



Age-Related Macular Degeneration What You Should Know



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
National Institutes of Health
National Eye Institute



What you should know about
age-related macular degeneration

1–6



Dry AMD

6–12



Wet AMD

12–14



Advanced AMD

15–16



Age-Related Eye Disease Study

16–18



Loss of Vision

18–22



Coping with AMD

23–29



Where can I get more information?

30



What you should know about age-related macular degeneration

Perhaps you have just learned that you or a loved one has age-related macular degeneration, also known as AMD. If you are like many people, you probably do not know a lot about the condition or understand what is going on inside your eyes.

This booklet will give you a general overview of AMD. You will learn about the following:

- Risk factors and symptoms of AMD
- Treatment options
- Low vision services that help people make the most of their remaining eyesight
- Support groups and others who can help

The aim is to answer your questions and to help relieve some of the anxiety you may be feeling

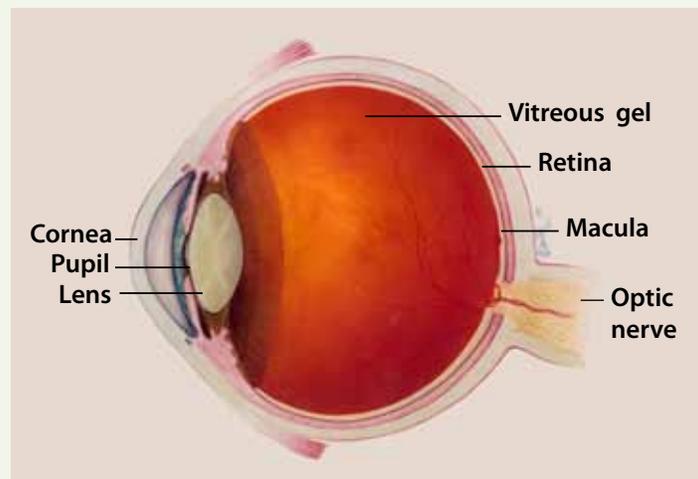
What is AMD?

AMD is a common eye condition among people age 50 and older. It is a leading cause of vision loss in older adults. It gradually destroys the macula, the part of the eye that provides sharp, central vision needed for seeing objects clearly.

In some people, AMD advances so slowly that vision loss does not occur for a long time. In others, the disorder progresses faster and may lead to a loss of vision in one or both eyes. The vision loss makes it difficult to recognize faces, drive a car, read, print, or do close work, such as sewing or fixing things around the house.

Despite the limited vision, AMD does not cause complete blindness. You will be able to see using your side (peripheral) vision.

The macula



The macula is made up of millions of light-sensing cells that provide sharp, detailed central vision. It is the most sensitive part of the retina, which is located at the back of the eye. The retina quickly turns light into electrical signals and then sends these electrical signals to the brain through the optic nerve. Next, the brain translates the electrical signals into images we see. If the macula is damaged, fine points in these images are not clear. The picture is there, but the fine points are lost.



Who is at risk?

AMD usually occurs in people who are age 50 and older. As people get older, the risk increases. Other risk factors include the following:

- **Smoking.** Research shows that smoking increases the risk of AMD two-fold.
- **Race.** Caucasians are much more likely to get AMD than people of African descent.
- **Family history.** People with a family history of AMD are at higher risk.

Does lifestyle make a difference?

Some lifestyle choices, like smoking, are linked to AMD although it remains unknown if altering any of these would alter the impact of AMD on an individual. Nevertheless, the following choices may have an impact on AMD and certainly promote healthy living, including the following:

- Avoiding smoking
- Exercising
- Maintaining normal blood pressure and cholesterol levels
- Eating a healthy diet rich in green, leafy vegetables and fish

How is AMD detected?

The early and intermediate stages of AMD usually start without symptoms. Only a comprehensive dilated eye exam can detect AMD. The eye exam may include the following:

- **Visual acuity test.** This eye chart measures how well you see at distances.
- **Dilated eye exam.** Your eye care professional places drops in your eyes to widen or dilate the pupils. This gives him or her a better view of the back of your eye. Using a special magnifying lens, he or she then looks at your retina and optic nerve for signs of AMD and other eye problems.
- **Amsler grid.** Your eye care professional also may ask you to look at an Amsler grid. Changes in your central vision may cause the lines in the grid to disappear or appear wavy, a sign of AMD.
- **Fluorescein angiogram.** Your eye care professional may suggest you see an ophthalmologist to perform a fluorescein angiogram. With this test, your doctor injects a dye into your arm. Pictures are taken as the dye passes through the blood vessels in your eye. The test allows your doctor to identify leaking blood vessels and decide the best treatment.



Questions to ask your eye care Professional

It is normal to have questions about AMD.

Below are a few questions you may want to ask your eye care professional. If you do not understand your eye care professional's responses, ask questions until you do understand.

If you think it would be helpful, ask your eye care professional to write down his or her instructions. Taking notes or getting a friend or family member to take notes is a good way to remember what your eye care professional tells you.

- What is my diagnosis and how do you spell the name of the condition?
- Can my AMD be treated?
- How will this condition affect my vision now and in the future?
- What symptoms should I watch for and how should I notify you if they occur?
- Should I make lifestyle changes?

What are the forms of AMD that can cause vision loss?

There are two forms of AMD: dry and wet. Either form can advance and cause severe vision loss. Later sections of this booklet describe the different types in greater detail. The following is a brief description of each:

- The dry form is more common and has three stages—early, intermediate, and advanced. It happens when the light-sensitive cells in the macula slowly break down, gradually blurring central vision in the affected eye.
- The wet form is considered advanced AMD and can be more severe. It happens when new blood vessels under the macula leak blood and fluid. Damage to the macula can occur rapidly.

All people who have the wet form had the dry form first.

Dry AMD

What is dry AMD?

Dry AMD is the most common form of AMD in its early or intermediate stages. It occurs in about 90 percent of the people with the condition.

Dry AMD happens when the light-sensitive cells in the macula slowly break down, gradually blurring central vision in the affected eye. As dry AMD progresses, you may see a blurred spot in the center of your vision. Your eye care professional may call this “geographic atrophy.”



Over time, central vision in the affected eye can be slowly lost as less of the macula works.

What are the symptoms?

Dry AMD has few symptoms in the early stages. It is important to have your eyes examined regularly before the disease progresses.

In the later stages, blurred vision is the most common symptom of dry AMD. Objects also may not appear to be as bright as they used to be.

As a result, you may have trouble recognizing faces. You may need more light for reading and doing other tasks. Both eyes can have dry AMD or one eye can be affected first.

What are drusen?

Drusen are another early sign of dry AMD. They are yellow deposits under the retina. They can be small or large in size.

Your eye care professional can see drusen when he or she examines the retina during a comprehensive dilated eye exam.

Drusen alone do not usually cause vision loss. But people with large drusen are at risk of developing a more severe form of AMD, which results in severe vision loss.



Normal Vision



The same scene as viewed by a person with age-related macular degeneration

Three stages of dry AMD

Dry AMD has three stages, all occurring in one or both eyes.

These stages are defined in part by the size and number of drusen under the retina:

- **Early AMD.** People with early AMD have either small drusen or a few medium-sized drusen. At this stage, you may not have any symptoms or vision loss.
- **Intermediate AMD.** People with this stage of AMD have either many medium-sized drusen or one or more large drusen. Many people will have no symptoms, so don't wait for symptoms to determine if you have an intermediate stage of AMD. Some people see a blurred



spot in the center of their vision. They often need more light to read and to do other tasks.

- **Advanced dry AMD.** In addition to drusen, people with advanced dry AMD have a breakdown of light-sensitive cells supporting tissue in the macula. This breakdown can cause a blurred spot in the center of your vision, often called geographic atrophy. Over time, the blurred spot may get bigger and dark, taking away a larger area of your straight-ahead vision.

Vision loss and dry AMD

If you have vision loss from dry AMD in one eye only, you may not notice any changes in your overall vision. With the other eye seeing clearly, you still can drive, read, and see fine details.

You may notice changes in your vision if dry AMD affects both eyes or if you develop the wet form of the disease. In any case, see an eye care professional for a comprehensive dilated eye exam if blurring occurs in your vision.

Can the dry form turn into the wet form?

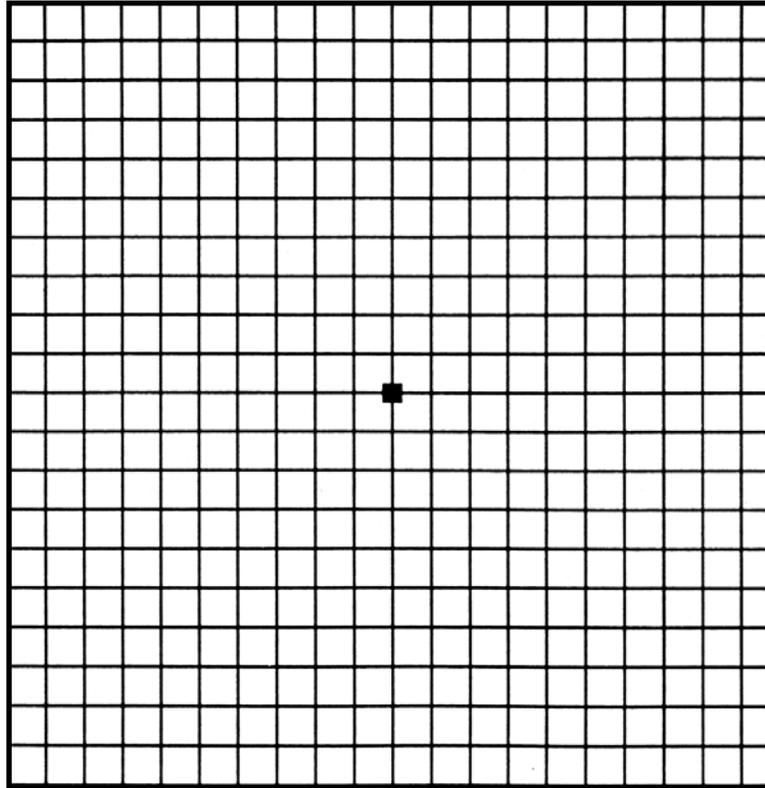
All people who have the wet form had the intermediate stage of the dry form first. The dry form also can suddenly turn into the wet form, even during early stage AMD. Eye care professionals have no way to tell if the dry form will turn into the more severe wet form.

Dry AMD can turn into wet AMD at any time. You should get an Amsler grid from your eye care professional to check your vision for signs of wet AMD.

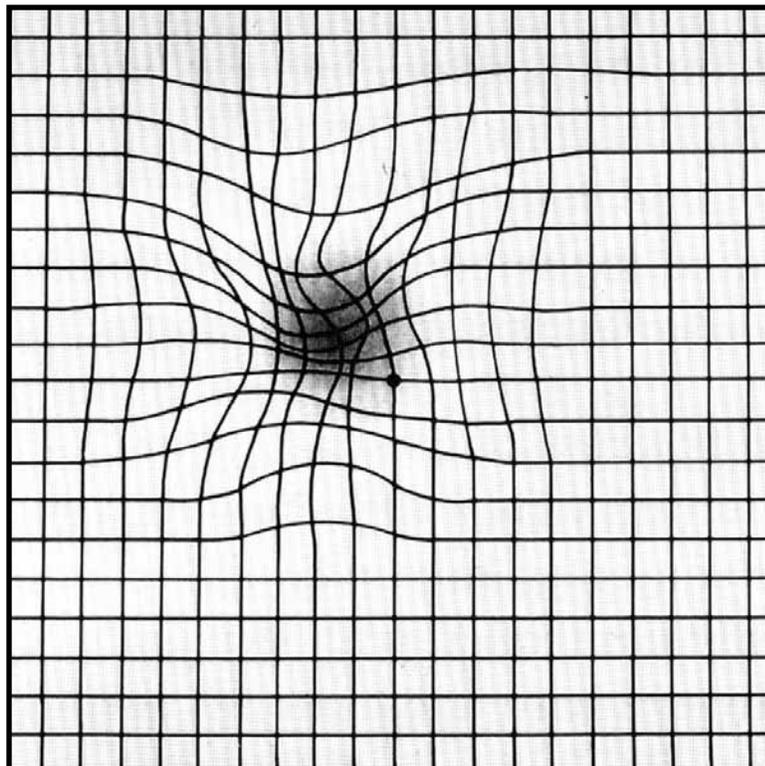
Diet might help

Studies have shown that people who eat a diet rich in green, leafy vegetables and fish have a lower risk of developing AMD.

While there is no definitive proof that changing your diet will reduce your risk of developing AMD or having it progress, to maintain good health in general, there is no reason not to eat a healthy diet, exercise, avoid smoking, and see your healthcare professional regularly.



Here is what an Amsler grid normally looks like.



This is what an Amsler grid might look like to someone with AMD.

A note about early stage dry AMD

Currently, no treatment exists for early stage dry AMD, which in many people shows no symptoms or loss of vision. Your eye care professional may recommend that you get a comprehensive dilated eye exam at least once a year. The exam will help determine if your condition is advancing.

If your condition gets worse, your eye care professional may suggest that you take a specific high-dose supplement that contains antioxidants and zinc. Do not take these high-dose supplements unless your doctor recommends them. Research shows that high doses of specific vitamins and minerals may slow the condition's progress. (See Age-Related Eye Disease Study section for details.)

Wet AMD

What is wet AMD?

Wet AMD affects about 10 percent of all people with AMD. This type, however, is more severe than the early and intermediate stages of the dry form.

Wet AMD happens when abnormal blood vessels behind the retina start to grow under the macula. These new blood vessels can be fragile and leak blood and fluid. The blood and fluid cause the macula to swell and damage occurs rapidly. The damage may also cause scarring of the retina.



Although loss of central vision can happen quickly, eye care professionals can slow down or stop the progression of wet AMD if it is detected before severe vision loss occurs.

What are the symptoms?

During the early stages of wet AMD straight lines may appear wavy. People with wet AMD also may develop a blind spot, which results in the loss of central vision.

If you notice these or other changes to your vision, contact your eye care professional at once. Again, eye care professionals may be able to treat the condition before severe vision loss occurs.

Treatment options for wet AMD

With early diagnosis and proper treatment, you can delay the progression of AMD. The earlier it is detected, the better your chances of keeping your vision. Wet AMD typically results in severe vision loss. However, eye care professionals can try different therapies to stop further vision loss. You should remember that the therapies described below are not a cure. The condition may progress even with treatment.

- **Injections.** One option to slow the progression of wet AMD is to inject drugs into your eye. With wet AMD, abnormally high levels of vascular endothelial growth factor (VEGF) are secreted in your eyes. This substance promotes the growth of new abnormal blood vessels. The anti-VEGF injection therapy blocks its effects.

If you get this treatment, you may need multiple injections. Your eye care professional may give them monthly. Before each injection, your eye care professional will numb your eye and clean it with antiseptics. To prevent the risk of infection, a doctor may prescribe antibiotic drops.

- **Photodynamic therapy.** This technique involves laser treatment of select areas of the retina. First, a drug called verteporfin will be injected into a vein in your arm. The drug travels through the blood vessels in your body, including any new, abnormal blood vessels in your eye. Your eye care professional then shines a laser beam into your eye to activate the drug in the blood vessels. Once activated, the drug destroys the new blood vessels and slows the rate of vision loss. This procedure takes about 20 minutes.
- **Laser surgery.** Eye care professionals sometimes treat certain cases of wet AMD with laser surgery, though this is less common than other treatments. This treatment is performed in a doctor's office or eye clinic. It involves aiming an intense beam of light at the new blood vessels in your eyes to destroy them. However, laser treatment



Questions to ask about treatment

- What is the treatment for wet AMD?
- When will treatment start and how long will it last?
- What are the benefits of this treatment and how successful is it?
- What are the risks and side effects associated with this treatment and how has this information been gathered?
- Should I avoid certain foods, drugs, or activities while I am undergoing treatment?
- Are other treatments available?
- When should I follow up after treatment?

also may destroy some surrounding healthy tissue and cause more blurred vision.

Advanced AMD

What is advanced AMD?

Both the wet form and the advanced dry form are considered advanced AMD. It can occur in the same eye or an eye may have just one form or the other. In most cases, only advanced AMD can cause vision loss.

Additional risk

People who have advanced AMD in one eye are at especially high risk of developing advanced AMD in the other eye.

However, research has shown that high doses of vitamins and mineral supplements may slow the progression of intermediate AMD to the more advanced stage.

Age-Related Eye Disease Study

NEI research found that patients taking high doses of antioxidants and zinc could reduce their risk of developing advanced AMD and experiencing severe vision loss. The findings were based on a 10-year clinical trial called the Age-Related Eye Disease Study (AREDS).

What is the AREDS formulation?

The AREDS formulation is a combination of antioxidants and zinc. The specific daily amounts of antioxidants and zinc tested in the AREDS clinical trial included the following:

- 500 milligrams of vitamin C
- 400 International Units of vitamin E
- 15 milligrams of beta-carotene (often labeled as the equivalent of 25,000 International Units of vitamin A)
- 80 milligrams of zinc as zinc oxide
- 2 milligrams of copper as cupric oxide



This formulation is commonly taken with meals in the morning and evening in two equally divided doses.

Researchers added copper to the AREDS formulation to prevent copper-deficiency anemia. This condition happens in people who take high levels of zinc.

Taking multivitamins

Diet alone will not provide the same high levels of the vitamins and minerals found in the AREDS formulation. Multivitamins also do not contain the same high levels.

Multivitamins do contain many important vitamins not found in the AREDS formulation. Therefore, you may want to take a multivitamin along with the AREDS formulation.

If you are already taking daily multivitamins and your doctor suggests you take the high-dose AREDS formulation, be sure you review your vitamin supplements with your eye care professional before you begin.

Who should take the AREDS formulation?

The study showed that the formulation was most beneficial for people who had:

- Intermediate AMD in one or both eyes
- Advanced AMD (dry or wet) in one eye, but not the other eye

People with early stage AMD did not benefit from taking the AREDS formulation.

Always talk to your doctor before taking any formulation.

A note about the AREDS formulation

Researchers stress that the AREDS formulation is not a cure. It will not restore vision already lost from the condition. But it may delay the onset of advanced AMD. It also may help people who are at a high risk of developing advanced AMD keep their remaining vision.

Loss of Vision

Coping with AMD and vision loss can be a traumatic experience. This is especially true of those who have just begun to lose their vision or have low vision. Having low vision means that even with regular glasses, contact lenses, medicine, or surgery, people find everyday tasks difficult to do. Reading the mail, shopping, cooking, seeing the TV, and writing can all seem challenging.



However, help is available. You may not be able to restore your vision, but low vision services can help you make the most of what is remaining. You can continue enjoying friends, family, hobbies, and other interests just as you always have. The key is not delaying use of these services.

What is low vision rehabilitation?

Low vision rehabilitation is a specialized practice. It usually includes ophthalmologists and optometrists who received special training in low vision services. Specialists in low vision also work as a team with eye care professionals, social workers, vision rehabilitation teachers, and others to help people cope with failing eyesight (see box on page 20).

The first step in getting services is a low vision examination. It is different from normal eye exams. During this appointment, the specialist in low vision will do the following:

- Examine your medical history and ask questions about your daily routines, hobbies, and goals
- Thoroughly test your vision to make sure current prescriptions work
- Introduce you to low vision devices for seeing objects that are near and distant
- Make referrals for additional services, such as counseling and support groups

By testing your vision and asking questions, the team is better able to choose a low vision device that would work best for you. Training can take place at the specialist's office, or a specialist will schedule a visit to set up and demonstrate equipment in your home. While there, he or she may evaluate lighting, mark appliances, and look for safety problems.

The low vision team

Specialist in Low Vision—An ophthalmologist or optometrist who is trained to evaluate and treat low vision.

Occupational Therapist—A licensed professional who teaches you how to use low vision devices.

Rehabilitation Teacher—An educator who teaches you different ways to handle the demands of daily living.

Orientation and Mobility (O&M) Professional—A professional who specializes in technologies that enable safe travel.

Social Worker—A professional who helps you cope with vision loss and emotional stress.

Technology Specialist or Adaptive Technology Specialist—A professional who is an expert in assistive and adaptive devices.



Where to go for services

Low vision services can take place in different locations, including the following:

- Ophthalmology or optometry offices that specialize in low vision
- Hospital clinics
- State, nonprofit, or for-profit vision rehabilitation organizations
- Independent-living centers

How to find a specialist

To find a specialist in low vision, talk with your eye care professional. He or she may be able to refer you to a variety of local resources to assist you.

What are some low vision devices?

Because low vision varies from person to person, specialists have different tools to help patients deal with vision loss. They include the following:

- Reading glasses with high-powered lenses
- Handheld magnifiers
- Video magnifiers

- Computers with large-print and speech-output systems
- Large-print reading materials
- Talking watches, clocks, and calculators

Keep in mind that low vision aids without proper diagnosis, evaluation, and training may not work for you. It is important that you work closely with your low vision team to get the best device or combination of aids to help improve your ability to see.

Computer aids and other technologies

Today, computers are helping people with low vision with reading and writing. New technology can increase text size on computer screens and allow computers to read what appears on the screen. People with low vision also are benefiting from scan-to-read devices, note takers, and other advanced technologies.

Questions to ask your eye care professional about low vision

- How can I continue my normal, routine activities?
- Are there resources to help me?
- Will any special devices help me with reading, cooking, or fixing things around the house?
- What training is available to me?
- Where can I find individual or group support to cope with my vision loss?



Coping with AMD

AMD and vision loss can profoundly affect your life. This is especially true if you lose your vision rapidly.

Even if you experience gradual vision loss, you may not be able to live your life the way you used to. These changes may force you to quit your job or cut back on volunteer and recreational activities. Your relationships with loved ones and friends may change. These changes can contribute to feelings of loss, lowered self-esteem, isolation, and despair. You may worry that you will become a “burden” on loved ones and friends. You may even go into denial and hide the fact that you have AMD.

These are natural reactions. Millions of people who suffer from AMD have these feelings as they try to adjust to their diagnosis and vision loss. However, support is available to help you maintain a fulfilling life.

AMD and depression

Given the changes, it is not surprising that some people who have AMD also experience depression.

Depression is more than just anger or sadness related to having AMD. It is a disease in its own right. Symptoms can last weeks or months. If untreated, it can worsen other

health problems or lead to thoughts of suicide. Sadly, depression is the leading cause of suicide among older people.

While depression is a serious disease, it can be treated. You should never accept it as a “normal” consequence of having AMD or getting older. Always remember that help is available. You do not have to face vision loss alone.

Signs of depression

- Constant feelings of sadness, anxiety, or emptiness
- Loss of interest in hobbies or activities that were once enjoyable
- Decreased energy
- Difficulty concentrating, remembering, making decisions
- Weight loss or gain
- Thoughts of death or suicide, suicide attempts
- Restlessness, irritability
- Persistent physical symptoms that do not respond to treatment, such as headaches, stomach disorders, and chronic pain



Engaging family and friends

Family and friends are important sources of support. But do not feel bad if the people you love most have trouble facing your vision loss. They, too, may need time to adjust to your diagnosis.

They, too, may be having feelings of shock, helplessness, and even anger. After all, it is natural that anything that greatly affects you will also affect them. They may need to make their own adjustments.

Let them know that they can help simply by being themselves.

They can offer comfort by listening and not by feeling they have to solve your problems. Tell them it is alright to ask questions or to talk about how they feel. Remind them that you are the same person you always were.

Coming to terms with the diagnosis and making the most of your remaining vision are the keys to living a fulfilling life. Your family and friends can be important resources as you adjust to living with AMD.

How to take control

The key to leading a rewarding life—despite vision loss—is taking control of the things you can. You can begin by doing the following:

- Learning more about your vision loss
- Understanding the grieving process
- Seeking counseling to cope with feelings of loneliness, helplessness, anxiety, and depression
- Visiting a specialist in low vision and getting devices and learning skills to help you with the tasks of everyday living
- Trying to stay positive. People who remain hopeful say they are better able to cope with the condition and vision loss

Professional counseling

Sometimes it is hard talking with loved ones. If you are feeling depressed and need to talk with someone, talk with your eye care professional or your regular doctor. He or she can refer you to a therapist who can talk with you about your feelings and may give you medicine that will help you feel less anxious and sad.

State agencies and nonprofit organizations also offer counseling services for those with vision loss and can provide referrals to other professionals based on individual needs.



Just taking the first step and deciding to get treatment can make all the difference.

Support groups

Some people find support groups very helpful. In a support group, people may talk about their feelings and what they are going through. They may share advice or help others who are dealing with the same issues. These groups typically meet in person or talk online.

People who attend these meetings say they often feel better about themselves. They find a new life focus. They make new friends. This helps them to cope better with AMD.

If you do not feel comfortable talking in front of a crowd, you might think about finding another person who has AMD.

The chance to talk with someone who understands your feelings can help you feel less alone and more hopeful about the future.

Information for family members

Shock, disbelief, depression, and anger are common reactions among people who are diagnosed with AMD. These feelings can last for days, weeks, months, or even years. This can be upsetting to family members and caregivers who are trying to be as caring and supportive as possible.

Following are some ideas family members might consider:

- Obtain as much information as possible about AMD and how it affects sight. Share the information with the person who has AMD.
- Find support groups and other resources within the community.
- Encourage family and friends to visit and support the person with AMD.
- Allow for grieving. This is a natural process.
- Lend support by “being there.”

The Internet offers a wealth of information about AMD, treatment, support groups, and other resources. You can start your research by visiting: www.nei.nih.gov/health/maculardegen.



Charles Bonnet syndrome

People with impaired vision sometimes see things they know are not there, but look real anyway. They may see simple patterns of straight lines or detailed pictures of people and buildings. If you experience this, do not worry. You are not losing your mind. Your eyes are playing tricks on you.

The condition is called “phantom vision” or the Charles Bonnet syndrome. It is similar to what happens to some people who have lost an arm or leg. Even though the limb is gone, these people still feel their toes or fingers or experience itching.

There is no cure for the Charles Bonnet syndrome, and it is not a sign that AMD is worsening, but the condition usually goes away after a year or so.

Where can I get more information?

For more information about age-related macular degeneration, you may wish to contact:

AMD Alliance International

1929 Bayview Avenue
Toronto, Ontario, Canada M4G 3E8
877-AMD-7171
416-486-2500, ext. 7505
E-mail: info@amdalliance.org
www.amdalliance.org

American Academy of Ophthalmology*

P.O. Box 7424
San Francisco, CA 94120-7424
415-561-8500
www.aao.org

American Foundation for the Blind

11 Penn Plaza, Suite 300
New York, NY 10001
800-232-5463
212-502-7600
E-mail: afbinfo@afb.net
www.afb.org



American Optometric Association*

243 North Lindbergh Boulevard

St. Louis, MO 63141-7851

800-365-2219

314-991-4100

www.aoa.org

Association for Macular Diseases

210 East 64th Street, Eighth Floor

New York, NY 10021-7471

212-605-3719

E-mail: association@retinal-research.org

www.macula.org

Council of Citizens with Low Vision International

800-733-2258

www.cclvi.org

EyeCare America

P.O. Box 429098

San Francisco, CA 94142-9098

877-887-6327

E-mail: pubserv@aao.org

www.eyecareamerica.org

Foundation Fighting Blindness

11435 Cronhill Drive
Owings Mill, MD 21117-2220
800-683-5555
410-568-0150
800-683-5551 (TDD)
E-mail: info@fightblindness.org
www.blindness.org

Lighthouse International

111 East 59th Street
New York, NY 10022-1202
800-829-0500
212-821-9200
212-821-9713 (TTY)
E-mail: info@lighthouse.org
www.lighthouse.org

Macular Degeneration Partnership

A program of the nonprofit Discovery Eye Foundation
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www.amd.org



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212–889–3141

E-mail: navh@navh.org

www.navh.org

National Eye Institute*

National Institutes of Health

2020 Vision Place

Bethesda, MD 20892–3655

301–496–5248

E-mail: 2020@nei.nih.gov

www.nei.nih.gov

Prevent Blindness America

211 West Wacker Drive, Suite 1700

Chicago, IL 60606

800–331–2020

E-mail: info@preventblindness.org

www.preventblindness.org

Senior Site

(A program of the American Foundation for the Blind)

800–232–5463

E-mail: seniorsite@afb.net

www.afb.org/seniorsitehome.asp

*These organizations also provide information on low vision.



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