

# NANOS Patient Brochure Optic Neuritis

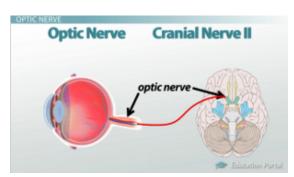
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# What is the optic nerve?

We need our eyes, nerves, and brain working normally in order to see clearly. Our eyes are like a digital camera that collects the light information, and our brain is like a computer that stores and interprets that light to give us sight. The **optic nerve** connects our eyes to our brains (like a computer cable), and sends the light information from our eyes to our brain.





The optic nerve connects the eye to the brain, similar to how an USB cable connects a digital camera to a computer. The eye captures the light and sends vision information to the brain.

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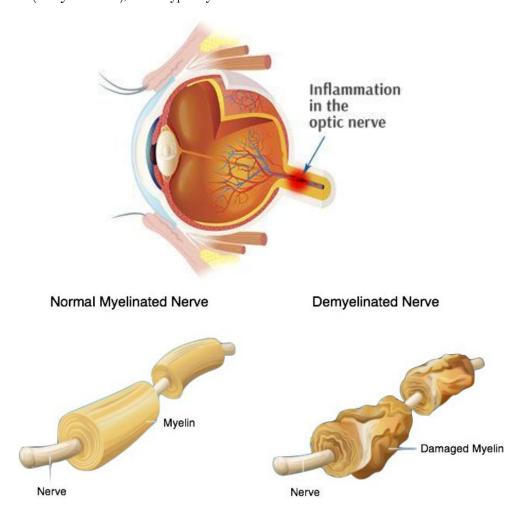
Left: http://www.breezesys.com/Images/DSLR%20Remote%20Pro%2030D%20350wide.jpg

Right: http://study.com/cimages/multimages/16/optive-nerve-diagram.jpg

The optic nerve is surrounded by a covering (or sheath) made of a substance called **myelin**, like insulation around a live wire. This myelin insulation ensures that the light information from the eye is sent to the brain quickly and in high definition. If the myelin is damaged for any reason, the signal from your eye to the brain may not be as clear – "bare wire" optic nerves transmit vision slower and at a lower resolution.

What is optic neuritis?

Optic neuritis is inflammation of the optic nerve. In optic neuritis, the myelin covering is damaged by the inflammation (**demyelination**), which typically results in blurred or dark vision.



**Top:** Optic neuritis is inflammation of the optic nerve, which occurs behind the eye.

**Bottom:** Myelin normally covers nerves to help transmit a clear signal. Inflammation, such as in optic neuritis, will damage the myelin and interfere with the signal, which can result in blurred vision.

### Image Credits:

Top: http://www.northshoreeye.com.au/wp-content/themes/ypo-theme/images/optic\_neuritis.jpg

Bottom: Modified from <a href="http://eyesite.sitesubstance.com/images/uploads/optic-neuritis-article.jpg">http://eyesite.sitesubstance.com/images/uploads/optic-neuritis-article.jpg</a>

# What causes optic neuritis?

Most cases of optic neuritis are caused by an **autoimmune reaction** to the optic nerve and the surrounding myelin. Your immune system normally protects your body from infections and triggers inflammation. However, some viruses and other types of infections can look very similar to normal body parts, such as nerves. When this happens, your immune system can become confused and attack your own body, even after the infection is no longer there.

Optic neuritis can be caused by systemic conditions, or may not have any known cause (**idiopathic**). If your symptoms are unusual, your doctor may decide to test for systemic diseases associated with optic neuritis. The following are some of the diseases that can cause optic neuritis:

Multiple sclerosis (MS) is an autoimmune disease that specifically attacks myelin along your brain and spinal cord. It causes inflammation of the nervous system that comes and goes; people who develop MS can have any number of neurological symptoms (such as stroke-like symptoms, dizziness, weakness, numbness, tingling, double vision, blurred vision, etc.) that clear up after days to weeks. MS has been strongly linked to optic neuritis. Most people who have multiple sclerosis (up to 80%, or 4 out of 5 people) will have at least one episode of optic neuritis sometime during their lifetime. Optic neuritis is also the first sign of MS in about 40% of people who have multiple sclerosis. In early cases of MS, the neurologic symptoms often return to normal. However, some people can develop a progressive form where their symptoms continue to worsen. Research has shown that early treatment can help reduce the long-term problems with MS.

**Neuromyelitis optica (NMO)** is a disease similar to multiple sclerosis that seems to specifically damage the myelin in the optic nerve and spinal cord (although the brain can also have similar damage). The vision loss in NMO is typically worse than in MS, often affecting both eyes at the same time, and weakness or numbness usually occurs within 8 weeks after the vision loss. It also tends to affect young adults. Because the symptoms can be more severe and permanent, aggressive treatment is often needed.

Sarcoidosis is a different type of autoimmune disease that can affect the entire body. It can also trigger inflammation in the lungs, skin, and other organs, especially the eye. Most people with sarcoidosis may not have any neurologic or eye-related symptoms. More common symptoms include rashes, fevers, night sweats, diarrhea, cough or shortness of breath, or swollen lymph nodes. Only 5% of people with sarcoidosis will have involvement of the brain or spinal cord; facial weakness is the most common neurological symptom. 25% (1 out of 4) of people with sarcoidosis will have eye involvement, which typically occurs as inflammation of the front part of the eye (iritis); the optic nerve is not as commonly affected. Because optic neuritis from sarcoidosis can cause severe vision loss (sometimes even to the point of being unable to see light ["no light perception"]), your doctor may test for this condition.

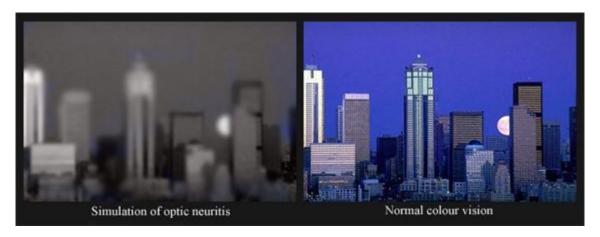
**Lupus** is another autoimmune disease that typically affects other parts of the body but can rarely cause optic neuritis. It can cause inflammation virtually anywhere in the body (including skin, joints, lungs, kidneys, heart, and brain), and can even trigger blood clots.

Syphilis is a sexually-transmitted infection that can occasionally cause optic neuritis. It most commonly causes ulcers on the genitals, mouth, skin, or rectum (chancre); if it is untreated, it can stay in the body for years, sometimes decades. Syphilis can eventually affect the heart and nervous system. Because syphilis is treated with antibiotics, your doctor may test for syphilis before starting other treatments.

Lyme disease is an infection carried by ticks. It can start as a rash on the skin, but can affect other parts of your body and nervous system. It can stay in your body for many years before it causes any symptoms. It can cause severe neurological problems, and can affect every part of the eye. Optic neuritis is rare in people with Lyme disease, but your doctor may test for this condition if you have ever had a tick bite.

# How does optic neuritis affect my eyes and vision?

In optic neuritis, the eye itself is not affected. Most forms of optic neuritis happen behind the eye, and damage the vision signal sent from your eyes to your brain. If this signal is broken up in any way, you may have blurred vision, darkened vision, decreased color vision, or decreased peripheral vision. The most common symptom of optic neuritis is decreased vision. Because inflammation happens suddenly, the vision loss is suddenly or quickly over the course of 1-3 days. Many people describe the blurring and darkening of their vision as "dimming" or like "the brightness is turned down." Optic neuritis does not affect your glasses prescription.



# Image Credit:

http://www.sonjabiggs.net/blog/assets/0 0 0 0 568 213 csupload 59895147.jpg?u=6351107378296339 98

Most people with optic neuritis will have eye pain or discomfort when looking in different directions. This is because some of the muscles that move the eye have some attachments to the optic nerve. When the optic nerve is inflamed, any pulling on the optic nerve can cause irritation. This pain typically goes away after 3-5 days.

Another common symptom is <u>decreased color vision</u>. Colors are often described as "washed out." Some people will see <u>flashes of light</u> (**phosphenes**), which can look like lights, sparkles, or shifting squares. Eye movements or loud noises may trigger these flashes, and can persist after vision returns. Some people will also have <u>episodes of blurred or graying vision that lasts from several minutes up to an hour that is <u>triggered by exercise or hot temperatures</u> (**Uhthoff's symptom**). This can occur in other conditions, but may be seen in optic neuritis. Uhthoff's symptom may continue, even after the optic neuritis has resolved.</u>

# What other symptoms can I have with optic neuritis?

If the optic neuritis is not caused by a systemic illness, all of the symptoms you may have will be around the eye. However, if you have a systemic autoimmune disease, you may experience other symptoms, which are varied (see above). Your doctor will likely ask you about symptoms elsewhere in your body to decide if you have any systemic condition that might cause your optic neuritis.

### How does my doctor know I have optic neuritis? What tests do I need to get?

Optic neuritis is typically diagnosed by a clinical history and a detailed eye exam. In most cases of optic

neuritis, your eye exam will be completely normal because the inflammation takes place behind your eye. In approximately 1 out of 3 people with optic neuritis, the optic nerve may look swollen. Your doctor may have you take a **visual field** test, which maps out your central and peripheral vision to look for blind spots. Your doctor may also obtain a scan of your optic nerves, which is called an **optical coherence tomography (OCT)**. An OCT can help your doctor measure the health of your optic nerves. Your doctor may order a **visual evoked potential (VEP)**, which is a test that measures the electrical signal sent from your eyes to your brain. It is performed by recording signals in your brain through electrodes on your head as you look at different checkerboard patterns. An **MRI of the brain performed with gadolinium contrast** (a dye injected into your arm) can help confirm the diagnosis of optic neuritis. Your doctor may order other tests, such as blood tests or a chest X-ray, to look for different causes of optic neuritis. There is no specific test for optic neuritis.

If your symptoms and eye exam are typical for classic optic neuritis, your doctor may choose to order very few tests at first. The current guidelines for testing for optic neuritis recommend a complete eye exam and an MRI of the brain with contrast. If your symptoms are unusual, your doctor may decide to order other tests.

# Could I have something other than optic neuritis?

Because the eyes and optic nerves look normal in most cases of optic neuritis, your doctor may be concerned about other causes for vision loss. Your doctor will ask you questions about your overall health, your diet, your activities, your pets, and other aspects of your life to help decide if you may need to be tested for other causes of vision loss.

The optic nerve can be swollen for many different reasons, including increased pressure on the optic nerves, loss of blood flow to the optic nerve, and inflammation inside the eye. For the people who have a swollen optic nerve, your doctor may consider further testing to determine if you have something other than optic neuritis causing your symptoms.

# Why does my doctor say I may have multiple sclerosis (MS)?

There has been a lot of research that links optic neuritis with multiple sclerosis. Most people with multiple sclerosis will have an episode of optic neuritis in their lifetime. While not everyone who gets optic neuritis will develop multiple sclerosis, people who have optic neuritis have a much greater risk for having MS in the future.

An MRI of the brain is recommended in optic neuritis because it can help determine the risk for developing MS in the future, and determine if you need additional treatment. If the MRI shows any abnormalities, your doctor may recommend that you see a neurologist to be screened for multiple sclerosis, even if you do not have any other symptoms. Studies have shown that around 75% (3 out of 4) people who have optic neuritis with abnormal MRIs will develop MS within 15 years. Even in people who have normal MRIs, 25% (1 out of 4) people with optic neuritis will still develop MS within 15 years. Because early detection and treatment can prevent you from having more severe problems, it is important to get testing and treatment when your doctor recommends it.

Your doctor may also test you for neuromyelitis optica (NMO), a disease similar to MS. It is diagnosed by a MRI scan of the brain and spinal cord and a blood test.

# Will I need treatment? What are the treatment options?

In typical cases of optic neuritis, no treatment is necessary. Research has shown that there is no difference in final vision between people with optic neuritis who were treated and those who were not treated. Treatment can speed up recovery, but there because the treatment for optic neuritis has many side effects, it is not recommended for everyone. However, there are two cases where your doctor may recommend treatment:

- 1. **Abnormal MRI.** If your MRI is abnormal, your doctor will suggest that you undergo treatment. The research has suggested (but not definitively proven) that treating optic neuritis, if there is an abnormal MRI, may decrease your risk of developing MS over the next 2 years.
- Atypical cases. If your symptoms are unusual, or your doctor is concerned that your vision may be
  worse than is typically expected in optic neuritis, he or she may recommend treatment, regardless of
  the MRI results.

Typically, treatment consists of IV steroids for 3 days, followed by pills that are taken by mouth (**oral**) for an additional 15 days. There have been other treatments that have been studied, including different medications and doses. There is now conclusive evidence that <u>using oral steroids (prednisone) alone in doses of 60-80 mg per day can actually increase the risk of recurrence of optic neuritis. Oral steroid treatment at higher doses similar to IV steroids is still under study. Talk with your doctor about what treatment(s) may be appropriate for your condition.</u>

Steroids have many side effects. Depending on your overall health, steroid treatment may not be safe for you. Steroids will commonly cause fluid retention, increased blood pressure, raised blood sugar, weight gain, increased appetite, mood and behavior problems, stomach irritation, and increased pressure in your eyes (glaucoma). Over the long term, steroids can decrease the ability to fight off infection, worsen diabetes, thinning of the bones (osteoporosis), thinning of the skin and hair, increased bruising, cataract formation, and increased fat deposits.

# What is my prognosis? Will my vision get better?

Most people with typical optic neuritis will get better with or without treatment. Vision typically begins to recover within 1 month. One of the major research studies on optic neuritis found that 92% of people with optic neuritis will recover most of their vision, even back to 20/20 vision, if that was what you were seeing before you had optic neuritis. However, because the myelin does not completely heal after optic neuritis, most people will continue to report some decreased quality in their vision, even though they may see the letters on the 20/20 line in the doctor's office. These changes are typically related to decreased color vision, distorted vision, or difficulty with contrast (distinguishing shades of light and dark).

Up to 35% of people with optic neuritis will have more than one episode. The risk for recurrence increases if you were only treated with oral steroids, or if you have multiple sclerosis or neuromyelitis optica. As of right now, there are no medications, supplements, or additional treatments that have been proven to reduce the risk of recurrence.

### How often do I need to have checkups for optic neuritis?

Your doctor will probably check your eyes and vision several times when you are first having symptoms (acute phase). After determining whether or not you need treatment, other testing, or a referral to a neurologist, your doctor will likely recheck your eyes and vision around 2 months. If your vision has returned to normal, your doctor may recommend that you have regular eye exams. As long as you do not have any new episodes, you can have annual eye exams.

### Additional Reading/Resources

- Optic Neuritis, by the National Library of Medicine on MedlinePlus (<a href="https://www.nlm.nih.gov/medlineplus/ency/article/000741.htm">https://www.nlm.nih.gov/medlineplus/ency/article/000741.htm</a>)
  - O This article, written by the U.S. National Library of Medicine, is short but provides a lot of useful information about optic neuritis.
- Optic Neuritis, by the Mayo Clinic (<a href="http://www.mayoclinic.org/diseases-conditions/optic-">http://www.mayoclinic.org/diseases-conditions/optic-</a>

### neuritis/basics/definition/con-20029723)

- O The Mayo Clinic has a several-page web article about optic neuritis. Less technical and more geared towards patients, this may be a helpful resource for more information from one of the leading medical centers in the United States.
- Optic Neuritis, by the American Academy of Ophthalmology's EyeSmart Project (<a href="http://www.aao.org/eye-health/diseases/what-is-optic-neuritis">http://www.aao.org/eye-health/diseases/what-is-optic-neuritis</a>)
  - o The American Academy of Ophthalmology's patient education portal has a limited but readable article about optic neuritis.
- Optic Neuritis, by the American Academy of Ophthalmology's EyeWiki Project (<a href="http://eyewiki.org/Demyelinating-Optic Neuritis">http://eyewiki.org/Demyelinating-Optic Neuritis</a>)
  - O This article is a more technical description of optic neuritis and may be too detailed for most readers, but contains up-to-date information about how doctors manage and treat optic neuritis.
- Optic Neuritis, by MedicineNet.com (http://www.medicinenet.com/optic\_neuritis/article.htm)
  - o This is WebMD's discussion on optic neuritis. For the most part, it is fairly readable and useful for basic understanding of the condition. It can get a little bit technical in some places, and there are many advertisements and other links that distract from the content of the article.
- Optic Neuritis, by Wikipedia (<a href="https://en.wikipedia.org/wiki/Optic neuritis">https://en.wikipedia.org/wiki/Optic neuritis</a>)
  - O This may also be too technical for most readers, but may be less difficult to read than the EyeWiki article. Because Wikipedia is written and edited by the general public, it may be less accurate than the above websites, which are expert-written. Nevertheless, it is helpful when used in addition to other resources.

# **Support Groups**

To our knowledge, there is no national support group or society specifically for optic neuritis. There are several individuals who have optic neuritis, who have created online support groups and forums. However, because many of those websites have not been updated for several years and do not have significant activity, those websites have not been listed below. If you would be interested in forming a support group (local, national, or online) for optic neuritis, please contact us at <a href="mailto:info@nanosweb.org">info@nanosweb.org</a>.

- National Multiple Sclerosis Society (<a href="http://www.nationalmssociety.org/">http://www.nationalmssociety.org/</a>)
  - Although not everyone who has optic neuritis will develop multiple sclerosis, there are many
    people with multiple sclerosis who have had optic neuritis. This organization both
    advocates for and supports people with multiple sclerosis and people suspected of having
    MS.
- Multiple Sclerosis Foundation (<a href="http://www.msfocus.org/">http://www.msfocus.org/</a>)
  - O This organization made up of many support groups throughout the United States. Their motto is "Motivating, Educating, Empowering." Their website lists local multiple sclerosis groups.
- Royal National Institute of Blind People (<a href="http://www.rnib.org.uk/eye-health-eye-conditions/optic-neuritis">http://www.rnib.org.uk/eye-health-eye-conditions/optic-neuritis</a>)
  - This is an organization in Great Britain that serves people who have vision loss due to various conditions. While the organization may not be very helpful for those not living in Great Britain, there are useful links and information about optic neuritis.