

Part 1: What should I know following my diagnosis?

What is wet age-related macular degeneration (AMD)?



The essential series to guide and support you through your wet AMD treatment.



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What information can I find in this booklet?

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1. What is wet AMD?

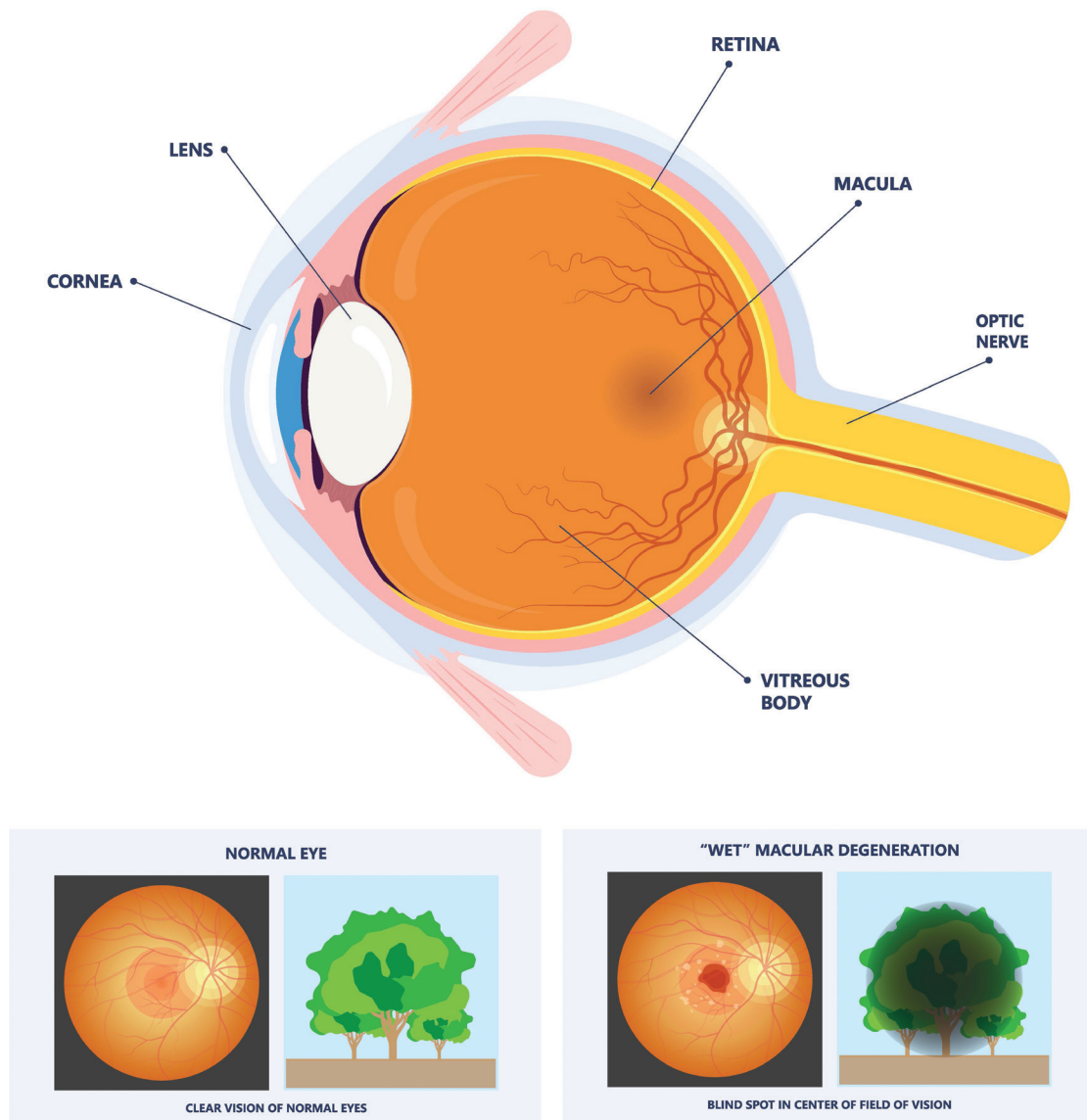
Age-related macular degeneration (AMD) is a long-term eye condition in which waste products (microscopic deposits, including a protein called drusen) accumulate in the macula (a tiny central part of the retina at the back of your eye that is responsible for translating light into images, so the brain can see things clearly). This changes the shape of the macula and affects your sharp central vision. The rest of the retina helps you with side vision and is also known as peripheral vision.¹⁻³ AMD does not cause pain and does not lead to the total loss of sight,^{3,4} but it can affect daily activities that rely on the macula functioning well (ie, good vision), such as driving, recognizing faces, reading, writing, shopping, meal preparation, and watching TV.

There are two types of AMD; dry AMD and wet (also known as neovascular AMD [nAMD]). People often have dry AMD to begin with, which involves the wearing out and death (atrophy) of cells in the macula, resulting in a gradual loss of central vision. The disease usually progresses slowly but dry AMD can turn into wet AMD and subsequently result in sudden vision loss, therefore, regular visits to an eye specialist are highly recommended.^{2,3,5,6} Research is ongoing to discover why the cells of the macula stop working and how to prevent this from happening. In most countries, there are currently no approved treatments for dry AMD. In the US, two treatments for dry AMD have been approved and are currently being evaluated in other countries.^{2,7,8} Additionally, vision aids can be used for support.

Wet AMD is the most common cause of vision problems in the developed world in people over the age of 50. Wet AMD develops in 10–15% of people with AMD. In wet AMD, the eye starts growing new blood vessels in response to the cells of the macula that are no longer working correctly.^{3,5,6,9,10} These abnormal blood vessels grow under the macula and are fragile and weak, and often leak tiny amounts of blood or fluid (hence the name “wet” AMD) to cause blurred or distorted vision. Wet AMD can develop very quickly, causing serious changes to your central vision in a matter of days or weeks, but most side vision remains unchanged.^{3,5,6}

What are the common symptoms?

- Initially there may be no symptoms
- A gradual or sudden decline in the ability to see objects clearly
- Difficulty reading that is not improved with new glasses
- Distorted vision in the central area and difficulty seeing people’s faces clearly
- Dimming of color vision
- Visual hallucinations
- A sudden shadow in the central part of your vision



Your eye is made up of various structures, each playing a vital role in helping you to see. These include the cornea (a transparent layer at the front of your eye), the iris (the colored part of your eye), the pupil (the black circle in the center of your iris that lets the light in), the lens (a transparent structure that transfers the light onto the retina), the retina (a structure made up of thin layers of cells including light sensitive photoreceptors that are essential for vision), and the macula (an area of your retina that is it particularly sensitive to light and is used specifically for central vision). Wet AMD is a long-term eye condition in which waste products accumulate in the macula, changing its shape and affecting your sharp central vision.^{2,3,11}

Treatment is available to stop these new blood vessels from growing and damaging your macula.³ Treatment of wet AMD cannot undo most of the changes already present in the eye, so often the goal of treatment is to prevent further loss of vision. This treatment usually needs to be given quickly before too much damage occurs. Without treatment, scarring and sight loss can occur rapidly, and are usually permanent.^{3,12} In addition to treatment, vision aids can also be used for support.

There are several risk factors that may contribute to developing wet AMD.

These include:

- **Age** – Older age is the most important risk factor for wet AMD. Wet AMD usually affects people over 50-years old but can happen earlier.^{2,13}
- **Family history** – You have a higher chance of having wet AMD if a close relative has wet AMD, this is because genetic factors often play a role in the development of wet AMD with several genes linked to the condition.^{2,3}
- **Lifestyle factors** – Smoking (smokers are more likely to have wet AMD than non-smokers), diet (a high-fat diet, low in omega-3 fatty acids, vitamins, and minerals is associated with wet AMD), as well as high blood pressure and lack of exercise.^{2,3,14,15}
- **Sunlight exposure** – High levels of sunlight exposure, particularly blue-violet and ultraviolet light, may increase your risk of developing wet AMD.^{3,16}

2. How is wet AMD diagnosed?

If a healthcare provider suspects that you have wet AMD, you will be immediately referred to an ophthalmologist. When you are seen by the ophthalmologist, your eyes will be examined to determine whether you have AMD. A variety of diagnostic tests may be used, and these could include:

- **Eye test (visual acuity test)** – This test measures your eyesight by having you look at an eye chart, one eye at a time, from a specific distance, and check up to what size of the letters on the eye chart you can see clearly. Your ability to read the letters at a certain distance (your visual acuity) is measured by your ophthalmologist. They may express this as a ratio comparing your vision to that of people who have normal vision.
- **Fundoscopy** – This examination of the fundus (the back of the eye, where the macula is located) allows the ophthalmologist to look at the blood vessels and any bleeding or fluid in your macula to spot any changes that AMD may have caused. You may need to have some eye drops to dilate your pupil before the examination, which will make your eyes sensitive to light and cause blurry vision. The effects of this will wear off after 3–6 hours. It is not safe for you to drive or use heavy machinery until the effects have worn off, so you should not drive yourself to your appointment, and it would be best to wear sunglasses to minimize the sensitivity to light.
- **Fundus autofluorescence** – This non-invasive scan provides high-quality images of the fundus to detect any accumulation of waste products in the retina and any damage that AMD may have caused.

- **Optical coherence tomography (OCT)** – This non-invasive detailed camera scan maps the layers of your retina at the back of the eye, which shows the doctor how much fluid is in your macula, to see if your macula is thicker than it should be, and to check for any signs of changes. You may need to have some drops to dilate your pupil before the scan. It is a painless and very quick procedure, that only takes a couple of minutes to complete and does not involve any physical contact with your eye. You should remain as still as possible while the scan is being conducted, but you can blink, as this will not disrupt the image collection process.

In some cases, you may need an angiogram to confirm that you have AMD or to find out whether you have dry AMD or wet AMD. An angiogram is a picture of the blood vessels. This may be done by several methods:

- **Fluorescein angiography** – This diagnostic scan provides more information about the blood vessels at the back of the eye that could be causing your problems. A yellow dye called fluorescein is injected into a vein in your arm or hand. The fluorescein travels through your bloodstream to your eye. Usually this is not painful, but it can make some people feel nauseous and allergic reactions are rare, but may happen. Once the dye reaches the eye, the dye will leak from the fragile, weak new blood vessels associated with wet AMD (and will not leak from normal blood vessels), and will show up on a series of pictures, which is taken over approximately 10 minutes, to give a very detailed view of the blood flow through the vessels at the back of your eye.
- **Indocyanine green angiography** – This test is similar to fluorescein angiography, but a green dye is used instead of the yellow fluorescein dye. It allows the doctor to see the deeper blood vessels under the retina, which is important in some forms of wet AMD.

- **OCT angiography** – This is similar to an OCT, which shows the damage to your retina, but gives even more information about the blood vessels at the back of the eye, similar to fluorescein angiography. However, this scan is non-invasive, meaning it does not require an injection.



3. Will I go blind, or lose part of my vision?

Wet AMD is painless and does not lead to blindness. As the macula and the surrounding area become damaged, you lose your central vision over time. However, side vision remains relatively unchanged for most people with wet AMD,^{3,4} which means that you should still be able to get around on your own and make use of this vision every day.

Treatment can stop the disease from progressing and help maintain your vision. In the long run, this can only be achieved through regular long-term treatment. Conversely, if left untreated or if treatment is stopped, the disease can progress rapidly and your central vision may deteriorate.^{3,12}

In addition to treatment, there are useful visual aids that can help you continue your daily life as usual.



Examples of vision impairment without treatment

Normal vision



Possible effects of wet AMD



Straight lines appearing wavy or bent



Gaps or black spots in vision

4. How could wet AMD affect my daily life and activities?

Wet AMD does not cause pain and does not lead to total loss of sight,^{3,4} but it can affect daily activities that rely on central vision, such as driving, recognizing faces, reading, writing, knitting, meal preparation, and watching TV. For many, these tasks are an important part of our daily lives and enable us to maintain social contact with others. Having to give these up can feel like you are losing independence, facing boredom, and becoming isolated; however, with forethought and planning, this can be avoided.

Low vision aids, adaptive technology, and learning to do things differently can help you continue taking part in your favorite activities. These may include:

- **Magnifiers:** There is a great range, from hand-held magnifiers to those with built-in lighting. Some of the more expensive electronic and video magnifiers have cameras to capture an image that is displayed on a built-in monitor, TV, or computer screen.
- **Talking appliances:** There is a wide range of talking appliances available these days, including scales, clocks, food thermometers, and calculators.
- **Color solutions:** Create contrast with differently colored items to highlight differences. For example, use placemats in vibrant colors with white crockery, and chop food on cutting boards that are different, contrasting colors.

If you are currently able to drive:

- Your ophthalmologist can explain how your wet AMD may affect your ability to drive safely and assess your fitness to drive. Vision loss will not automatically rule out driving. For example, if only one eye is affected and you meet certain vision standards, you may be eligible for a conditional license that allows you to drive under certain conditions (eg, only during the day) in certain countries.



Your ophthalmologist can explain how your wet AMD may affect your ability to drive safely and may assess your fitness to drive.

5. Is there a simple way to explain wet AMD to my family and friends?

Explaining what wet AMD is and how it affects your vision in a way that is easy and simple to understand for your family and friends, can be difficult. An example of a way to describe and explain wet AMD is provided below:

- Imagine the back of your eye as a floor with a carpet (your macula). As long as the carpet can lay flat against the floor below (your macular layers allowing images to be transmitted to your brain via your optic nerve), you can see images and the world as normal.
- When you have wet AMD, it is like someone has placed a series of electrical extensions cords underneath the carpet (poor and leaky blood vessels growing within the macular layers). Those extension cords are now raising the carpet in certain areas (fluid) in the center of the floor, resulting in the carpet no longer lying flat, in some cases this can occur due to aging as well. These raised areas of the carpet (macular) are where your eyes can now no longer transmit images accurately across, causing distortions in vision in those particular spots.
- When treatment is given, it essentially aims to remove as many of those extension cords allowing the carpet to once again lay flat against the floor below, and images to be seen properly again. Treatment may not be successful in removing the extension cords that are already there, but it is still important to not allow any more extension cords to be added under the carpet.

Where to find extra information and support?

Healthcare professional contact information

Use this space to note the details of your clinic, your ophthalmologist or nurse.



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Notes

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The Barometer Program is managed by clinical leaders in ophthalmology as well as representatives from the International Federation on Aging (IFA), International Agency for the Prevention of Blindness (IAPB) and Bayer. The activities of the Barometer Program are funded and facilitated by Bayer where the scientists and representatives from IFA and IAPB retain decision authority to the research scope, methods, analysis of findings and dissemination of the outputs of the Barometer Program.

Feel free to ask your ophthalmologist for other parts of this series.

- How is wet AMD treated?
- What does a wet AMD treatment plan look like?
- How is wet AMD treated over time?
- What does long-term management of wet AMD mean?



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