision loss.

By the way.... congratulations, you have now become a carpenter! Yes, a carpenter...meaning you now need to assemble a new tool box of 12-24 new 'vision-loss' tools to help you with seeing both near, intermediary and distance objects.

In this report, I have outlined 12 ideas for you or a loved one to consider when diagnosed Macular Degeneration. It is important to note that not all these action steps are required, but they should be given strong consideration.

Now Go - Take Action!



# 1. OPHTHALMOLOGIST

#### Schedule an Appointment

The first step is to schedule an appointment with your Ophthalmologist - Primary Eye Doctor. They will medically examine your eyes and recommend a form of treatment, likely treating your eye condition with surgery or injections.

Your Ophthalmologist specializes in eye and vision care, completes 12 years of education and training, and are licensed to practice medicine and surgery.

As a result of their advanced training, your Ophthalmologist is able to diagnose and treat a wider range of conditions than Optometrists and Opticians.

Your Ophthalmologist diagnoses and treats all eye diseases, performs eye surgery and prescribes and fits eyeglasses and contact lenses to correct vision problems.

Because your Ophthalmologist is a medical doctor, they can sometimes recognize other health problems that aren't directly related to the eye, referring patients to the right medical doctors for alternate treatments.

As applicable, your Ophthalmologist can also prescribe an Occupational therapist who can work

Ophthalmologist's are able to diagnose and treat a wider range of conditions.

alongside you to assist with low vision rehabilitation and training.





## 2. OPTOMETRIST

#### Schedule an Appointment

Not all Optometrists specialize in Low Vision. Make sure to schedule an appointment with a Low Vision Optometrist. Ask your Ophthalmologist if they have access to an Optometrist who specializes in low vision rehabilitation.

Low vision rehabilitation is critical because this type of Optometric specialist will have access to a suite of options from low vision optical lenses, hand-held magnifiers with high magnification, monocular scopes, glare shields, and some may be able to introduce bioptic lenses and electronic video magnification.

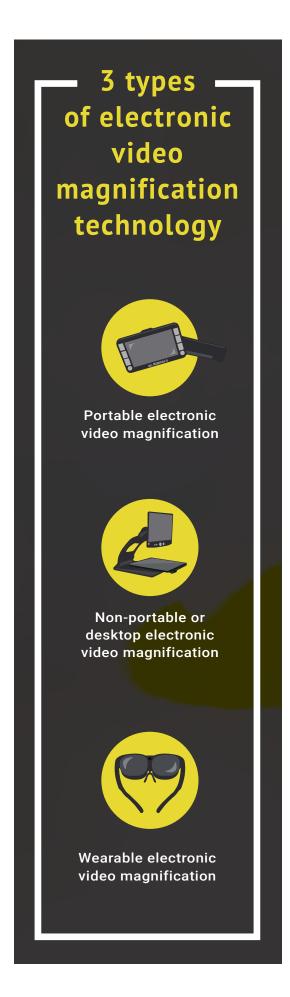
Your Low Vision Optometrist is an eye doctor who has earned the Doctor of Optometry (OD) degree. Your Optometrist can examine your eyes for both vision and health problems, and correct refractive errors by prescribing eyeglasses and contact lenses.

Some Optometrists, but not many, may also provide low vision care and vision therapy. It is critical to know if your Optometrist specializes in Low Vision Rehabilitation.

Some Optometrists in the United States also are licensed to prescribe medications to treat certain eye problems and diseases. The scope of medical care that can be provided by optometrists is determined by state law. Your Optometrist may also participate in your pre and post-operative care if you have eye surgery performed by an ophthalmologist.

Does Your

With few exceptions, Optometrists in the U.S. are not trained or licensed to perform eye surgery. Generally, your Optometrist must **Optometrist** complete a four-year college degree program in the sciences, plus four Specialize in Low years of postgraduate professional Vision Rehabilitation? training in optometry school.



# 3. ASSISTIVE **TECHNOLOGY EXPERTS**

#### Get in Touch With a Local **Technology Company**

Technology is essential. Don't believe it? Give me your phone for a day. Don't want to give it, do you? Most need their phone as a vital daily, if not hourly tool. Like your phone, the same rule applies for assistive technology for managing your life with Macular Degeneration. You need it. It is critical.

Make an appointment with a local assistive technology company, who specializes in the leading electronic video magnification technology low vision aids for people with Macular Degeneration. Sometimes the term Closed Circuit Televisions (CCTV) have been used to identify electronic video magnification technology. What a wheelchair is to someone who has trouble walking, so electronic video magnification is to someone who has trouble seeing.

Electronic video magnification technology is a fundamental tool for any patient requiring low vision rehabilitation. For someone who has trouble walking, one may initially try a cane, or crutches or even a walker. For someone who has trouble seeing, one may initially try a

magnifying glass, however, often more "horsepower" is needed.

For someone who has trouble walking, if a cane, or crutches or a walker does not fully help, then the next step is to use a wheelchair. In the same way, for someone who has trouble seeing; if a magnifying glass does not fully help or is frustrating and slow because it is not providing enough magnification or viewable field, then the next step is electronic video magnification technology.

#### **Electronic video magnification** technology can be organized into 2-3 categories:

Because of the different categories of electronic video technology, it is very important to receive a no obligation demonstration of multiple types of electronic video magnification systems PRIOR to making a purchasing decision.

Whichever electronic video magnification you select, it is important to follow up and get the right training on how to use the new technology for your specific application.

Be sure you find a known, trusted Low Vision Technology Rehabilitation Expert! Often, those same trainers can help you set up your home correctly i.e., a Smart Home – the future for people who are blind or visually impaired.

Using only your voice, imagine how great it would be if you could: Check in on a loved one in another state: schedule calendar appointments with reminders; make phone calls; lock your doors; adjust lighting; listen to music; add items to a

shopping list; read books; order products online; track packages; hear the weather forecast and latest news; have the time spoken to you; and much more.

#### Portable electronic video magnification

This category is when a person has a need to have high powered magnification on the go. Typical tasks for portable electronic video magnification are price tags, nutritional or prescription information, menus, thermostats, credit card information and phone numbers.

#### Non-portable or desktop electronic video magnification

This primary category is the most helpful for productivity. For people wanting to "get stuff done", such as paying bills or managing finances, reading books, newspapers, newsletters, documents, or writing tasks like letters, cards, lists, ledgers, etc. If productivity to maintain independence is needed, then the primary tool to use is a 'non-portable or desktop' electronic video magnification.

#### Wearable electronic video magnification

The third and less used category, is more of a specialty category, and it is referred to as wearable electronic video magnification. Wearable electronic video magnification is often used for the one task that is not accomplished by either non-portable or portable electronic video magnification. Some examples are theatre, movies, stadium viewing, school performances, sightseeing, sheet music, business or classroom viewing and seeing people faces.

## 4. VA HOSPITAL

#### Are You a Veteran?

Are you a veteran? If so, then your visual impairment qualifies you to receive amazing benefits not found anywhere else other than the VA. All your care, including technology, is covered by the VA as an earned benefit.

The Veterans Health Administration (VHA) recognizes the importance of providing blind and low vision rehabilitation care to Veterans. The VA offers a wide variety of services along the continuum of visual impairment ranging from primary eye and low vision care to Visual Impairment Center to Optimize Remaining Sight (VICTORS) programs and Blind Rehabilitation Centers (BRCs).

Optometrists strive to help visually impaired Veterans maintain functionality and independence by addressing visual problems, determining goals, and evaluating specialized devices to aid Veterans in achieving their goals.

The VA recognizes that vision loss can have a significant impact on a veteran's ability to perform the routine activities of daily living. Functional losses may include decreased ability to read or recognize faces, difficulty paying bills, writing checks and taking care of personal finances, difficulty watching television, cooking, and participating in hobbies or avocational activities.

Vision loss can have a profound effect on mobility, with the loss of ability to drive, or worse, the loss of safe ambulation. A significant problem for elderly Veterans may be the inability to self-medicate because of the difficulty in reading the labels on medicine bottles.

A variety of low vision devices may be prescribed for the visually impaired Veteran, including specialized lens designs and prescriptions, illuminated and non-illuminated stand, pocket and handheld magnifiers, prismatic eyeglasses, telescopes, special lighting, tints and filters, nonoptical devices, and electronic video magnification technology such as Closed Circuit Televisions (CCTVs) and head-mounted displays.



## 5. STATE SERVICES

#### Reach Out to Ask for Help

Be sure that you are in contact with your state services for the blind and low vision.

Services offered by the state government contributes to providing the highest quality rehabilitation and social services to state residents who are blind, leading to their independence and full community participation.

#### Most states have at least three (3) divisions of support services:



#### Vocational Rehabilitation

Vocational rehabilitation, where help is tailored to individuals who want to overcome barriers to accessing, maintaining, or returning to employment or other useful occupation.



#### Social Rehabilitation

Social rehabilitation help is geared to those who are not employed—typically seniors or youth—who need assistance to become more independent.



#### Deaf-blind and/or legally blind with cognitive issues

This support service is for consumers who are deaf-blind and or legally blind with cognitive issues, where trained professionals are able to assist with a wide variety of support needs.



State Services are typically the point of entry for vocational and social rehabilitation services for residents who are declared to be legally blind by an eye professional.

It is common that anyone who qualifies for state services will have all technology and training time funded by tax dollars allocated to state services.



## 6. NON-PROFIT ORGANIZATION

#### A Valuable Priority

Make it a priority to learn about the various non-profit organizations in your local area who serve people who are low vision or blind, including your local Lion's Club. Non-profit organizations offer valuable, progressive, multi-faceted resources committed to improving the lives of people with low vision and blindness.

A common mission of many nonprofit organizations is to prepare people of all ages who are low vision or blind with the education. confidence, and skills needed to realize their potential, maximize their remaining sight and learn to use adaptive strategies for completing daily tasks.

The majority of individuals experiencing vision loss are elders living with eye diseases such as; macular degeneration, cataracts, glaucoma, or diabetic retinopathy. One in six people over the age of sixty-five experiences vision loss, and that number rises to half of elders over eighty.

Some non-profit organizations partner with respected members of

the healthcare community to create high impact, cost-effective services that meet the crucial need for low vision services. Many non-profit organizations mission is the ongoing promise of improving the lives of people with vision-related problems. Some non-profit organizations have been around for 100+ years and have helped to pioneer many innovative services allowing people who are low vision or blind to learn the skills needed to be independent in their homes, in class settings, and in their workplaces.

It is common for many non-profit organizations to include services such as vision rehabilitation, vocational and transitional programs as well as assistive technology training. Additionally, they can provide educational support and recreation opportunities for individuals who are visually impaired of all ages. Nonprofit organizations are very useful in providing help for thousands of people who are visually impaired or blind with diverse opportunities for success and independent living.

# 7. TEACHER OF THE VISUALLY IMPAIRED (TVI'S)

#### You Must Identify a TVI in Your School

Are you a student with a visual impairment? Are you a parent of a student with a visual impairment? If so, then make it a priority to identify a TVI in your school or district.

TVI's are teachers who work with visually impaired students. TVI's are commonly referred to as "vision teachers." The TVI's responsibility is to help students who are visually impaired receive a comprehensive education while also teaching them strategies to live a full life, regardless of their disability. Sight is a crucial aspect of learning and without the ability to see, much of the world is unknown.

This presents many unique challenges to educating students who are visually impaired, who have the same capacity to learn as any other student, but they require special teachers to assist them throughout the process.

Remember your own experience in school and try to envision having

a significant visual impairment. It would be a struggle to read your teacher's notes on the board at the front of the class. It would be a struggle to make out the graphs and diagrams included in your textbooks. It would be daunting trying to navigate a maze of school hallways filled with crowds of students.

These are just some of the demands that visually impaired students face in a traditional education setting. Vision teachers draw on a number of specialized resources and methods to accomplish all of the traditional goals of education.

It is the TVI's job to evaluate the learning needs of students with visual impairments and tailor personalized education programs to support them. With proper support, students who are visually impaired can receive all the benefits of a comprehensive education, and TVI's are critical in helping guide them along the way.



# 8. CERTIFIED LOW VISION REHABILITATION THERAPIST (CVRT)

#### Contact a Seasoned Professional

Make sure you ask state services regarding a Certified Low Vision Rehabilitation Therapist. Often, the services provided by a CVRT are funded by the residents of the state through taxes. These certified professionals are extremely helpful with all types of support services in the home, and they have a network of options for wider areas of support, including orientation and mobility, and counseling. CVRTs help people to achieve their maximum life goals for education, employment, personal safety and independence.

CVRTs work in areas that enhance vocational opportunities, independent living, and the educational development of persons with vision loss, and may include working in center-based or itinerant settings.

CVRTs engage in a comprehensive approach to vision rehabilitation addressing visual, physical, cognitive, psychosocial, safety and emotional concerns through training and through the integration of existing and emerging technology and targeted adjustment counseling.

CVRTs are committed to excellence in serving individuals who are blind or have low vision to facilitate dignity, independence, and respect with successful outcomes for enhancement of quality of life and/or engaging in substantial gainful employment.

CVRTs can enhance vocational opportunities, independent living & more.



This is about navigating your environment.

Remember to ask your primary care provider about COMS and how to contact one near you.

# 9. CERTIFIED ORIENTATION & MOBILITY SPECIALIST (COMS)

#### A COMS Relationship is So Important

Make sure that you are in contact with a certified orientation and mobility specialist.

This is about navigation. Navigation with a visual impairment is easier said than done and you will likely need some assistance. COMS professionals are extremely helpful with working and teaching you how to navigate your environment with a visual impairment.

Training will include walking and may include how to use a cane. Orientation and mobility instruction are a sequential process in which people with a visual impairment are taught to utilize their remaining senses to determine their position within their environment and to negotiate safe movement from one place to another.

#### COMS skills include, but are not limited to:



#### **Concept Development**

(((•))) Sensory Development

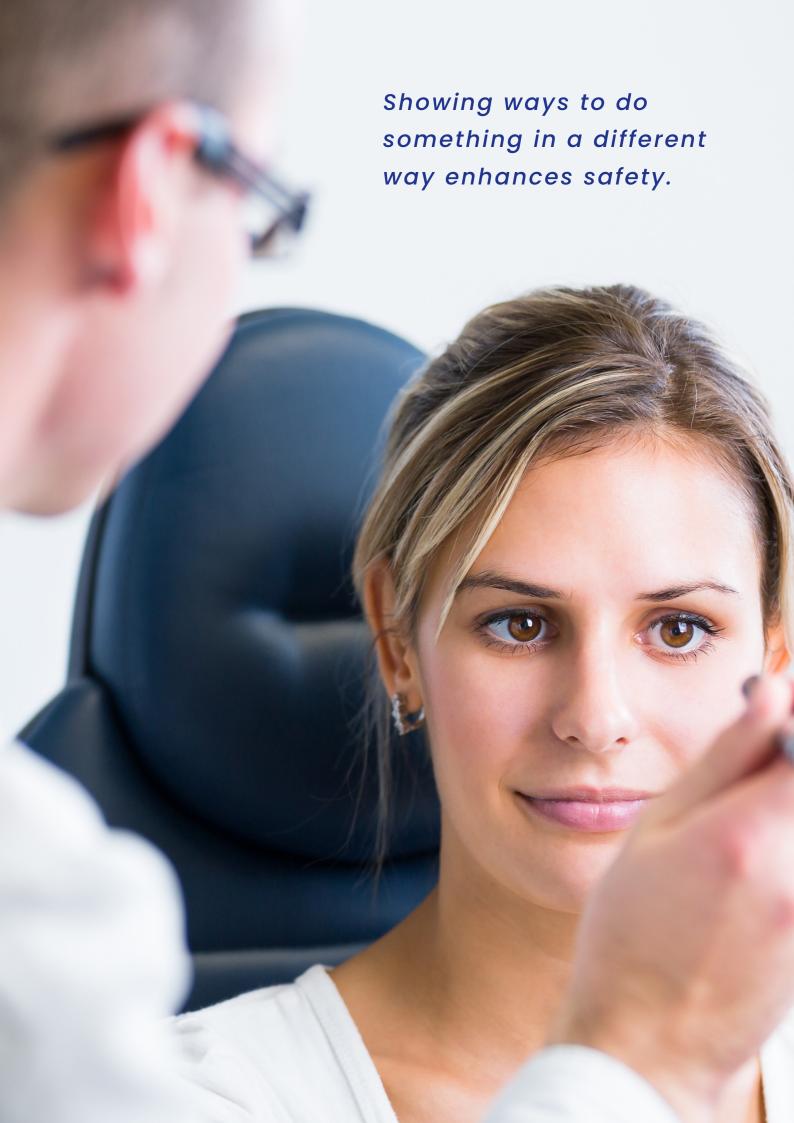
Includes body image, spatial, temporal, positional, directional, and environmental concepts



#### **Motor Development**

Motor skills needed for balance, posture, and gait, as well as the use of adaptive devices and techniques to assist those with multiple disabilities

Visual, auditory, vestibular, kinesthetic, tactile, olfactory, and proprioceptive senses, and the interrelationships of these systems



# 10. OCCUPATIONAL THERAPIST

#### Ask Your Ophthalmologist for an OT Referral

Ask your Ophthalmologist if they have access to a trained low vision occupational therapist. Occupational therapy is paid for by Medicare, however, the prescription needs to be written by either an Ophthalmologist or an Optometrist depending on your geographical area.

An Occupational Therapist will be able to work with you on finetuning all the different skills that you might need in order to become and remain independent at your home, including but not limited to: lighting, tactile marking of a microwave oven, thermostat, laundry machine, etc.

To start, your Occupational Therapist will help you to function at the highest possible level by offering tips to prevent accidents and injury. They can recommend lighting that will be most effective for a particular area and activity, pointing out potential hazards and offering solutions, and

showing ways to do something in a different way enhances safety.

Your Occupational Therapist can also teach new techniques such as eccentric viewing, visual tracking, and visual scanning which can help you learn to use your remaining vision more efficiently and effectively. Your Occupational Therapist can also help you to modify the task or environment by suggesting individualized changes to improve function, such as recommending adapted equipment tailored to your needs, and providing training in low-vision tools such as magnifiers.

Your Occupational Therapist can also help you to promote a healthy and satisfying lifestyle and suggest how to incorporate a holistic approach to help ensure that you're able to engage in the things you want and need to do, from basic activities of daily living to recreational and leisure activities.

## 11. SUPPORT GROUPS

#### Practical and Emotional Support

Make sure to ask anyone in the above-mentioned steps about local support groups. Support groups provide practical, emotional support, as well as useful tips and strategies to individuals coping with serious sight loss.

Support groups provide the opportunity for participants to share fears, frustrations, coping mechanisms, and resources as their vision impairment progresses or changes. Groups are often led by peer coordinators who are also visually impaired. Support groups provide an opportunity for people who are newly blind and visually impaired to come together to discuss issues relating to their vision loss.

Individuals in each group have a variety of eye diseases and conditions. Topics of discussion typically focus on specialized equipment to use in the home or on the job, how to maintain independence, aging and vision loss, or the effects of vision loss on family and friends.

It is common that most support groups meet monthly in various community locations. Some support groups meet during the day, others meet in the evening, and it is likely that accommodations for transportation can be provided when possible.

> Support groups provide practical and emotional support.



# 12. ATTITUDE

#### Many Like This as Idea #1

Attitude is everything, and you know it. We have all experienced someone with a bad attitude and someone with a good attitude. It is a good attitude that is worth imitating. A bad attitude does not need to be taught, it is very easy, and takes no effort or skill.

There are no sections in the library filled with books on how to have a bad attitude, or how to complain. There are, however, plenty of books on how to maintain a positive attitude. A positive attitude takes effort. You need it to help you, your family, and even your health.

Be careful, having a positive attitude is contagious, and you will likely infect others and spread it more easily than you have expected.

So, don't underestimate something you already intuitively know. Keep deciding to have a positive attitude, keep good thoughts. Don't let vision loss blind your soul, blind your happiness or blind your joy.

Keep the flame of your positive attitude burning brightly and don't let one negative thought remain in your head.

As Helen Keller once said, "Although the world is full of suffering, it is full also of the overcoming of it."





# Here are some basic reminders of the benefits of having a positive attitude.

- When you develop a positive attitude, you unleash the power to find your own happiness.
- You will benefit from motivation to help you accomplish things and reach your defined goals.
- A positive attitude changes your perspective and turns the problems in your life into opportunities.
- You will find that you have better self-esteem, and you will begin believing in yourself again, that you are capable of doing great things.
- Stress elimination is another huge benefit as it contributes to overall health. You will see that by maintaining a positive attitude affects your body chemistry to more easily release natural body chemicals to stay positive.
- Don't be surprised if you begin getting involved in creative thinking. Since you no longer view things as problems, you'll find creative solutions to your obstacles.
- It is also natural that more people will want to be around you simply because of your positive attitude, and you will make more friends.
- Your overall energy will also increase, and depression subsides the more you are able to accomplish.
- Many also enjoy receiving the benefit of more respect from others, as well as having more influence over other people.

# **LEARN MORE**

### bring hope



To learn more about all the available technology solutions offered, or to schedule a no obligation demonstration, contact a Technology Specialist at

New England Low Vision and Blindness to learn more. Toll free number 888-211-6933 or email us at info@nelowvision.com.

Our two(2) state-of-the-art technology showrooms are a wonderful resource, showcasing a variety of leading electronic low vision magnifiers and blindness products. You can schedule an appointment with one of our Technology Specialists who can help you find the right technology, training and care solution, specific for your needs.

If you cannot come to us, our staff can even drive out and bring our Vision Store to you, for a no-obligation product demonstration. We offer a comprehensive line of products including electronic magnification low vision aids, blindness products, and leading low vision products for people with glaucoma, macular degeneration and other forms of vision loss.





#### About the Author

Scott V. Krug is the President of New England Low Vision and Blindness, a company located in New England, and specializes in bringing hope to people who are low vision or blind through technology, training, and care. Scott has been working in the field of technology and optics for people who are low vision or blind since 1992.

"What a wheelchair is to someone who has trouble walking, so electronic video magnification is to someone who has trouble seeing...."

-Scott V. Krug, President



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