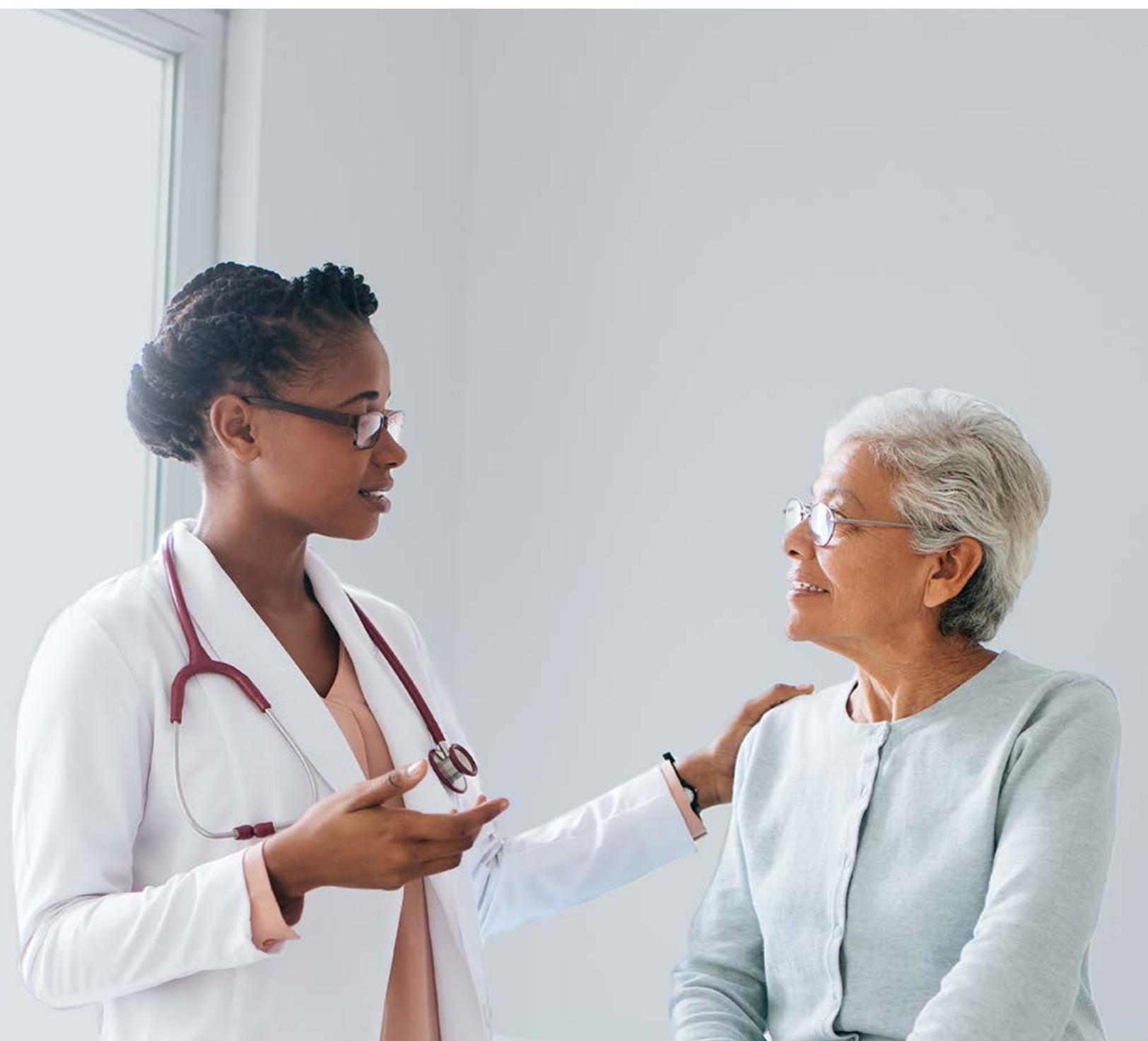


Ask Your Eye Care Team

Patient & Caregiver Conversation Guide

Helping to navigate your treatment journey
with macular degeneration



A Guidebook to Help You

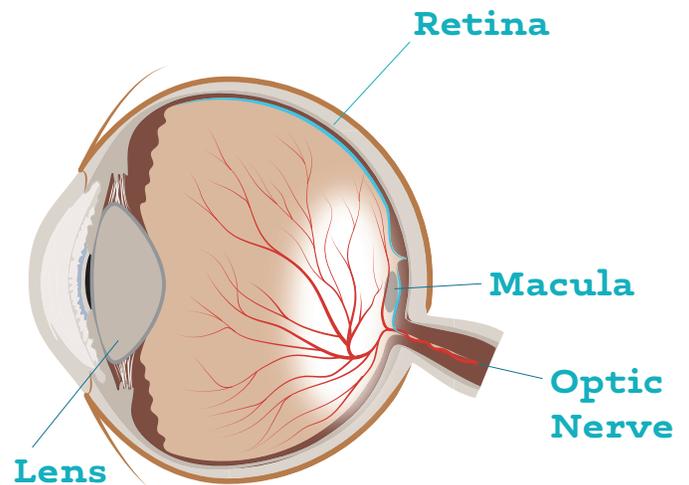
This guide will help you throughout your treatment journey with macular degeneration. It is a tool that you can use to learn more about your condition and features questions to help guide conversations about your treatment with your doctor and eye care team.

Anatomy of the Eye

To understand how macular degeneration affects the eye, it helps to know the basic anatomy. The image to the right depicts several key components, including the retina and macula.

Retina: a layer at the back of the eye containing cells that are sensitive to light, where a visual image is formed.

Macula: the center of the retina and is necessary for sharp vision.



Graphics are not drawn to scale

What is Macular Degeneration?

There are two forms of macular degeneration: dry and wet.

Worldwide, the number of people with macular degeneration is expected to be 196 million in 2020.

All macular degeneration begins as “dry.” Dry macular degeneration occurs when parts of the macula thin with age and tiny clumps of protein grow, causing slow loss of the sharp, central vision that lets you see things directly ahead.

Dry macular degeneration can, without pain or other warning signs, develop into “wet” macular degeneration, a more advanced form. In fact, in 10-20% of cases, dry macular degeneration progresses to wet.

Wet age-related macular degeneration, or wet AMD, affects an estimated 20 million people worldwide, and is a leading cause of vision loss among people 65 and older. Effective treatments for wet AMD are available.

- Wet AMD is caused by an excess of vascular endothelial growth factor (VEGF), which leads to the growth of abnormal blood vessels inside the eye. These abnormal blood vessels leak fluid and blood, destroying the macula.
- Wet AMD typically starts in one eye, and may eventually affect both eyes.
- Often, it diminishes central vision, resulting in blurring, obscuring, or distorting what you see when you look straight ahead.

Some Helpful Facts about Wet AMD

There are a lot of misconceptions about wet AMD. Here are some helpful facts.

Impact on vision – With wet AMD, you may see a blank area in your vision or straight lines may look wavy. It may be difficult to read a book, locate the edge of a curb, or recognize faces.

Since wet AMD generally occurs in one eye at a time, it is important to test each eye individually for these symptoms.



These pictures are simulations and individual experiences may vary.

Symptoms of Wet AMD

Wet AMD can cause the following symptoms:

- Distorted and/or blurry vision
- An empty or dark area in the middle of vision
- Objects that appear to be the wrong size or shape
- Perceiving a waviness to straight lines, known as distortion
- Visual difficulty with everyday activities, like reading, watching TV, or driving

Talking with Your Doctor & Eye Care Team about Wet AMD

The following questions may help you to prepare for conversations about your treatment with your doctor and eye care team.

1 Am I going to go blind and lose my sight completely?

Without treatment, wet AMD can cause profound loss of reading and driving vision. Since it affects the macula (center of the retina), some individuals affected with wet AMD may retain peripheral vision.

You will best manage the disease if you understand and stick to your treatment plan, allowing your doctor to monitor fluid, which will give you the best chance of driving, reading, and seeing the faces of the people you love.

If you have any questions about your treatment plan, be sure to ask your eye care team.

“

The worst is not being able to drive - it's like going to jail. You're lost without your vision! Blind! That was one word I remember and I'll never forget. I can't drive now, but he says that once I'm through with the shots and the glasses I can drive and I'll be more independent!

Marley, macular degeneration patient

2 Why is it important to monitor fluid in my retina?

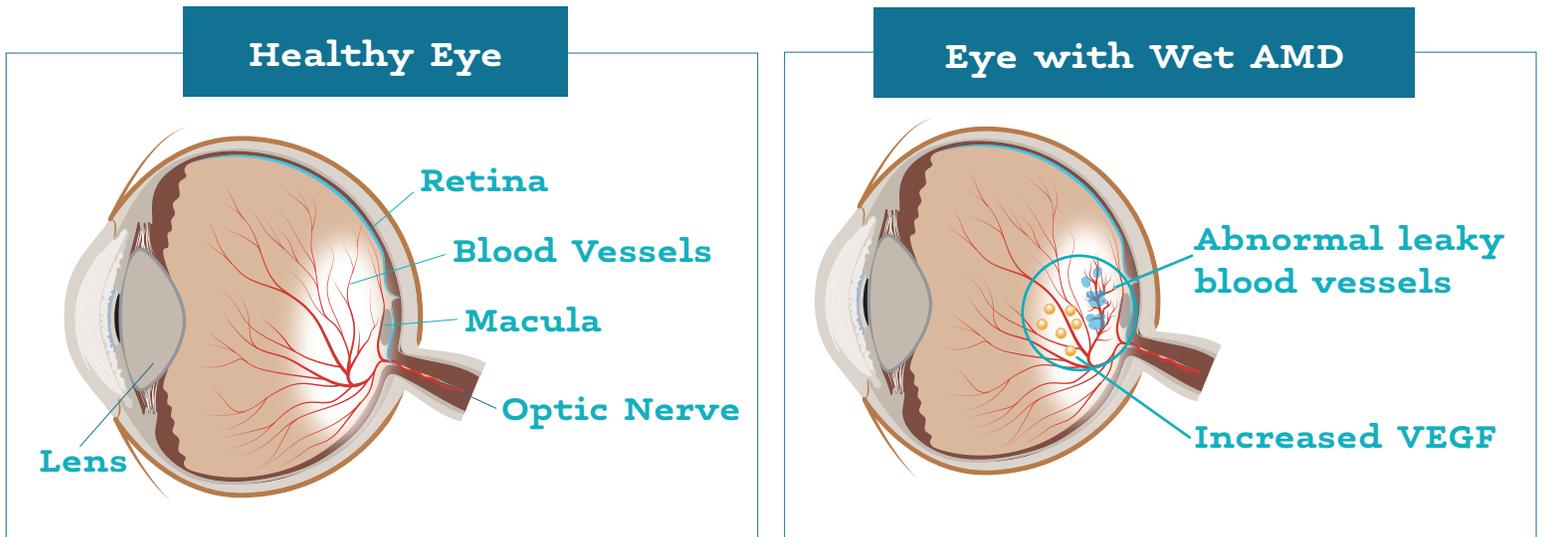
Similar to other chronic diseases, it is important to closely monitor your wet AMD.

Wet AMD is characterized by abnormal blood vessel growth under the retina. These vessels can leak fluid and blood, which may lead to damage of the macula and loss of sharp, central vision.

Treatment for wet AMD aims to address this fluid and keep the retina as dry as possible.

At your appointments, an imaging technique, Optical Coherence Tomography (OCT), may be used to detect fluid in the retina.

It is important to schedule an appointment with your doctor if you experience any change in vision.



Graphics are not drawn to scale

3 How can I preserve my sight?

The best way to manage wet AMD is to ask about and follow your treatment plan. Always contact your doctor immediately if you experience any changes in vision.

Wet AMD is most often treated with injections of anti-VEGF medications into the eye. The injections are administered by your doctor on a continuing basis and the frequency may vary. Your treatment plan for wet AMD should be discussed thoroughly with your doctor.

“

They claim they can control it, so at my age, I go with the flow. You do what you have to do! I didn't question the diagnosis, I trusted them and I went to the retina specialist who has a good reputation.

Alex, macular degeneration patient

4 Will the injections cause pain and discomfort?

The eye is numbed before the anti-VEGF injection is given.

Many patients say the worry is worse than the procedure.

Injections are critical to managing wet AMD and may prevent the formation of new leaky blood vessels and more fluid from accumulating in the retina, which can lead to further loss of vision.



During my first injection I was tense like a board. But by the third injection it was no big deal.

Tony, macular degeneration patient

5 How can I monitor my vision changes between appointments?

Between appointments, it's important to monitor your vision changes from home. The space below is designed to help you note any improvements or changes to discuss with your doctor.

Possible questions may include:

What has changed since the last visit?

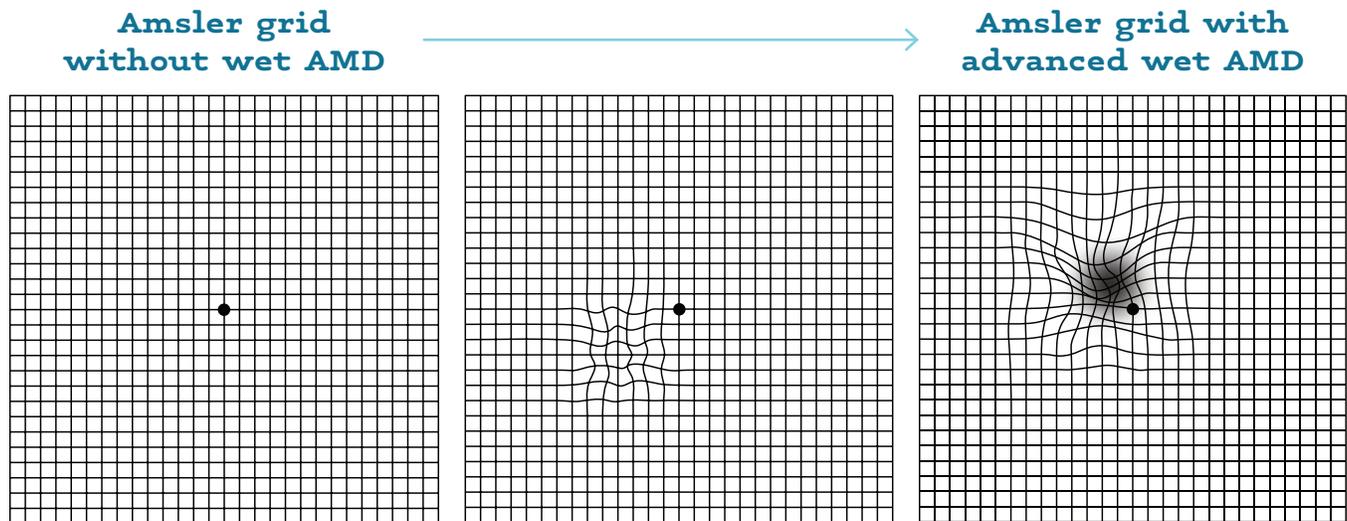
What has gotten better?

What has gotten worse?

How are you feeling emotionally?

For example, your eye care team can show you how to monitor the progression of macular degeneration using an Amsler grid. This grid can help track blurring, distortion, and blank spots in your vision.

- Be sure to cover one eye and check the grid with the other, so that each eye is monitored individually.
- Another option would be to cover one eye and make sure you read as you did before and then do the same thing the other eye.



Keeping up with your treatment is key to managing wet AMD. If you ever notice a change when you look at the Amsler grid, schedule an appointment with your doctor.

6 Will I ever be able to stop treatment?

Macular degeneration is a chronic disease that requires ongoing treatment. If you stick to your treatment plan and keep all of the appointments with your eye care team, you will improve the chances of maintaining your vision.

No matter where you are in your treatment journey, you can find comfort, control, and independence by planning for ways to best live with wet AMD.

In addition to your eye care team, it's helpful to build a support network of friends and family who can help with daily and longer-term needs, such as grocery shopping and traveling to your doctor's appointments.

There are also patient organizations that provide additional education and support services for patients and their caregivers.

Glossary of terms:

Here are helpful terms and definitions that might come up during your appointments.

Amsler Grid: A black and white grid used to monitor the progression of wet AMD that you can use to keep track of your own vision.

Anti-VEGF Treatment: Anti-Vascular endothelial growth factor (VEGF) injections have proven effective in preventing the formation of new leaky blood vessels and preventing more fluid from accumulating in the retina, as fluid can lead to further loss of vision. Anti-VEGF treatment is injected into the eye.

Dry macular degeneration: The most common form of macular degeneration, which occurs when proteins build up causing the macula to thin.

Macula: The center of the retina that is responsible for sharp, central vision.

Optical Coherence Tomography Image (OCT): A common, non-invasive imaging technique, similar to photography, which is used to detect fluid in the retina.

Retina: A layer at the back of the eye containing cells that are sensitive to light, where a visual image is formed.

VEGF Protein: VEGF is a protein that helps form blood vessels within eye. An excess of VEGF protein promotes the growth of abnormal blood vessels that leave fluid in the retina of people with wet AMD.

Wet AMD or nAMD: An advanced form of macular degeneration characterized by abnormal blood vessel growth that produces fluid and/or blood in the retina. It may also be referred to as neovascular age-related macular degeneration or nAMD.

The following resource was created by Novartis in collaboration with the following patient advocacy representatives:

Dr. Alan R. Morse

President and Chief Executive Officer
The Lighthouse Guild
New York, USA



Chris White

Group Chief Executive
National Council for the Blind of Ireland (NCBI)
Dublin, Ireland



Novartis would like to thank the patient representatives for their expert input and support.

We would also like to thank **Dr. Anat Loewenstein**, Tel Aviv Sourasky Medical Center, Israel, and **Dr. Nancy Holekamp**, Pepose Vision Institute and Washington University School of Medicine, USA, for their expert review.

All trademarks and brands are property of their respective owners