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Macular Telangiectasia

What is macular telangiectasia?

Macular telangiectasia [teh-LAN-jee-ek-TAY-zuh], also called MacTel, is a rare eye disease that affects the part of the eye called the **macula**. The macula is a small area in the center of the **retina** that is responsible for sharp, straight-ahead vision. MacTel causes a slow loss of central vision, which affects vision for tasks such as reading and driving. Most people with MacTel will not lose peripheral (side) vision.

There are three types of MacTel:

MacTel Type 1

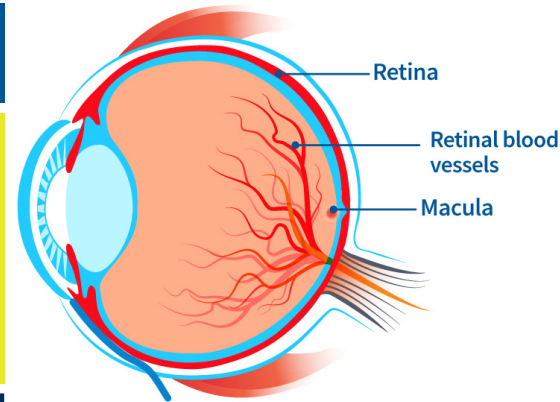
- Usually affects only one eye
- Present at birth (congenital)
- More common in males
- May be associated with Coats' disease

MacTel Type 2*

- Most common type, affecting about 0.1% of the population¹
- Usually affects both eyes, but one eye may be worse than the other
- Often diagnosed between the ages of 40-50
- Risk factors include smoking, high blood pressure, and diabetes

MacTel Type 3

- Usually affects both eyes
- Extremely rare
- Often associated with medical conditions that affect blood flow to the brain



* *MacTel Type 2 is the most common type of macular telangiectasia. The information presented in the rest of this document will focus on MacTel Type 2.*

What causes MacTel Type 2?

There is no known cause for MacTel Type 2. There may be a genetic link, but no specific gene has been identified. The condition often develops over time - possibly linked to aging and way of life. People who smoke, have diabetes, or have high blood pressure may be more likely to develop MacTel.

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Questions to ask your doctor:

- How do I manage living with MacTel Type 2?
- Can you suggest a vision rehabilitation center in my area?
- How often do you recommend getting an eye exam?
- What tests will you do, and what do the tests involve?
- Am I eligible to take part in a clinical trial?
- Will glasses or contact lenses help me see clearer?
- Will injections help me see better?
- Can you suggest things that will help me cope with my vision loss?

Recent studies suggest that MacTel is a neurodegenerative disease,² which means that over time, certain cells become damaged and unable to work well.

MacTel damages the retina tissue, decreasing the retina's ability to sense light. MacTel can also lead to changes in the tiny blood vessels in the retina. This deterioration occurs slowly and can result in the loss of central vision, usually over a period of 10 to 20 years.

What symptoms might I have with MacTel Type 2?

The most common symptom of MacTel is a gradual loss of central vision in one or both eyes. MacTel develops slowly, so it may take several years to notice any vision issues. Most people don't notice symptoms until they are over 40 years old. MacTel typically does not affect peripheral (side) vision.



Normal Vision



MacTel Simulation

Symptoms may include:

- Decreased central vision
- Blurry or distorted vision
- Difficulty with tasks such as reading, working, or driving
- Trouble seeing at night or in dim lighting

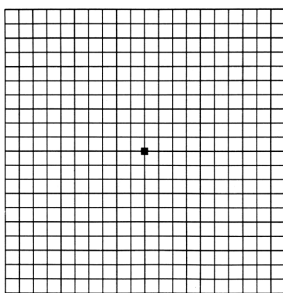
How is MacTel Type 2 diagnosed?

Because vision loss happens gradually with MacTel Type 2, most people are 40-50 years old when diagnosed.

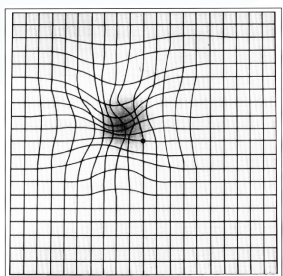
Diagnosis of MacTel typically starts during an eye examination with an eye doctor. If the eye doctor thinks you have a problem with your retina, they may ask you to see a retina specialist, an eye doctor more experienced in diagnosing and treating retinal diseases. The retina specialist will ask about your medical history, review your family medical history, and conduct further testing to confirm your diagnosis.

Some tests your eye doctor may perform include:

- **Visual acuity:** A measure of your ability to see detail up close and at a distance.
- **Amsler grid:** This will test for problems in the macula. An Amsler Grid is made of straight horizontal and vertical lines. MacTel may make the straight lines in the grid appear faded, broken, or wavy.



Normal Amsler Grid



Distorted Amsler Grid

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Learn more about clinical trials

- Find out how clinical trials are conducted at [PreventBlindness.org/clinical-trials-for-eye-diseases-and-vision](https://www.preventblindness.org/clinical-trials-for-eye-diseases-and-vision)
- Search for current clinical trials for MacTel at [ClinicalTrials.gov](https://www.clinicaltrials.gov)
- As you explore clinical trials, talk to your eye doctor, and consider the following advice from the Federal Trade Commission:
 - Never participate in a study that asks you to pay to be in their study or to learn about their study.
 - Never participate in a study that asks for your Social Security number, bank account, or credit card during recruitment or screening.
 - Do an online search before you join any study. Search using the name of the clinical trial and the words “scam,” “review,” or “complaint.”

- **Dilation:** Eye drops are put into the eye to widen the opening on the front of the eye, called the pupil. This allows the eye doctor to examine the health of the retina.
- **Imaging:** The eye doctor will conduct a series of imaging tests to view different parts of the eye. These tests might include:
 - **Retinal photographs:** Photos taken of the inside surface of the eye.
 - **Fluorescein angiography:** A test that uses a fluorescent dye injected in the vein of the arm or hand and pictures taken of the retina through dilated pupils.
 - **Optical Coherence Tomography (OCT):** A test that takes cross-sectional pictures of the retina. This allows your ophthalmologist to map and measure the thickness of the retina.
 - **Fundus autofluorescence:** A test used to create a density map of the layers of the retina.

What is the treatment for MacTel Type 2?

There is currently no FDA-approved treatment for MacTel Type 2, but there are clinical trials in process that may lead to treatment options. Continue to see your eye doctor as recommended and report any changes in your vision. It is important to have an eye doctor check your eyes regularly as other eye health conditions can occur.

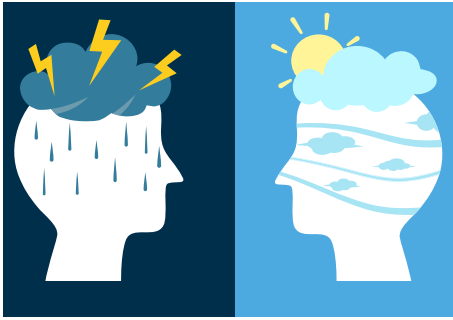
MacTel can cause abnormal blood vessels to grow and sometimes leak into the retina. This is called choroidal neovascularization [nee-oh-vas-kyuh-ler-uh-ZEY-shuhn]. If you have these unusual blood vessels, your eye doctor may treat them by injecting medication into your eye.

While there is no cure for MacTel Type 2, you can take some general steps to protect your eyes:

- Get a comprehensive eye exam regularly as recommended by your eye doctor. If you notice any changes in your vision between visits, call your eye doctor to schedule an appointment.
- Talk to your primary care doctor about ways to control your blood pressure and blood sugar. If you smoke, your doctor can also provide resources to help you quit.
- Wear a hat and sunglasses outside to protect your eyes from sunlight.
- If you are sensitive to glare, try wearing anti-reflective lenses to reduce glare, increase contrast, and block blue light from the sun and digital devices.
- Wear protective sports eyeglasses when playing sports or working in or around potentially dangerous conditions. [PreventBlindness.org/tips-for-buying-sports-eye-protectors](https://www.preventblindness.org/tips-for-buying-sports-eye-protectors)

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“I received my MacTel diagnosis 24 years ago and today I still consider myself very functional, especially with adaptations. Being diagnosed with a degenerative eye disease motivated me to enjoy life to the fullest.”

– Debbie T., patient living with MacTel

How does MacTel affect mental health?

MacTel can cause loss of vision. For some, loss of vision can lead to feelings of depression, anxiety, and loss of independence. Some individuals may notice a change in their desire to socialize with others, or increased frustration with the additional time it may take to accomplish tasks of daily living. Not everyone who has vision loss will experience mental health symptoms, but if you do, there is help available.

To help support your mental health while living with MacTel:

Talk to your primary care doctor, mental health professional, or eye doctor: Talk to your doctor about any changes in your emotional well-being. Ask your eye doctor how MacTel might affect your daily life and work. Seek assistance on how to cope with the changes in your life due to MacTel.

Seek support: Look for support groups of others who are living with MacTel. These groups can help you learn about your condition, share your experience, and find support.

Connect with others and the things that bring you joy: Stay connected with friends and family to keep you from feeling isolated. Over time, you can find new ways to do the things you love or discover new hobbies that bring you happiness.

Exercise: Physical activity can improve symptoms of depression or anxiety and help you feel better. Talk to your health care professional to determine what exercise routine may work best for you, especially if you have changes to your vision due to MacTel.

Seek vision rehabilitation: Ask your eye doctor to recommend a low vision specialist. The specialist can help to maximize the use of the vision you have.

To learn more about your mental health, check out the following resources:

- **Vision Loss and Mental Health** [CDC.gov/visionhealth/resources/features/vision-loss-mental-health.html](https://www.cdc.gov/visionhealth/resources/features/vision-loss-mental-health.html)
- **Centers for Disease Control and Prevention (CDC): The Mental Health of People with Disabilities** [CDC.gov/ncbddd/DisabilityandHealth/Features/Mental-Health-for-All.html](https://www.cdc.gov/ncbddd/DisabilityandHealth/Features/Mental-Health-for-All.html)
- **American Psychological Association: Depression** [APA.org/topics/depression](https://www.apa.org/topics/depression)
- **National Alliance on Mental Illness (NAMI): Signs and Symptoms** [NAMI.org/About-Mental-Illness/Warning-Signs-and-Symptoms](https://www.nami.org/About-Mental-Illness/Warning-Signs-and-Symptoms)

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Additional Resources for those with MacTel:

Living Well with Low Vision: Find practical ways to improve your quality of life and relieve the emotional trauma that often accompanies low vision. [LowVision.PreventBlindness.org](https://www.LowVision.PreventBlindness.org)

The ASPECT Program: The ASPECT Program (Advocacy, Support, Perspective, Empowerment, Communication, and Training) empowers individuals to be engaged in their eye health. [PreventBlindness.org/aspect-patient-engagement-program](https://www.PreventBlindness.org/aspect-patient-engagement-program)

Uncovering MacTel: Learn more about MacTel, get tips for living with MacTel, and find support. [UncoveringMacTel.com](https://www.UncoveringMacTel.com)

The Blind Life: Find videos, tips, and insight for those living with vision loss. [TheBlindLife.net](https://www.TheBlindLife.net) and [YouTube.com/c/theblindlife](https://www.YouTube.com/c/theblindlife)

Thriving Blind Academy: Access free and paid programs promoting literacy, employment, and financial awareness in the blind community. [ThrivingBlindAcademy.org](https://www.ThrivingBlindAcademy.org)

Hadley: Hadley offers practical help, connection and support free of charge to anyone with a visual impairment, their families and professionals supporting them. [HadleyHelps.org](https://www.HadleyHelps.org)

Guide Dogs of America: Find information on guide dog services in the United States. [GuideDogsofAmerica.org](https://www.GuideDogsofAmerica.org) and [GuideDog.org](https://www.GuideDog.org)

Connect with others who understand.

- **The Macular Telangiectasia - Mactel Group:** This is a Facebook group for people with MacTel to share information, resources, and support. [Facebook.com/TheMacularTelangiectasiaGroup](https://www.Facebook.com/TheMacularTelangiectasiaGroup)
- **Eye2Eye:** This free, phone-based peer support program is designed to assist adults who are blind or visually impaired and their families. [SHP.Rutgers.edu/psychiatric-rehabilitation/eye2eye](https://www.SHP.Rutgers.edu/psychiatric-rehabilitation/eye2eye)
- **Inspire:** This online community connects patients and caregivers around the world. Search “MacTel” or “Macular Telangiectasia” to find relevant groups and posts. [Inspire.com](https://www.Inspire.com)

These resources are being provided for informational and educational purposes only. Prevent Blindness is not responsible for the content of external sites, and any views or opinions expressed in external groups represent only the individuals providing them.

References

1. Klein R, Blodi BA, Meurer SM, Myers CE, Chew EY, Klein BE. The prevalence of macular telangiectasia type 2 in the Beaver Dam eye study. *Am J Ophthalmol.* 2010;150(1):55-62.e2. doi:10.1016/j.ajo.2010.02.013
2. Kedariseti KC, Narayanan R, Stewart MW, Reddy Gurrani N, Khanani AM. Macular Telangiectasia Type 2: A Comprehensive Review. *Clin Ophthalmol.* 2022;16:3297-3309. Published 2022 Oct 10. doi:10.2147/OPHT.S373538