

# Macular Degeneration Essential Facts



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Have you ever taken the Amsler grid eye test? It's a simple chart that can help detect early signs of macular degeneration and other diseases of the eye. We discuss that test and more in this brochure.

At Macular Degeneration Research, a BrightFocus Foundation program, we know how important it is that you get the latest information on prevention, early detection, regular eye exams, treatments, and coping strategies.

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## Age-related macular degeneration (AMD) is a common eye disease among people 60 and older. For Caucasians older than 40, it is the leading cause of legal blindness. It is also a leading cause of irreversible vision loss throughout the world.

AMD causes deterioration of the macula, the central area of the retina. The paper-thin macula has millions of light-sensitive cells, used by the retina to send visual signals to the brain.

Sharp, clear, straight-ahead (central) vision is processed by the macula. Macular damage results in blurred or distorted vision and, potentially, the development of blind spots.

Many daily activities, such as driving and reading, become increasingly difficult when the macula is damaged.

As many as 11 million people in the United States have some form of macular degeneration, a number expected to double by 2050. More than 2 million Americans are living with the most advanced forms of the disease.



### AMD Quick Facts

- AMD can affect one or both eyes.
- The disease can progress slowly or rapidly.
- There are two forms of AMD, dry and wet.
- A person with AMD may have either or both forms.
- Dry AMD can suddenly change into the wet form of the disease.
- Dry AMD can advance and cause loss of vision without changing into the wet form of the disease.

### Dry AMD

Between 85 and 90 percent of people who have AMD suffer from the dry form. In most cases, both eyes are affected. In some people, one eye loses vision while the other remains unaffected.

With dry AMD, the cells of the macula slowly start to break down, causing yellowish deposits called drusen to form. As the number and size of drusen grow, vision becomes blurred, particularly the central vision. This region grows larger as the disease progresses.

#### The dry form of AMD has three stages:

**Early:** There are no symptoms or vision loss at this stage.

**Intermediate:** Some people may need additional light for tasks such as reading. A

blurry spot may appear in the center of the visual field.

**Advanced:** A large blurry spot may appear in the center of the visual field and 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, abnormal blood vessels sometimes grow behind the macula. These vessels are fragile and will leak fluid and blood (hence the term “wet” macular degeneration). This accumulation of fluids lifts the macula, which distorts vision and causes damage to the macula.

In wet AMD, straight lines may appear wavy, and central vision loss can occur rapidly. Straight-ahead 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 produces 90 percent of AMD-caused legal blindness. All wet AMD is considered an advanced form of the disease.

## Specific Changes Caused by AMD

Dry and wet AMD do not cause pain. However, both forms can produce certain symptoms.

In dry AMD, as fewer macular cells function, vision becomes blurred. People see details in front of them, such as faces or words in a book, less clearly. Often this blurred vision will go

away in brighter light. If the loss of these light-sensing cells becomes great, a person with the condition may see a small—but growing—blind spot in the middle of his or her field of vision.

### **In terms of daily life, AMD can lead to the following problems:**

**Visual field defect:** The wide angle of vision observable by a healthy eye is called the “visual field.” As AMD progresses, the center of a person’s visual field may become smudged, distorted, or lost. This causes problems with reading, driving, watching TV, and recognizing faces.

**Contrast sensitivity:** It becomes more difficult to see textures and subtle changes in the environment. An inability to see slight contrasts and textures in pavements or stairs can be dangerous and lead to an increased risk of falls. There may be difficulty in distinguishing between two colors of a similar hue when placed side by side.

**Poor tolerance for changing light levels:** It may become difficult for the eyes to adjust when driving and walking at sunset, or when going from a well-lit room to a darker one. Glare can worsen the problem. 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 also make walking harder, potentially leading to missteps and falls.

## Detecting AMD

**To detect AMD, your comprehensive eye exam should include:**

**Eye dilation:** To view the back of your retina, the doctor dilates the pupils with eye drops. Dilation allows the doctor to see your retina more easily to determine optic nerve damage.

**Fundoscopy or ophthalmoscopy:** The doctor aims a bright beam of light into your dilated eye to view the retina, blood vessels, optic disk, and other structures.

**Visual acuity test or eye chart test:** This test measures your sight from various distances.

**Fundus photography:** After dilating, the doctor focuses light through the cornea, pupil, and lens, and uses a customized camera to photograph the back of the eye—including the retina, macula, and optic nerve—to look for signs of disease. This helps the clinician to measure changes between visits.

**Fluorescein angiography:** If the wet form of AMD is suspected, this test may be conducted to detect leaking blood vessels. The doctor injects fluorescent dye into your arm and traces it through the blood vessels in the retina, where the appearance of fluorescent patches can reveal leakage.

During an eye exam, you may be asked to look at an Amsler grid, a special eye test for AMD. (See page 12.) The grid resembles graph paper in which straight lines intersect at right angles. You will cover one eye and stare at a black dot in the center of the grid. While staring at the dot, if the straight lines in the grid appear wavy or are missing, this could be a sign of AMD. The Amsler grid is also a useful tool for at-home monitoring.

## Treating Dry AMD

Once dry AMD reaches the advanced stage, there is no form of treatment at present to prevent further vision loss. However, there are intervention measures that could delay and possibly prevent intermediate AMD from progressing to the advanced stage in which vision loss occurs.

The National Eye Institute's Age-Related Eye Disease Study (AREDS) found that the progression of AMD could be delayed or prevented by taking nutritional supplements with a specific high-dose formulation of antioxidants (vitamins C and E and beta-carotene), zinc, and copper.

A follow-up trial (AREDS2) was completed in May 2013. In that study researchers found



that the addition of omega-3 fatty acids to the supplements did not improve the formula's success. The antioxidants lutein and zeaxanthin proved safer than beta-carotene, which increases the risk of lung cancer for smokers or ex-smokers.

The AREDS2 recommendation for the supplement formula is:

- 500 mg of vitamin C
- 400 IUs of vitamin E
- 10 mg of lutein
- 2 mg of zeaxanthin
- 80 mg of zinc
- 2 mg of copper

### Implantable Miniature Telescope

Approved by the FDA in 2010, the implantable miniature telescope (IMT) may help those with end-stage AMD gain back some vision.

The tiny telescope is inserted into one eye, which then provides central vision while the other eye provides peripheral vision. The telescope projects images over healthy areas of the retina. The IMT can usually be implanted by an eye surgeon during an outpatient surgical visit. After surgery, patients must participate in a structured vision rehabilitation program to learn how to perform daily activities using the device.



## Treating Wet AMD

Wet AMD can be treated with injections of angiogenesis inhibitors into the eye, with photodynamic therapy, or with laser surgery. None of these treatments will cure wet AMD, but each may slow the rate of vision decline or stop further vision loss. However, the disease and loss of vision may also progress despite treatment. Options should be discussed with a doctor.

### Angiogenesis Inhibitors

Angiogenesis inhibitors work by blocking the activity of vascular endothelial growth factor (VEGF), a protein that promotes blood vessel growth.

Three treatments for wet AMD using angiogenesis inhibitors—EYLEA®, Lucentis®, and Macugen®—were approved by the U.S. Food and Drug Administration (FDA) in 2011, 2006, and 2004, respectively. There is also a fourth drug, called Avastin®, approved by the FDA as a blood vessel growth inhibitor to treat colorectal and other cancers, that has been used off-label (i.e., for purposes other than the approved uses) by some doctors to treat AMD.

### EYLEA®

After numbing the eye, the doctor injects EYLEA into the clear, jelly-like substance (the vitreous) that fills the eye from the lens back to the retina and then monitors the patient's progress. After an initial three-month period of injections every four weeks, EYLEA can be administered every eight weeks.

In comparison, treatments with the other angiogenesis inhibitors are normally given every four weeks (Lucentis and Avastin) or every six weeks (Macugen). The actual number of injections needed is determined by

the physician, taking the individual patient's disease status and response to treatment into consideration.

The most commonly reported side effects of EYLEA (affecting no more than five percent of patients) include hemorrhage of the conjunctiva (the membrane that covers the white of the eye), eye pain, risk of cataract, vitreous detachment, vitreous floaters (specks or clouds moving in the field of vision), and increased eye pressure. There is a greater risk for endophthalmitis (severe inflammation of the eye interior) and retinal detachments, as can follow any injection into the vitreous.

### Lucentis®

Lucentis is also injected into the vitreous portion of the eye after it has been numbed. Injections are given regularly over a period of time. The frequency and actual number of injections needed are determined by the physician and the individual patient's disease status and response to treatment. Findings from international studies announced in 2012 indicate that an injection every four weeks may be optimal.

The most commonly reported side effects of Lucentis include hemorrhage of the conjunctiva, floaters, eye pain, increased eye pressure, and inflammation of the eye. Rare but serious adverse events include endophthalmitis, retinal detachment, retinal tear, increased eye pressure, and traumatic cataract.

### Macugen®

Macugen is also injected into the vitreous portion of the eye that has been numbed. It is usually administered every six weeks. The actual number of injections needed is determined by the physician, taking the individual patient's disease status and response to treatment into

consideration. Macugen is still available for treatment of wet AMD, but is not used as often as other injectable angiogenesis inhibitors.

Common side effects of Macugen include inflammation of the eye, blurred vision, other changes in vision, cataracts, bleeding in the eye, swelling of the eye, eye discharge, irritation or discomfort of the eye, and "spots" in vision. Injection can also make the eye susceptible to infection for a period of time.

### Avastin®

Avastin is an FDA-approved cancer therapy drug manufactured by the same company that makes Lucentis. Avastin has been used by doctors as an off-label treatment for AMD. Both drugs are similarly administered. However, Avastin is much less expensive, and many doctors believe these drugs are equally effective against macular degeneration. The National Eye Institute of the National Institutes of Health conducted clinical trials (Comparison of Treatments Trials, or CATT) to study the relative efficacy and safety of Avastin and Lucentis. In May 2011, they reported that Avastin and Lucentis were found to be nearly



equally effective in treating AMD. In April 2012, CATT findings showed that the best results for maintaining visual acuity are achieved with injections every four weeks, with comparable results for either Avastin or Lucentis injected monthly. The report showed that receiving doses of either drug “as needed” was less effective for maintaining visual acuity than monthly dosing.

Although Avastin was associated with a greater number of serious adverse events than Lucentis, the researchers could not determine whether these differences were due to statistical chance or to real differences between the safety profiles of the two drugs.

### Photodynamic Therapy

Photodynamic therapy (PDT) is most effective in a subtype of wet AMD called predominantly classic subfoveal AMD, in which blood vessel growth and leakage in the fovea—the small region in the center of the macula—are well defined. It should be noted that PDT is rarely

used now that there are drugs (EYLEA, Lucentis, Macugen, and Avastin) that specifically block the vessel-promoting VEGF protein. During the PDT procedure, a drug called Visudyne® is injected into the arm. The drug courses through the body and is absorbed by the fragile, leaking blood vessels in the eye.

Because Visudyne is activated by light, the doctor directs a low-intensity laser at the retina for a little over a minute. This activates the Visudyne, allowing it to destroy the abnormal vessels. One treatment normally takes about twenty minutes and is relatively painless.

The most common side effects of PDT include headache, injection site reaction, and blurred or reduced vision. Because the drug is activated by light, it is important to avoid exposing eyes or any part of the skin to sunlight or bright indoor light for up to five days after treatment.

PDT may help to stabilize vision, but it will not restore lost vision.

### Laser Surgery

Laser photocoagulation surgery was the first treatment used for wet AMD, but it is only an option for a small number of patients. During the outpatient procedure, the eye is numbed, and a high-energy laser heats, seals, and destroys abnormal leaky blood vessels. This can potentially prevent further vision loss, but it results in a permanent blind spot due to scarring.

Some patients experience mild pain during and/or shortly after the procedure. When successful, laser surgery is done once. However, if new blood vessels grow, surgery may have to be repeated.



## Protecting Your Vision After Diagnosis

### Dry AMD

If you have dry AMD, you should have a comprehensive dilated eye exam at least once a year so your doctor can monitor your condition and check for other eye diseases.

Dry AMD can turn into wet AMD at any time, so use an Amsler grid frequently to evaluate your vision for signs of wet AMD. You can read more about the grid on page 12 of this brochure or get a grid from your doctor, from [www.brightfocus.org/amsler](http://www.brightfocus.org/amsler) (PDF download), or by calling BrightFocus Macular Degeneration Research at 1-855-345-6637.

### Wet AMD

If you have wet AMD and your eye doctor advises treatment, do not wait. Vision loss can happen quickly in some cases. After drug injections, laser surgery, or PDT, you will need frequent eye exams to detect any recurrence of leaking blood vessels. Remember: monitor frequently at home with the Amsler grid. If you detect any changes, contact your eye doctor immediately.

## A Healthy Lifestyle

These suggestions may help protect vision and improve overall health, and they may lower the risk of developing AMD. Even after diagnosis, continue these healthy habits:

- Maintain a healthy weight.
- Eat a nutritious diet that includes green leafy vegetables, yellow and orange fruit, fish, and whole grains.
- Don't smoke.

- Maintain normal blood pressure and control other medical conditions.
- Exercise regularly.
- Wear sunglasses and hats outdoors.
- Get regular eye exams, and consult your doctor if you notice vision changes.

## Living With AMD

The best way to adapt to vision loss is to learn new ways of doing things. Visual rehabilitation will help you adjust and function better with your remaining vision, though it cannot restore vision that has been permanently lost.

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

The doctor can then prescribe optical devices, such as magnifiers (see next section).

Your doctor may also refer you to a vision rehabilitation center, an eye clinic, or other organization where a low vision therapist can work with you to help you adapt and resolve specific problems. You can also modify your environment, develop your senses of hearing and touch, practice using peripheral vision, and use low vision aids.



## Optical Devices, Low Vision Aids, and Services

Many types of magnifying glasses and devices are available to assist with reading and other close work. These devices range from the simple and inexpensive—such as a hand-held or free-standing magnifier—to expensive, high-tech products such as software that reads the text on a computer screen aloud and special magnifying screen monitors that can be used with computers or TVs. There are also reader applications for smart phones and tablets.

Simply carrying a hand-held magnifying glass with you at all times can contribute a great deal toward your daily independence. Magnifiers—some of them small enough to fit in your wallet—allow you to read labels on medicine bottles, mail, price tags, and restaurant menus.

Commonly used household items with large-print numbers and letters are available, as well as others that “talk.” There are also many sources for large-print books and audio materials, and services that read newspapers and magazines by phone or over the radio.

**For these and other resources, see the Low Vision Resource List on the BrightFocus Foundation website:**

[www.brightfocus.org/vision-resources](http://www.brightfocus.org/vision-resources)

Or call us at 1-855-345-6637, to request a copy.

## Suggestions for the Home

- Use overhead lights, task lights, night-lights, and extra lighting on stairs.
- Mark the edges of steps with bright tape; for additional safety, install and use handrails.
- Use bright tape or puff paint to mark light switches, electrical outlets, and other fixtures.



- Keep walking areas clear.
- In the bathroom, use skid-free mats, install grab bars, and use contrasting colors to differentiate the various surfaces (toilet seat, floor mat, bottom of the bathtub, etc.).
- Label medications with large-print stickers, or identify them with colored rubber bands.
- Consider removing doors; make thresholds flush with the floor.
- Use large-print stickers on the thermostat, stove, and other appliances. Mark key positions with raised labels.

## From Dependence to Independence

With AMD, the extent of vision loss varies from patient to patient. Each person's rehabilitation will depend on the amount of help needed. Don't be afraid to ask for assistance, and be clear about your wants and needs. Try to stay positive and take on challenges as they arise.

As you learn to do things differently, you can become more independent. Through patience and determination, you can continue to enjoy a productive and full life.



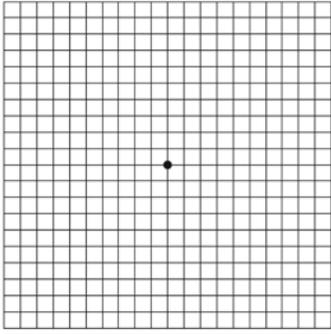
## Essential Questions to Ask Your Doctor About Macular Degeneration

### At your regular vision screening:

- Exactly what tests are you conducting?
- Am I at risk for developing macular degeneration?

### If you are diagnosed with AMD:

- What kind of macular degeneration do I have?
- How advanced is my macular degeneration?
- Is it in one or both eyes?
- If only one, how likely am I to get it in the other eye?
- Have I already lost any vision?
- Are there lifestyle changes I should make?
- How can I best monitor the progression of my disease?
- Are there devices I can use to make better use of the vision I have?
- What should I do if I notice a difference in my vision?
- What treatments are you recommending?
- Are there certain vitamins or minerals I should take? What if I've been a tobacco user?
- Will this require injections? If so, are they done on a specific schedule or as needed?



## The Amsler Grid Eye Test

When visiting an eye care specialist, you may be asked to look at an Amsler Grid. (Reduced illustration at left **not for use.**)

This test can help

detect early signs of macular degeneration or other retinal diseases. The test can also help monitor changes in vision after diagnosis.

1. The actual grid is 10 x 10 centimeters in size (about 3-5/8 inches square), and is held at a comfortable reading distance, generally, about 12-14 inches away from the eyes. You should wear reading glasses if you normally use them.
2. You will be asked to cover one eye and focus on the black dot in the middle of the grid.
3. You will then be asked to cover the other eye and repeat the test.

If the lines appear to be wavy, dim, irregular or fuzzy your eye care specialist will probably ask you to take further tests, as this is one indicator of macular degeneration or other retinal diseases.

If you would like to order a free Amsler Grid Test from Macular Degeneration Research for testing yourself at home, just fill out and send the tear-off card at the end of this brochure. Or call 1-855-345-6637.

**NOTE: A HOME AMSLER GRID EYE TEST DOES NOT REPLACE REGULAR EYE EXAMS.**

## For more information

Visit our website:

[www.brightfocus.org/MDRresources](http://www.brightfocus.org/MDRresources)

Or call

1-855-345-6637

Para información en español, visite [www.brightfocus.org/espanol](http://www.brightfocus.org/espanol)

## Additional BrightFocus Resources

- Macular Degeneration Insights Articles
- Low Vision Resource List
- Macular Degeneration Research News
- Videos and Podcasts

BrightFocus is at the forefront of brain and eye health,  
advancing catalytic research around the world and  
promoting better health through our three programs:

**Alzheimer's Disease Research**  
**Macular Degeneration Research**  
**National Glaucoma Research**



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