

Living with  
**MACULAR DEGENERATION**

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# FOREWORD

**People with age-related macular degeneration (AMD)** can continue to live life fully and independently. This booklet describes how to make adjustments to accomplish this and provides information on the disease itself, diagnosis and treatment to help better understand and cope with AMD and vision loss.

After developing AMD you may find yourself doing fewer of the things you previously enjoyed. Any activity that requires use of your eyesight – reading, gardening, going to movies or playing sports – can seem more difficult. Diminished vision may make you reluctant to go out in public. You may fear not being able to read signs, or be concerned about accidentally tripping and falling. Initially, vision loss can cause feelings of isolation, frustration and depression.

The good news is that there are ways to meet these challenges and overcome negative emotions. People with impaired vision can continue to

lead productive lives, accomplishing daily tasks and doing activities that give them pleasure. First, learn as much as possible about AMD. Then investigate the many resources available to help you and your loved ones cope with the disease and its effects.

Reading this booklet is a positive step on the path to adjusting to low vision and enjoying life.



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# INTRODUCTION

**Age-related macular degeneration (AMD)** is a common eye disease among seniors. It remains the leading cause of vision loss for those over age 65.

Approximately 1.8 million Americans 40 years and older have advanced AMD. Another 7.3 million people with intermediate AMD face a substantial risk of vision loss. The government estimates that by 2020 2.9 million people will have advanced AMD.

Because macular degeneration is usually age-related, its symptoms overlap with the normal visual changes that occur as we grow older.

To help you deal with AMD as successfully as possible, *Living with Macular Degeneration* provides information on:

- Forms of the disease (dry and wet AMD)
- AMD's effects on vision
- Diagnosis and treatment options
- Resources to help patients successfully cope with AMD's challenges



# Age-related Macular DEGENERATION

**AMD** causes deterioration of the macula, the central area of the eye's retina. The paper-thin macula processes sharp, clear, "straight-ahead" vision.

AMD causes deterioration of the macula, the central area of the eye's retina. Sharp, clear, "straight ahead" vision is processed by the light sensitive cells of the macula. The macula is also responsible for enabling one to see fine details clearly, as when reading or recognizing faces. It also plays an important role in helping us to see color. Damage to this area results in blurred or distorted vision, and potentially the development of blind spots.

When the macula becomes damaged, many daily activities such as driving and reading become increasingly difficult. Scientists are still learning about the causes and treatment of this disease.

## Dry and Wet AMD

There are two forms of AMD: dry and wet.

It is possible for a person to suffer from both forms. AMD can affect one or both eyes. The disease can also progress slowly or rapidly.

Dry AMD may advance and cause loss of vision without turning into the wet form of the disease. Early-stage dry AMD, however, can suddenly change into the wet form of the disease.

## Dry AMD

Dry AMD is the most common form, affecting approximately 85 to

90 percent of people with the disease. Both eyes are usually affected by dry AMD, although one eye can lose vision while the other eye remains unaffected.

In dry AMD the cells of the macula slowly start to break down, causing yellowish deposits of material called drusen to begin forming beneath the retina. Initially, there may be no noticeable change in vision. However, as the number and size of drusen increase, there is a gradual loss of central or “straight-ahead” vision. Eventually, this can create what most people describe as a “blind spot.”

The dry form of AMD initially causes slightly blurred vision. The center of vision in particular may become blurred and this region grows larger as the disease progresses. Patients with dry AMD may also notice increased difficulty in recognizing faces, or a need for extra lighting when reading or writing.

Dry AMD has three stages: Early, Intermediate and Advanced. The risk of developing advanced dry AMD or progressing from dry to wet AMD rises as the number or size of the drusen increases. Dry AMD may advance and cause loss of vision with-

out turning into the wet form of the disease.

The three stages of the dry form of AMD are:

- **Early:** No vision loss or symptoms at this stage.
- **Intermediate:** Some people may need additional light for certain tasks. A blurry spot may appear in the center of the visual field.
- **Advanced:** A large, blurry spot occurs in the center of the visual field and can become larger and darker, eventually causing a complete loss of central vision.

## **Wet AMD**

Wet AMD is usually preceded by the dry form of the disease. As the dry form worsens, some people experience abnormal growth of blood vessels behind the macula. These vessels are fragile and they leak fluid and blood (hence ‘wet’ macular degeneration), causing rapid damage to the macula.

In wet AMD, straight lines may appear wavy and central vision loss can occur quickly. “Straight ahead” (central) vision can become distorted



or lost entirely in a short period of time—sometimes within days. Wet AMD accounts for approximately 10 percent of AMD cases, but results in 90 percent of the cases of legal blindness. All wet AMD is considered an advanced form of the disease.

# Recognizing the SIGNS OF AMD

**Neither dry nor wet AMD causes any pain.** The most common early sign of dry AMD is blurred vision. As fewer cells in the macula are able to function, people will see details less clearly in front of them, such as faces or words in a book. Often this blurred vision will go away in brighter light. If the loss of these light sensing cells becomes great, people may see a small—but growing—blind spot in the middle of their field of vision.

A common early symptom of wet AMD is that straight lines appear crooked. This happens when fluid from the leaking blood vessels gathers and lifts the macula, distorting vision. A small blind spot may also appear in wet AMD, resulting in loss of central vision.

In terms of daily life, AMD leads to the following problems:

- **Visual Field Defect:** The details of some part of the field of vision, in this case the center, are either distorted or missing. As the disease progresses, the center of the

patient's visual field may become smudged. This causes problems with reading, driving, watching TV and recognizing faces.

- **Contrast Sensitivity:** It becomes more difficult to see textures and subtle changes in your environment. An inability to see slight contrasts and textures in pavements can lead to difficulty walking and even make it hard to see stairs. People may have trouble distinguishing between two colors of similar hue when placed side by side.

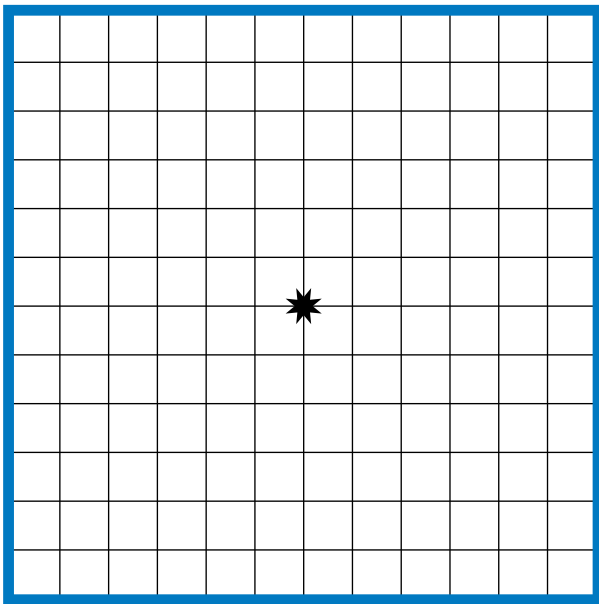
- **Poor Tolerance for Changing Light Levels:** It may become difficult to see when going from a well-lighted room to a darker one, or when driving and walking when the sun is going down. The problem can be made worse by glare. For example, a bright shaft of sunlight streaming in through a window may cause everything outside the glare to “black out.”
- **Need for Higher Light Levels:** Brighter light levels may be needed for reading, cooking, and performing day-to-day tasks.
- **Impaired Depth Perception:** An inability to properly judge distances can make walking harder, potentially leading to missteps and falls.



# Detecting Age-related Macular DEGENERATION

**When visiting an eye care specialist,** a person may first be asked to look at an Amsler Grid (Figure 1). This grid is composed of lines such as would be found on a checkerboard, with a large black dot in the center. To people with AMD, the lines may appear wavy, distorted or disappear completely when they stare at the black dot.

Figure 1 | **Amsler Grid**



A comprehensive eye exam allows the eye doctor to detect AMD. The exam may include the following:

- **Dilated Eye Exam:** To view the back of the retina, an eye care specialist will place drops into the eyes to dilate the pupils. Dilation makes it easier to see the retina and determine if there is any damage.
- **Fundoscopy or Ophthalmoscopy:** A bright beam of light from an ophthalmoscope is aimed into the eyeball to view the retina, choroid, blood vessels and optic disk.

- **Visual acuity test:** This test measures the clarity of vision at different distances.
- **Fluorescein angiogram:** If there is evidence of wet AMD, a dye is injected into the arm and is traced through to the retina where an eye care specialist can detect leakage of blood vessels.
- **Fundus photography:** The pupil is dilated, light is focused through the cornea, pupil and lens, and a customized camera photographs the back of the eye, including the retina, macula and optic nerve.
- **Race** (Non-Hispanic Caucasians, especially those with fair complexions and light-colored eyes, are at higher risk than African Americans.)
- **Prolonged sun exposure** (Visible and ultraviolet light may damage the retina.)
- **A high fat diet**, and/or one that is low in nutrients and antioxidants.
- **Obesity**

## Risk Factors for AMD

According to studies, the following factors may contribute to development of AMD.

- **Age**
- **Smoking**
- **Family history of AMD**
- **Gender** (Women appear to be at slightly higher risk.)

# Treatment Options for DRY AND WET AMD

## Dry AMD Treatment

**There is currently no specific treatment for dry AMD.** However, the National Eye Institute's Age-Related Eye Disease Study (AREDS) found that taking a particular high-dose combination of antioxidant vitamins and zinc may delay or prevent AMD from progressing to the advanced stage.

The high dosages of antioxidant vitamins and zinc in the AREDS formula cannot be provided through an ordinary diet or multivitamin. The formula includes high amounts of vitamins C, E and beta-carotene, and the mineral zinc.

### Patient Recommendations for AREDS

It should be noted that the AREDS formulation does not restore lost vision and is not a cure for AMD, but rather a preventative measure that will best benefit those who are at risk of developing advanced AMD.

The AREDS formula is not required for those with early stage AMD. However, if you note significant changes in your vision prior to your next scheduled eye exam, report these to your eye care specialist immediately. If signs of worsening disease are detected early, there is a better chance for successful treatment (Table 1).

## Treating Wet AMD

Wet AMD can be treated with injections into the eye, photodynamic therapy and laser surgery that all work to stop the growth of new, fragile and often leaky blood ves-

sels. There is no cure for wet AMD. These treatments can slow the progression of vision loss, but results are not guaranteed. If you are diagnosed with wet AMD, discuss treatment options with your doctor to determine which may be best for you.

## Macugen®

Macugen (pegaptanib sodium injection) was approved in 2004 by the U.S. Food and Drug Administration (FDA) as a treatment for wet AMD. It can be used for all patients with the wet form of the disease. Macugen blocks vascular endothelial growth factor (VEGF), a protein that promotes blood vessel growth.

Macugen is injected into the vitreous portion of the eye (the clear jelly-like substance that fills the eye from the lens back to the retina). Multiple injections are needed, usually given about six weeks apart.

The eye is numbed before each injection. After the injection, patients remain in the doctor's office for a while so their eyes may be monitored. The injection may make the eye more susceptible to infection for a period of time. Macugen may slow vision loss from AMD.

The most common side effects of Macugen include inflammation of the eye, blurred vision or changes in vi-

*Table 1* | **Who Should Take the AREDS Formula?**

Stage of AMD	Recommendation
<b>Early AMD</b>	Taking the AREDS formula is not proven to have any effect on those with early stage AMD. Visiting the doctor regularly is the best form of defense.
<b>Intermediate AMD</b>	Those with intermediate AMD in one or both eyes should take the AREDS formula as it may slow vision loss or development of advanced AMD.
<b>Advanced AMD</b>	Whether wet or dry, if a patient has advanced AMD in only one eye, the AREDS formula is recommended.

sion, cataracts, bleeding in the eye, swelling of the eye, eye discharge, irritation or discomfort of the eye, eye pain, and “spots” in vision.

## **Lucentis®**

Lucentis (ranibizumab injection), approved by the FDA in 2006, is an antibody fragment that binds to and inhibits the activity of VEGF, a protein that promotes the formation of new blood vessels.

The drug is injected into the vitreous portion of the eye (the clear jelly-like substance that fills the eye from the lens back to the retina). Routine administration over a period of time is required.

The most common adverse events include bleeding in the membrane that covers the white part of the eye (conjunctiva), eye pain, floaters, increased eye pressure and inflammation of the eye. Serious side effects such as endophthalmitis (severe inflammation of the interior of the eye), retinal detachment, retinal tear, increased eye pressure and traumatic cataract are rare and often related to the injection procedure.

Avastin®, a drug manufactured by the same company that makes Lucentis (Genentech, Inc.), has been used by doctors as an “off-label” treatment for AMD, but is actually an FDA-approved cancer therapy. Both drugs are similarly administered. However, Avastin costs much less than Lucentis, and many doctors believe these drugs are equally effective. The National Eye Institute is conducting clinical trials to study the relative efficacy and safety of Avastin and Lucentis.

## **Photodynamic therapy (PDT)**

PDT is effective for a subtype of wet AMD called predominantly classic subfoveal, in which blood vessel growth and leakage in the fovea, the small region in the center of the macula, are well defined. While the great majority of wet AMD cases are subfoveal, only 25 percent of these cases fall into this subtype.

During the PDT procedure, a drug called Visudyne® (verteporfin) is injected into the patient’s arm. The drug courses through the body and is absorbed by the fragile, leaking blood vessels in the eye. Since Visudyne is activated by light, the eye care professional will direct a laser into the

eye for a little over a minute. When activated, the drug destroys the new blood vessels, and slows the rate of vision loss.

PDT is not painful, can be completed in 20 minutes in a doctor's office and does not destroy healthy blood vessels. However, multiple treatments may be required and results might be temporary.

Also, people undergoing this treatment must be careful to completely avoid bright lights or sunlight for five days following the surgery, as any bright light touching the skin could activate the drug.

## **Laser surgery**

Laser photocoagulation surgery was the first treatment used for wet AMD, but it is only appropriate for a small subset of patients. During the outpatient procedure, the eye is numbed, and a high-energy laser is used to heat, seal and destroy abnormal leaky blood vessels. This can prevent further vision loss, but it results in a permanent blind spot. Some patients experience mild pain during and shortly after the procedure. When successful, laser surgery is a one-time treatment. However, if new

blood vessels grow, surgery may have to be repeated.

## **Preventative Measures**

There are some recommendations that could lower your risk of developing AMD. Continue these healthy habits even if you have the disease:

- Get regular exercise.
- Give up smoking.
- Eat a healthy diet including leafy green vegetables, fruit, fish, whole grains, and foods with vitamins D, E and C, beta-carotene and omega-3 fatty acids (“oily” fish, certain nuts and oils).
- Keep blood pressure at a normal level.
- Maintain a healthy weight.
- Get regular eye exams, and be aware of any changes in your vision. Visit an eye care specialist if you notice vision changes.
- Wear sunglasses and brimmed hats outdoors.

## Potential Treatments

Scientists continue to research better treatments and potential cures for AMD. Experimental therapies, including different types of surgery and implants, are being tested in the laboratory and in early human clinical trials.



# Protecting Your Vision AFTER DIAGNOSIS

## Dry AMD

- Use an Amsler grid daily to track your vision for signs of wet AMD.
- Have your vision checked at least once a year and upon any sign of further vision trouble.
- If prescribed by a doctor, regularly take the AREDS formula.

## Wet AMD

- Undergo any doctor-recommended treatments as soon as possible.
- Consistently maintain all follow-up visits to thwart redevelopment of leaky blood vessels.
- Use an Amsler grid daily and notify your doctor if you notice changes in your vision.



# Living with Age-related Macular DEGENERATION

**Both forms of AMD cause specific visual problems.** When central vision is lost, only peripheral vision remains. This peripheral vision, however, is often fuzzy enough to be classified as legal blindness.

## Visual Rehabilitation

The best way to adapt to vision loss is to learn new ways of doing things. The goal of visual rehabilitation is not to restore vision that has been permanently lost, but to adjust and help you function better with the vision you have left.

Visual rehabilitation may be undertaken with a professional low vision therapist at an eye clinic or other organization serving the visually impaired, or it may simply involve efforts you make to modify your environment and use low vision aids.

Either way, visual rehabilitation can help you adjust to your reduced vision and restore much of the independence you may feel you have lost.

## Vision Rehabilitation Centers

Rehabilitation begins by letting your eye doctor know what kind of functional limitations you are experiencing due to vision loss.

He or she can then prescribe optical devices such as magnifiers and, if appropriate, refer you to a vision rehabilitation center. If you opt to go to a vision rehabilitation center, a low vision therapist can work with you to help you adapt to specific problems.

The services offered at low vision centers vary. They can include everything from instruction in how to use Braille, to teaching you to modify your environment to make it easier

for you to navigate, to training in the use of magnifiers and special optical devices. Some low vision therapists specialize in outdoor orientation and mobility, and can teach you to function in outdoor environments more safely and with self-confidence.

## Financial Considerations

Medicare and Medicaid coverage policies for low vision rehabilitation training and devices are changing. Check with local low vision rehabilitation centers to find out whether any program costs are covered. Some low vision rehabilitation centers provide free training. In addition, there are many organizations that offer financial assistance to help defray the cost of low vision services and aids. State-funded services for the visually impaired can also be found through local offices of Area Agencies on Aging. For more information, see the Resource List.

If you do decide to work with a low vision therapist, the first step will be to evaluate your functional limitations and assess your needs. A good rehabilitation program will be as unique as you are, taking into consideration your home, lifestyle, needs and desires.

## A Program for You

If you live alone or don't ordinarily have other people nearby to assist you, you need to make sure your therapist designs a program with this in mind. The emphasis of your training should be on the activities that are important to you (for example, using the computer, reading mail, writing checks and reading labels on medicine bottles).

When you talk with your therapist, be as specific as possible about the activities you need help with, including hobbies and other sources of pleasure. The next steps in your visual rehabilitation will be learning about and using available optical devices.

## Using Optical Devices

A wide variety of magnifying glasses and devices is now available to assist you with reading and other close work. These devices range from the simple and inexpensive, such as hand-held or freestanding magnifiers, to more expensive high-tech products, such as computer screen reading software and special magnifying screen monitors that can be used with your computer or television.

Simply carrying a hand-held magnifying glass with you at all times can contribute a great deal toward your daily independence by allowing you to read labels on medicine bottles, mail, price tags in stores and restaurant menus. Initially, some visually impaired people feel self-conscious about using a magnifier in public. But before you rule out this option, you should ask yourself, “Would I rather be able to go shopping or eat out whenever I want to, or wait until I have someone to go with me and help me?”

There are various styles of magnifiers, many of them discreet, that can be found at your drug store, a medical supply store or ordered through low vision product catalogs. Magnifiers that also provide illumination usually work best for people with AMD, who need extra light as well as magnification. These are battery operated, and there are many styles available.

Inexpensive, freestanding magnifying glasses can be kept at different places in your home near where you typically do close work such as threading needles or addressing envelopes. They can also be used to apply makeup or for daily grooming.

A freestanding magnifying screen can be purchased through a medical supply store or catalog and placed in front of your television to magnify the image.

Other magnifiers come in the form of glasses or clip onto your glasses to free your hands to do other things. Many magnifiers can be ordered through the companies listed in the back of this booklet

## **Practicing with Magnifiers**

As helpful as devices such as magnifiers are, you will still have to adjust to using them, and this takes practice. All magnifiers produce a certain amount of distortion, usually around the outer edges of the glass. In general, they also decrease the field of view and reduce the depth of focus.

Distortion can be created by placing the wrong distance between you and the magnifying glass and between the glass and the object you wish to see more clearly. The proper distance between you, your magnifier and the object will vary according to the strength of the magnification, and you will need to practice until you find the right distance.

## Other Suggestions

Even with the use of magnifying devices, it helps to be creative in the identification of frequently used items. For example, put one or more red rubber bands around bottles of important medications, such as a heart drug, to make them easier for you to identify.

Brightly colored or black tape can also be placed around outlets, light switches and thermostats to first find them, then use your hand-held magnifier to help see the details. Additionally, most utility companies will come to your home at no charge and place large-print stickers on your stove and thermostat to make them safer and easier to use.

As you continue to adapt to your reduced vision, you can develop more tricks and techniques to help you do the things that are important to you.

## Other Low Vision Products

Today there is a tremendous array of commonly used household items designed to help make life easier for people living with low vision. Most of them can be purchased through low vision catalogs online or by phone

(see Resource List at back of booklet). They range in cost from a few dollars to a few thousand dollars.

Large-numbered or talking clocks and calculators, telephones with large numbers, large-button remote controls for TVs, lamps that magnify as well as illuminate, and audio tapes and CDs are just a few of the modified products available for the sight-impaired.

Not all of these products are expensive, and you may find that a few well-chosen ones tailored to your specific needs can make life safer and easier.

More expensive vision aids are also available, including computerized speech synthesizers that can be connected to a home computer. These electronic devices turn your spoken words and commands into written text.

## Changes to Your Home

Making some basic changes to the home can greatly simplify life for people with AMD.

- Keep “travel areas” throughout the home open and uncluttered. Furni-

ture can be rearranged so that sharp edges and other features do not jut into walking areas.

- Make chairs and sofas stand out with bright or light-colored towels or blankets thrown over them.
- Use bright, contrasting colors for towels, rugs, placemats, tableware, etc. so they can be seen more easily.
- Use overhead lights, task lights, extra lighting on stairs and night lights.
- Eliminate anything you might trip over. All rugs should have corners and edges tacked or taped down to prevent slips and falls.
- Use handrails on stairs and grab bars in bathrooms.

## Doors

Doors can become a hazard for those with poor eyesight who can easily bump into them if they are left open.

If you live alone or if privacy is not an issue, you might consider removing the interior doors in your home to eliminate the problem. Another solution that provides some privacy is to

replace doors with curtains. An added advantage to curtains is that wheelchairs can easily pass through them.

The thresholds of doors are a major source of falls for older people, especially the sight-impaired. If possible, all door thresholds should be planed or beveled down to make them as flush with the floor as possible.



## Tape It

Your local hardware store is a great resource for inexpensive items to help you mark things you have difficulty seeing. If you have trouble finding light switches, the plates can be replaced with illuminated ones, or as mentioned, black tape can be placed around them.

Bathrooms with floor tiles and fixtures that are the same color can be extremely frustrating for those with low vision. Place black tape along the edges of bathtubs and sinks to make them stand out, and replace your white toilet seat with one of a darker color. Put a contrasting, non-skid mat in the center of the bathtub to help you locate the tub and prevent falls.

If you live in a multi-level home and seeing steps is a problem, consider moving to a house or apartment with only one level. If moving is not an option, make your steps stand out by placing reflecting tape along the edge of every step. If the color of the tape contrasts sharply with the carpet color, the steps will be more easily seen.

## Stay Organized

Always put frequently used items such as keys, shoes, coats, toothbrushes, combs, pots, pans and glasses in the same place so you'll remember where they are.

Try to develop a system for clothes in your closets, grouping your clothes by the season and the type of garment. Put certain types of food in the same cabinet or part of the refrigerator.

Remember, your system should make sense for you and be based on where you would look for something.

Over time you may come up with your own innovative solutions to help you function better in your home. After all, you have no control over the outdoors or any public buildings you may visit, but your home should reflect your needs and allow you the greatest possible ease of operation.

## Learning to "See" Differently

Low vision devices and technologies, as well as changes in your environment, can help you function more independently, but your overall ad-

justment to vision loss depends very much on you. Keep a positive attitude toward your rehabilitation to help you learn new ways of doing things.

Establishing new habits requires time and effort, and until your new habits become “second nature,” you are likely to find them tiring. After all, you must train your eyes and brain to see differently.

## Using Peripheral Vision

You’ve spent a lifetime depending primarily on your central vision, and this habit can be hard to break. Now that you have AMD, your best sight area probably lies somewhere in the peripheral field of vision. Make a conscious effort to locate this area and use it fully.

To do this, place a brightly colored object somewhere in front of you. Face the object and look up, down, left and right. After practicing a few times, you will probably find a spot in your peripheral vision that is less fuzzy than the rest of the field.

Once you’ve located this area, it takes practice to learn to “favor” it. You may have to turn your head slightly away from the object you

wish to see, and this will feel unnatural at first.

In the beginning, you will need to practice seeing with your peripheral vision for several minutes at different intervals of each day, resting your eyes between each interval. It takes time to learn to see with peripheral vision, but if you practice consistently, at some point your new way of looking will become habitual.

## Improving Your Other Senses

Adapting to low vision also entails learning to depend more on your other senses.

Most people rely on their sight for informational input far more than any other sense. As a result, those with adequate vision rarely develop their senses of hearing, touch and smell to their full potential. After an initial period of adjustment, most people with low vision are surprised to find out how much information their other senses can supply.

## Hearing Better

Using your sense of hearing, for example, by listening to books on tape

and CD, may seem difficult at first, but will become easier over time. Listening more means remembering more. Again, most of us never develop our ability to remember what we hear to its fullest potential. To improve listening skills you need to give your full attention to what you hear rather than dividing your attention between what you see and what you hear.

You may still receive visual cues from your eyesight, but most of your focus needs to shift to listening. As you grow more accustomed to listening to books, newspapers and magazines and working with screen-reader software, you will gradually find yourself remembering more of what you hear.

You can learn to “tune in to” your sense of hearing in many practical ways to assist with daily functions. For example, locating the sound of the hum of your refrigerator can let you know you are entering the kitchen. The sound of cars and other street noises outside can indicate an open window and its location.

## Using Touch

You can also learn to rely more on your sense of touch. Selecting clothes

from the closet, for example, will be easier if you focus on the textures of fabrics and associate them with mental pictures of the garments.

If you have severe vision loss, the use of a cane or walker when outdoors allows you to use your sense of touch to get more information about your environment. These “feelers” can help detect changes in the pavement, the closeness of objects and the presence of stairs. Even without a cane or walker, using your feet to feel your way, especially when climbing or descending stairs, can augment your diminished vision and prevent dangerous falls.

## Finding Resources

There has been enormous growth in recent years in products and services designed for the visually impaired. However, some are underused due to lack of awareness.

There are many sources of print and audio materials for those with low vision. For example, the Library of Congress administers a free circulation program of Braille and recorded materials for eligible borrowers through a network of cooperating libraries. Radio reading services pro-

vide audio information for the visually impaired. There are also programs that will read newspapers by telephone free of charge. The Resource List at the back of this booklet includes information on low vision aids and organizations, audio and print materials, and many other sources of help for the visually impaired. There are many ways to stay informed, be entertained and live life fully despite the limitations of AMD.

## **From Dependence to Independence**

In AMD, the extent of vision loss varies from person to person. Each patient's rehabilitation will depend on the amount of help needed. Those who lose vision gradually to the dry form of AMD may find themselves adjusting and adapting as they go along. Wet AMD, by comparison, often results in a sudden loss of vision. This may require a longer period of dependence on others before successfully adjusting to a new way of seeing.

It takes strong and steady motivation to learn to do so many things differently in your life. Visual rehabilitation experts believe this self-motivation is one of the greatest determining factors in a patient's success.

Try to think of these adjustments as challenges to overcome. Resolve problems as they arise so that you don't become overwhelmed. Don't be afraid to ask for help, and be clear about your wants and needs with family, friends and professionals. Consider joining a support group of people facing similar issues.

Keep trying to learn how to do things differently until you have developed as much independence as is possible. Through patience and determination you will succeed.

# Low Vision RESOURCE LIST

## **Macular Degeneration Research, a program of the American Health Assistance Foundation**

Resource for the latest research news, prevention strategies, treatment and adjustment to low vision.

**22512 Gateway Center Dr.  
Clarksburg, MD 20871  
Phone: (301) 948-3244  
Toll-free: 1-800-437-2423  
[www.ahaf.org](http://www.ahaf.org)**

*The following organizations are not affiliated with the American Health Assistance Foundation (AHAF), and AHAF does not endorse any programs offered by these organizations.*

## **Eye Care Professional Organizations**

### **American Academy of Ophthalmology**

Search for ophthalmologists and eye specialists by state and locality. Also links to [www.geteyesmart.com](http://www.geteyesmart.com) which includes information on eye health and other eye-related topics.

[www.aao.org](http://www.aao.org)

### **American Optometric Association**

Provides contact information for state optometry associations which can in turn help locate an optometrist.

**243 N. Lindbergh Blvd.  
St. Louis, MO 63141  
Phone: (314) 991-4100  
Toll-free: 1-800-365-2219  
[www.aoa.org](http://www.aoa.org)**

## Financial Aid

### **BenefitsCheckUp<sup>®</sup>, National Council on Aging**

Provides information on federal and state programs that offer assistance in paying for prescription drugs, utility bills, healthcare and other needs of older Americans.

[www.benefitscheckup.org](http://www.benefitscheckup.org)

### **Hill Burton Program**

The program ended in 1997, but about 300 hospitals and healthcare facilities are still obligated to provide free or reduced-cost care. The website has a directory of participating healthcare facilities.

#### **Health Resources and Services Administration**

**5600 Fishers Ln.**

**Rockville, MD 20857**

**Phone: (301) 443-5656**

**Toll-free: 1-800-638-0742 or  
1-800-492-0329 in Maryland**

**[www.hrsa.gov/hillburton](http://www.hrsa.gov/hillburton)**

### **Knights Templar Eye Foundation**

Provides financial assistance to those

unable to pay for eye surgery but who are not eligible for assistance from social or government agencies. A letter of denial from a social or government agency is required to qualify.

**1000 East State Pkwy., Suite I  
Schaumburg, IL 60173-4592**

**Phone: (847) 490-3838**

**Fax: (847) 490-3777**

**[www.knightstemplar.org](http://www.knightstemplar.org)**

### **Lions Clubs International**

Provides financial assistance to those who need eye care. Check the phone book for local Lions Clubs.

**300 W. 22nd St.**

**Oakbrook, IL 60523-8842**

**[www.lionsclubs.org](http://www.lionsclubs.org)**

### **The Medicine Program.com**

Coordinates with physicians to assist those who do not have insurance coverage for outpatient prescription medications and do not qualify for governmental programs.

**P.O. Box 1089**

**Poplar Bluff, MO 63902-1089**

**Phone: (866) 694-3893**

**[www.themedicineprogram.com](http://www.themedicineprogram.com)**

## **New Eyes for the Needy**

Helps provide eyeglasses for the poor worldwide. Applicants must provide written proof that they have no other source of assistance.

**549 Millburn Ave.**  
**Short Hills, NJ 07078**  
**Phone: (973) 376-4903**  
**Fax: (973) 376-3807**  
**[www.neweyesforthe needy.org](http://www.neweyesforthe needy.org)**

## **Partnership for Prescription Assistance**

Helps qualifying patients who lack prescription coverage get the medicines they need through appropriate public or private programs.

**950 F St. NW, Suite 300**  
**Washington, DC 20004**  
**Toll-free: 1-888-4PPA-NOW**  
**(477-2669)**  
**[www.pparx.org](http://www.pparx.org)**

## **RxAssist**

Offers information on patient assistance programs sponsored by pharmaceutical companies that provide free medications to those who cannot afford them.

**Phone: (401) 729-3284**  
**[www.rxassist.org](http://www.rxassist.org)**

## **Seniors EyeCare Program**

Sponsored by the American Academy of Ophthalmology Foundation and the Knights Templar Eye Foundation, the Seniors EyeCare program supports the Diabetes EyeCare Program and Age-Related Macular Degeneration EyeCare Program, which provide free and low-cost eye exams and surgical care for U.S. citizens 65 and older who have not had access to an ophthalmologist in three or more years.

**Toll-free: 1-800-222-EYES (3937)**  
**[www.eyecareamerica.org](http://www.eyecareamerica.org)**

## **SEE International**

Serves disadvantaged patients who are not eligible for any social service programs such as Medicare or Medicaid. Contact SEE for information on qualification requirements.

**7200 Hollister Ave., Unit A**  
**Goleta, CA 93117**  
**Phone: (805) 963-3303**  
**Toll-free: 1-800-208-6733**  
**Fax: (805) 965-3564**  
**[www.seeintl.org](http://www.seeintl.org)**

## **Social Security Administration**

Provides some financial assistance to those who are legally blind or who have vision problems that prevent them from employment.

**Toll-free: 1-800-772-1213**

**[www.ssa.gov](http://www.ssa.gov)**

## **Vision USA**

Managed by the American Optometric Association and its affiliated state agencies, this national nonprofit charity provides free basic eye health and vision care services to individuals who have no other means of obtaining care.

**Toll-free: 1-800-766-4466**

**[www.aoa.org/visionusa.xml](http://www.aoa.org/visionusa.xml)**

## **Federal Government Resources**

### **Eldercare Locator**

Website of the U.S. Department of Health and Human Services provides resource information for older adults in any U.S. community; referrals to state and local area agencies on aging and community-based organizations that serve many elder care needs;

English and Spanish speaking information specialists.

**[www.eldercare.gov](http://www.eldercare.gov)**

**1-800-677-1116**

### **GovBenefits.gov**

A partnership of federal agencies that provides access to government assistance programs.

**[www.govbenefits.gov](http://www.govbenefits.gov)**

**1-800-FED-INFO (1-800-333-4636)**

### **Medicaid**

Program funded by federal and state governments to assist those who do not have the resources to pay for healthcare. Check the phonebook or online by state.

### **Medicare**

Federal program that pays for certain healthcare expenses. Call 24:7 for assistance; English and Spanish-speaking customer service.

**[www.medicare.gov](http://www.medicare.gov)**

**1-800-633-4227**

## **National Eye Institute, National Institutes of Health**

Supports eye disease and vision research; develops public and professional education programs to help prevent blindness, reduce visual impairment, and increase awareness of low vision services and devices.

**2020 Vision Place  
Bethesda, MD 20892-2510  
Phone: (301) 496-5248  
[www.nei.nih.gov](http://www.nei.nih.gov)**

## **National Institute on Aging, National Institutes of Health**

Conducts and supports biomedical, social and behavioral research and public education to promote healthy aging. Website database has information on over 250 national organizations that help older people.

**Building 31, Room 5C27  
31 Center Dr. MSC 2292  
Bethesda, MD 20892  
Phone: (301) 496-1752; TTY  
1-800-222-4225  
[www.nia.nih.gov](http://www.nia.nih.gov)  
[www.nihseniorhealth.gov](http://www.nihseniorhealth.gov)  
(general information)**

**[www.nia.nih.gov/  
HealthInformation/  
ResourceDirectory.htm](http://www.nia.nih.gov/HealthInformation/ResourceDirectory.htm)  
(database)**

## **State and Local Resources**

### **Healthcare Professionals**

Healthcare providers (physicians, nurses, etc.) are the first source of information for those facing health issues.

### **State and Area Agencies on Aging**

Each state and territory in the U.S. has an Agency on Aging office located in its capital city, as well as local offices. Check the phone book or online by state and area. They provide information on nutrition and support services, elder rights programs, long-term care, ombudsman programs, legal services, outreach and elder abuse prevention.

### **State Departments of Health and Social Services**

Each state in the U.S. has these departments, as well as local offices. They can provide information on

support and respite services, facilities, financial assistance, and regulations and licensing. Check the phone book or online by state and locality.

## **Low Vision Aid Resources**

### **ABLEDATA**

Provides information on assistive technology and rehabilitation equipment from domestic and international sources.

**8630 Fenton St., Suite 930**  
**Silver Spring, MD 20910**  
**Toll-free: 1-800-227-0216**  
**[www.abledata.com](http://www.abledata.com)**

### **Ai Squared**

Develops computer access software for the visually impaired.

**P.O. Box 669**  
**Manchester Center, VT 05255**  
**Phone: (802) 362-3612**  
**Toll-free: 1-800-859-0270**  
**[www.aisquared.com](http://www.aisquared.com)**

### **Beyond Sight**

Offers a wide variety of items for the visually impaired, including computers, talking clocks, kitchen items, magnifying glasses and closed circuit TVs.

**5650 South Windermere St.**  
**Littleton, CO 80120**  
**Phone: (303) 795-6455**  
**[www.beyondsight.com](http://www.beyondsight.com)**

### **Bossert Specialties, Inc.**

Offers magnifiers and other low vision aids.

**5130 N. 19th Ave., Suite 7**  
**Phoenix, AZ 85015**  
**Phone: (602) 956-6637**  
**Toll-free: 1-800-776-5885**  
**[www.wemagnify.com](http://www.wemagnify.com)**

### **The Braille Institute of America**

Offers an online low vision products catalog called Vistas.

**Toll-free: 1-800-BRAILLE**  
**(272-4553)**  
**[www.brailleinstitute.org](http://www.brailleinstitute.org)**

## **Enhanced Vision Systems**

Offers a full line of vision tools and magnifiers.

**5882 Machine Dr.**  
**Huntington Beach, CA 92649**  
**Phone: (714) 374-1829**  
**Toll-free: 1-888-811-3161**  
**[www.enhancedvision.com](http://www.enhancedvision.com)**

## **Freedom Scientific**

Provides assistive and adaptive low vision technology including portable and desktop video magnifiers, and magnification and screen reading software.

**11800 31st Court North**  
**St. Petersburg, FL 33716-1805**  
**Phone: (727) 803-8000**  
**Toll-free: 1- 877-775-9474**  
**[www.low-vision-help.com](http://www.low-vision-help.com)**

## **G. W. Micro**

Offers software and hardware solutions for the blind and visually impaired.

**725 Airport N. Office Park**  
**Fort Wayne, IN 46825**  
**Phone: (260) 489-3671**  
**[www.gwmicro.com](http://www.gwmicro.com)**

## **HumanWare**

Designs and manufactures technology solutions for the visually impaired including the SmartView™ video magnifier.

**175 Mason Cir.**  
**Concord, CA 94520**  
**Phone: (925) 680-7100**  
**Toll-free: 1-800-722-3393**  
**[www.pulsedata.com](http://www.pulsedata.com)**

## **Independent Living Aids, Inc.**

Offers a catalog of low vision products.

**P.O. Box 9022**  
**Hicksville, NY 11802**  
**Phone: (516) 937-1848**  
**Toll-free: 1-800-537-2118**  
**[www.independentliving.com](http://www.independentliving.com)**

## **Innoventions, Inc.**

Created and offers the Magni-Cam™ electronic magnifier.

**9593 Corsair Dr.**  
**Conifer, CO 80433-9317**  
**Phone: (303) 797-6554**  
**Toll-free: 1-800-854-6554**  
**[www.magnicam.com](http://www.magnicam.com)**

## **J. Bliss Imaging Systems**

Offers computer programs and applications for the visually impaired.

**P.O. Box 7382**  
**Menlo Park, CA 94026**  
**Phone: (650) 327-5477**  
**Toll-free: 1-888-452-5477**  
**(or 888-4JBLISS)**  
**[www.jbliss.com](http://www.jbliss.com)**

## **LS&S**

Offers a catalog of both low vision and hearing impaired products.

**P.O. Box 673**  
**Northbrook, IL 60065**  
**Toll-free: 1-800-468-4789**  
**[www.lssgroup.com](http://www.lssgroup.com)**

## **Maxi Aids**

Offers a catalog of low vision devices.

**42 Executive Blvd.**  
**Farmingdale, NY 11735**  
**Toll-free: 1-800-522-6294**  
**[www.maxiaids.com](http://www.maxiaids.com)**

## **MONS International, Inc.**

Offers products for the visually impaired, including Braille watches, talking calculators, 4-track recorders, kitchen aids, writing guides, computer software and accessories, greeting cards and talking scales.

**6595 Roswell Rd., NE #224**  
**Atlanta, GA 30328**  
**Phone: (770) 551-8455**  
**Toll-free: 1-800-541-7903**  
**[www.magnifiers.com](http://www.magnifiers.com)**

## **Ocutech, Inc.**

Offers various types of magnifier attachments to enhance the vision of the partially sighted; produces the VES AutoFocus telescope.

**109 Conner Dr., #2105**  
**Chapel Hill, NC 27514**  
**Phone: (919) 967-6460**  
**Toll-free: 1-800-326-6460**  
**[www.ocutech.com](http://www.ocutech.com)**

## **OVAC**

Offers a complete line of closed circuit TV products for the visually impaired.

**67-555 E. Palm Canyon  
Bldg. C-103  
Cathedral City, CA 92234  
Toll-free: 1-800-325-4488  
[www.ovac.com](http://www.ovac.com)**

## **Telesensory**

Offers products for video magnification and speech output.

**650 Vaqueros Ave., Suite F  
Sunnyvale, CA 94085  
Toll-free: 1-800-804-8004  
[www.telesensory.com](http://www.telesensory.com)**

## **Vision Cue**

Offers Braille, low vision and speech products from a variety of manufacturers.

**4858-A SW Scholls Ferry Rd.  
Portland, OR 97225  
Toll-free: 1-888-318-2582  
[www.visioncue.com](http://www.visioncue.com)**

## **Low Vision Organizations**

### **Low Vision Rehabilitation Centers**

Ophthalmologists or local hospitals can help locate low vision rehabilitation centers. These centers evaluate

and train those with low vision, and offer devices and services.

## **American Council of the Blind**

Provides a wide variety of services to visually impaired persons with an emphasis on employment opportunities.

**1155 15th St., NW, Suite 1004  
Washington, DC 20005  
Phone: (202) 467-5081  
Toll-free: 1-800-424-8666  
[www.acb.org](http://www.acb.org)**

## **Association for Education & Rehabilitation of the Blind and Visually Impaired**

An association of those engaged in the education, guidance, vocational rehabilitation or occupational placement of the blind and partially-sighted. The organization conducts certification programs, maintains job exchange services and works with local, state, and national governments on legislation affecting services to the blind and visually impaired.

**1703 N. Beauregard St., Suite 440  
Alexandria, VA 22311  
Phone: (703) 671-4500  
Toll-free: 1-877-492-2708  
[www.aerbvi.org](http://www.aerbvi.org)**

## **Columbia Lighthouse for the Blind**

Offers programs that enable the blind or visually impaired to remain independent; including early intervention services, training and consultation in assistive technology, career placement services, comprehensive low vision care and rehabilitation services.

**1120 20th St., NW**  
**Suite 750 South**  
**Washington, DC 20036**  
**Phone: (202) 454-6400**  
**Fax: (202) 454-6401**  
**Toll-free: 1-877-324-5252**  
**[www.clb.org](http://www.clb.org)**

## **International Association of Audio Information Services**

Website includes directory of radio reading services in the U.S., Canada and several other countries.

**[www.iaais.org](http://www.iaais.org)**

## **Lighthouse International**

Provides education and vision rehabilitation services, and supports research and advocacy.

**111 East 59th St.**  
**New York, NY 10022-1202**  
**Phone: (212) 821-9200**  
**Toll-free: 1-800-829-0500**  
**[www.lighthouse.org](http://www.lighthouse.org)**

## **National Association for Visually Handicapped**

Serves as a clearinghouse for information about services available to the partially sighted from public and private sources. Conducts self-help groups and provides information on large print books and educational tools, publishes a quarterly newsletter and maintains a large print loan library for the visually impaired.

**22 W. 21st St., Sixth Floor**  
**New York, NY 10010**  
**Phone: (212) 889-3141**  
**[www.navh.org](http://www.navh.org)**

## **NFB-NEWSLINE®**

Developed and operated by the National Federation of the Blind, offers free nationwide telephone newspaper service for the blind and visually impaired.

800 Johnson St.  
Baltimore, MD 21230  
Phone: (410) 659-9315  
Toll-free: 1-866-504-7300  
[www.nfb.org/nfb/newspapers\\_by\\_phone.asp](http://www.nfb.org/nfb/newspapers_by_phone.asp)

## **The Seeing Eye**

Matches specially bred and trained dog guides with blind people in the U.S. and Canada.

P.O. Box 375  
Morristown, NJ 07963  
Phone: (973) 539-4425  
Fax: (973) 539-0922  
[www.seeingeye.org](http://www.seeingeye.org)

## **Print and Audio Materials for the Visually Impaired**

### **American Printing House for the Blind**

Provides special media, tools and materials for the blind and visually impaired.

1839 Frankfort Ave.  
Louisville, KY 40206  
Phone: (502) 895-2405  
Toll-free: 1-800-223-1839  
[www.aph.org](http://www.aph.org)

## **Associated Services for the Blind**

Offers Braille, tape and large-print materials for the blind and visually impaired.

919 Walnut St.  
Philadelphia, PA 19107  
Phone: (215) 627-0600  
Fax: (215) 922-0692  
[www.asb.org](http://www.asb.org)

## **Books on Tape, Inc.**

Produces, rents and sells unabridged audio books on cassettes, CDs and MP3-CDs.

C/O Random House  
400 Hahn Rd.  
Westminster, MD 21157  
Toll-free: 1-800-521-7925  
[www.booksontape.com](http://www.booksontape.com)

## **Choice Magazine Listening**

Provides free audio tapes of current magazine articles to those who are blind, visually impaired or unable to read because of other physical limitations.

85 Channel Dr.  
Port Washington, NY 11050  
Phone: (516) 883-8280  
Fax: (516) 944-6849  
[www.choicemagazinelisting.org](http://www.choicemagazinelisting.org)

### **National Library Service for the Blind and Physically Handicapped**

The Library of Congress provides free Braille and recorded materials; loans record and cassette players to eligible borrowers through a network of cooperating libraries. Books and magazines in recorded form (talking books) or in Braille are delivered and returned by postage-free mail.

1291 Taylor St. NW  
Washington, DC 20011  
Phone: (202) 707-5100  
Toll-free: 1-800-424-8567  
[www.loc.gov/nls/](http://www.loc.gov/nls/)

### **Recording for the Blind & Dyslexic**

Provides free, recorded educational books for those with visual, perceptual or other physical disability. The master library contains over 90,000 titles.

20 Roszel Rd.  
Princeton, NJ 08540  
Toll-free: 1-866-732-3585  
[www.rfbd.org](http://www.rfbd.org)

### **Clinical Trials**

#### **National Institute on Aging, National Institutes of Health**

Provides information on government-sponsored human trials and recruitment, with locations, purpose, eligibility requirements and phone contacts.

[www.nia.nih.gov/  
HealthInformation/  
ClinicalTrials.htm](http://www.nia.nih.gov/HealthInformation/ClinicalTrials.htm)  
[www.clinicaltrials.gov/](http://www.clinicaltrials.gov/)

#### **CenterWatch Clinical Trials Listing Service**

Provides information about clinical research, including listings of active industry and government-sponsored clinical trials, research on new drug therapies and drugs recently approved by the Food and Drug Administration.

[www.centerwatch.com](http://www.centerwatch.com)

# Macular Degeneration Research PUBLICATIONS

## **Amsler Grid Eye Test**

The Amsler grid can help detect early signs of retinal disease and monitor changes in vision after diagnosis. It should not substitute for the advice of a qualified healthcare professional and is not intended to constitute medical advice. *Free*

## **Living with Macular Degeneration**

This 36-page booklet discusses the types of age-related macular degeneration (AMD), treatments, visual rehabilitation, optical devices and other low vision products, and creating a safe home environment. A valuable low vision resource list is also included. *Free*

## **Low Vision Resource List**

An extensive list of organizations to assist the visually impaired. *Free*

## **Macular Degeneration Research News**

This quarterly newsletter published by AHAF's Macular Degeneration Research (MDR) program provides easily understood updates on research currently funded MDR and other timely information about AMD. *Free*

## **Macular Degeneration: The Essential Facts**

This 17-page brochure discusses the two forms of AMD, diagnosis, risk factors, prevention strategies, treatment and adjustment. *Free*

## Safety and the Older Driver

This 28-page booklet discusses medical conditions that can affect driving, safety driving tips and strategies, a self-test for drivers, how to evaluate and discuss unsafe driving practices, and options for maintain-

ing independence once a decision is made to stop driving. *Free*

*Publications can be ordered by phone at 1-800-437-2423 or online at [www.ahaf.org](http://www.ahaf.org).*



For further information contact:  
Macular Degeneration Research  
a program of the American Health Assistance Foundation  
22512 Gateway Center Drive  
Clarksburg, Maryland 20871  
(301) 948-3244  
1-800-437-2423  
[www.ahaf.org](http://www.ahaf.org)





22512 Gateway Center Drive  
Clarksburg, MD 20871

(301) 948-3244  
1-800-437-2423  
fax (301) 258-9454

[www.ahaf.org](http://www.ahaf.org)