

Diabetic Retinopathy



What **you**
should know



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
National Institutes of Health
National Eye Institute

Diabetic Retinopathy: What you should know

This booklet is for people with diabetic retinopathy and their families and friends. It provides information about diabetic retinopathy and answers questions about the cause and symptoms of this progressive eye disease. Diagnosis and types of treatment are described.

The National Eye Institute (NEI) conducts and supports research that leads to sight-saving treatments and plays a key role in reducing visual impairment and blindness. The NEI is part of the National Institutes of Health (NIH), an agency of the U.S. Department of Health and Human Services.

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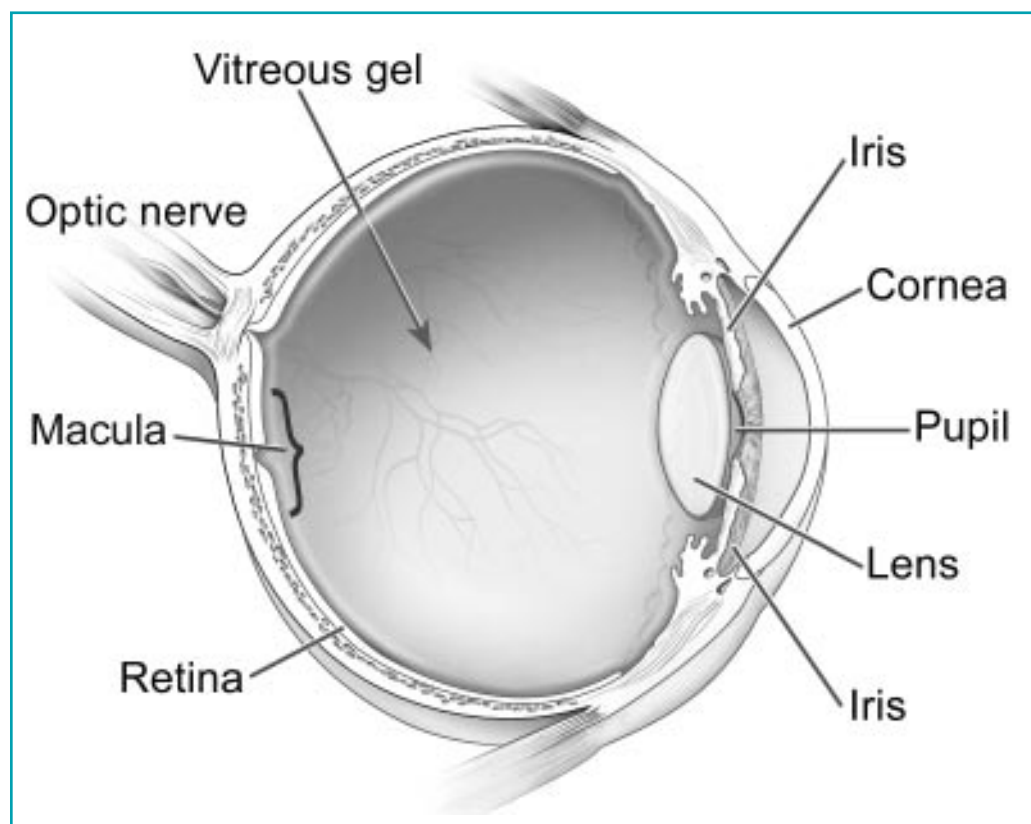
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What is diabetic retinopathy?

Diabetic retinopathy is a complication of diabetes and a leading cause of blindness. It occurs when diabetes damages the tiny blood vessels inside the retina, the light-sensitive tissue at the back of the eye. (See diagram below.) A healthy retina is necessary for good vision.

If you have diabetic retinopathy, at first you may notice no changes to your vision. But over time, diabetic retinopathy can get worse and cause vision loss. Diabetic retinopathy usually affects both eyes.



What are the stages of diabetic retinopathy?

Diabetic retinopathy has four stages:

1. **Mild Nonproliferative Retinopathy.** At this earliest stage, microaneurysms occur. They are small areas of balloon-like swelling in the retina's tiny blood vessels.
2. **Moderate Nonproliferative Retinopathy.** As the disease progresses, some blood vessels that nourish the retina are blocked.
3. **Severe Nonproliferative Retinopathy.** Many more blood vessels are blocked, depriving several areas of the retina with their blood supply. These areas of the retina send signals to the body to grow new blood vessels for nourishment.
4. **Proliferative Retinopathy.** At this advanced stage, the signals sent by the retina for nourishment trigger the growth of new blood vessels. This condition is called proliferative retinopathy. These new blood vessels are abnormal and fragile. They grow along the retina and along the surface of the clear, vitreous gel that fills the inside of the eye. (See diagram on previous page.)

By themselves, these blood vessels do not cause symptoms or vision loss. However, they have thin, fragile walls. If they leak blood, severe vision loss and even blindness can result.

Who is at risk for diabetic retinopathy?

All people with diabetes—both type 1 and type 2—are at risk. That's why everyone with diabetes should get a comprehensive dilated eye exam at least once a year. Between 40 to 45 percent of Americans diagnosed with diabetes have some stage of diabetic retinopathy. If you have diabetic retinopathy, your doctor can recommend treatment to help prevent its progression.

During pregnancy, diabetic retinopathy may be a problem for women with diabetes. To protect vision, **every** pregnant woman with diabetes should have a comprehensive dilated eye exam as soon as possible. Your doctor may recommend additional exams during your pregnancy.

How does diabetic retinopathy cause vision loss?

Blood vessels damaged from diabetic retinopathy can cause vision loss in two ways:

1. Fragile, abnormal blood vessels can develop and leak blood into the center of the eye, blurring vision. This is **proliferative retinopathy** and is the fourth and most advanced stage of the disease.
2. Fluid can leak into the center of the macula, the part of the eye where sharp, straight-ahead vision occurs. The fluid makes the macula swell, blurring vision. This condition is called **macular edema**. It can occur at any stage of diabetic retinopathy, although

it is more likely to occur as the disease progresses. About half of the people with proliferative retinopathy also have macular edema.



Normal vision



Same scene viewed by a person with diabetic retinopathy

Does diabetic retinopathy have any symptoms?

Diabetic retinopathy often has no early warning signs. **Don't wait for symptoms.** Be sure to have a comprehensive dilated eye exam at least once a year.

What are the symptoms of proliferative retinopathy if bleeding occurs?

At first, you will see a few specks of blood, or spots, “floating” in your vision. If spots occur, see your eye care professional as soon

as possible. You may need treatment before more serious bleeding occurs. Hemorrhages tend to happen more than once, often during sleep.

Sometimes, without treatment, the spots clear, and you will see better. However, bleeding can reoccur and cause severely blurred vision. You need to be examined by your eye care professional at the first sign of blurred vision, before more bleeding occurs.

If left untreated, proliferative retinopathy can cause severe vision loss and even blindness. Also, the earlier you receive treatment, the more likely treatment will be effective.

How are macular edema and diabetic retinopathy detected?

Macular edema and diabetic retinopathy are detected during a comprehensive eye exam that includes:

- **Visual acuity test.** This eye chart test measures how well you see at various distances.
- **Dilated eye exam.** Drops are placed in your eyes to widen, or dilate, the pupils. Your eye care professional uses a special magnifying lens to examine your retina and optic nerve for signs of damage and other eye problems. After the exam, your close-up vision may remain blurred for several hours.
- **Tonometry.** An instrument measures the pressure inside the eye. Numbing drops may be applied to your eye for this test.

Your eye care professional checks your retina for early signs of the disease, including:

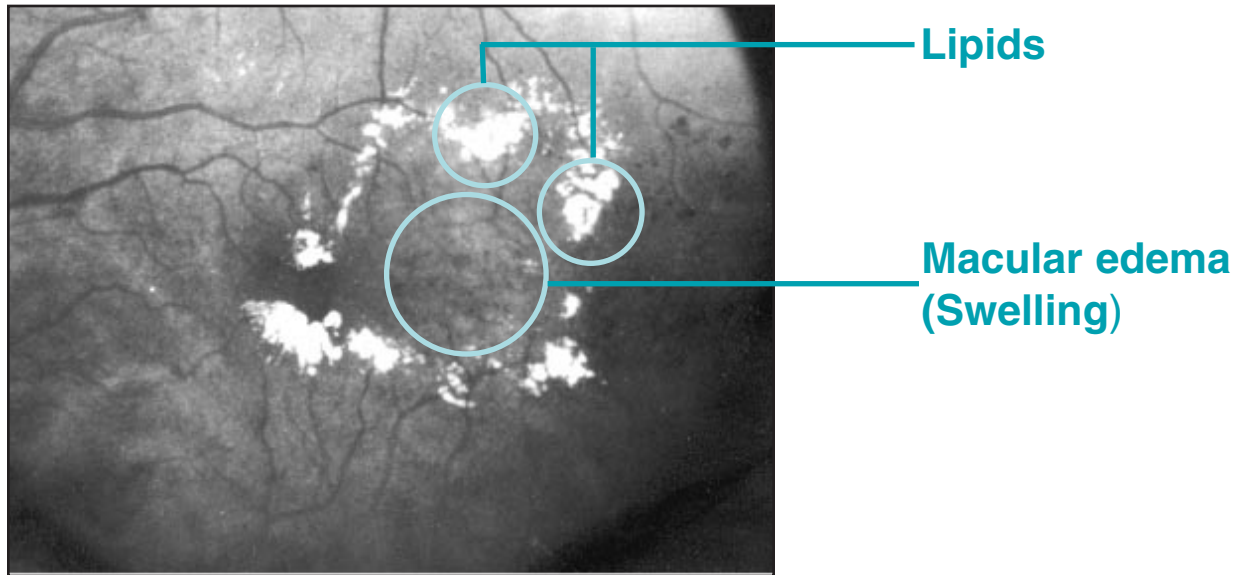
- Leaking blood vessels.
- Retinal swelling (macular edema).
- Pale, fatty deposits on the retina—signs of leaking blood vessels.
- Damaged nerve tissue.
- Any changes to the blood vessels.

If your eye care professional believes you need treatment for macular edema, he or she may suggest a **fluorescein angiogram**. In this test, a special dye is injected into your arm. Pictures are taken as the dye passes through the blood vessels in your retina. The test allows your eye care professional to identify any leaking blood vessels and recommend treatment.

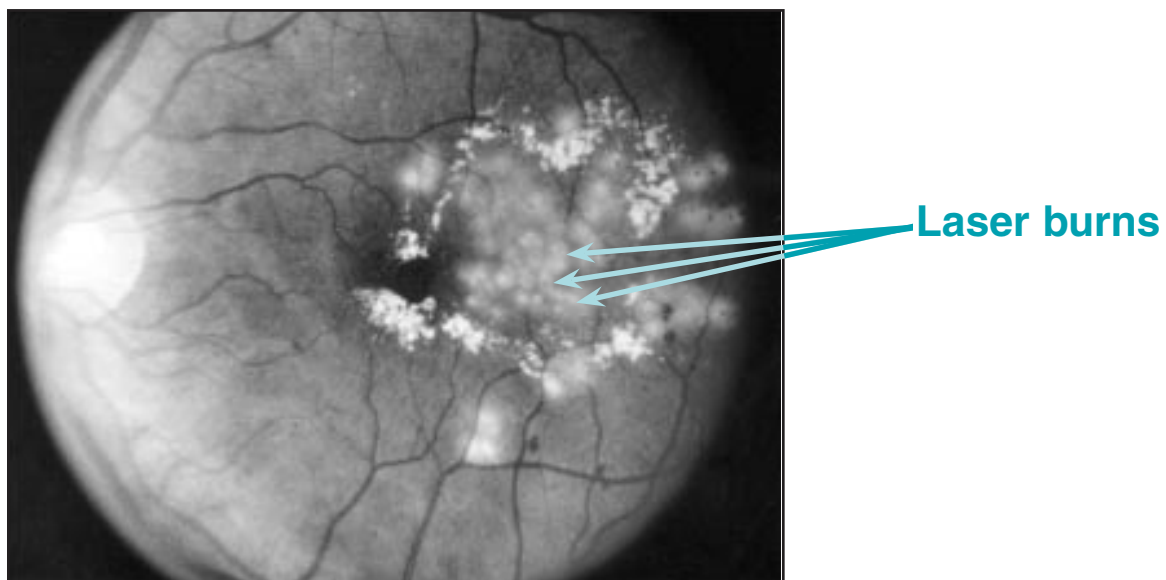
How is macular edema treated?

Macular edema is treated with laser surgery. This procedure is called focal laser treatment. Your doctor places up to several hundred small laser burns in the areas of retinal leakage surrounding the macula. These burns slow the leakage of fluid and reduce the amount of fluid in the retina. The surgery is usually completed in one session. Further treatment may be needed.

A patient may need focal laser surgery more than once to control the leaking fluid. If you have macular edema in both eyes and require laser surgery, generally only one eye will be treated at a time, usually several weeks apart.



The retina prior to focal laser treatment



The retina immediately after focal laser treatment

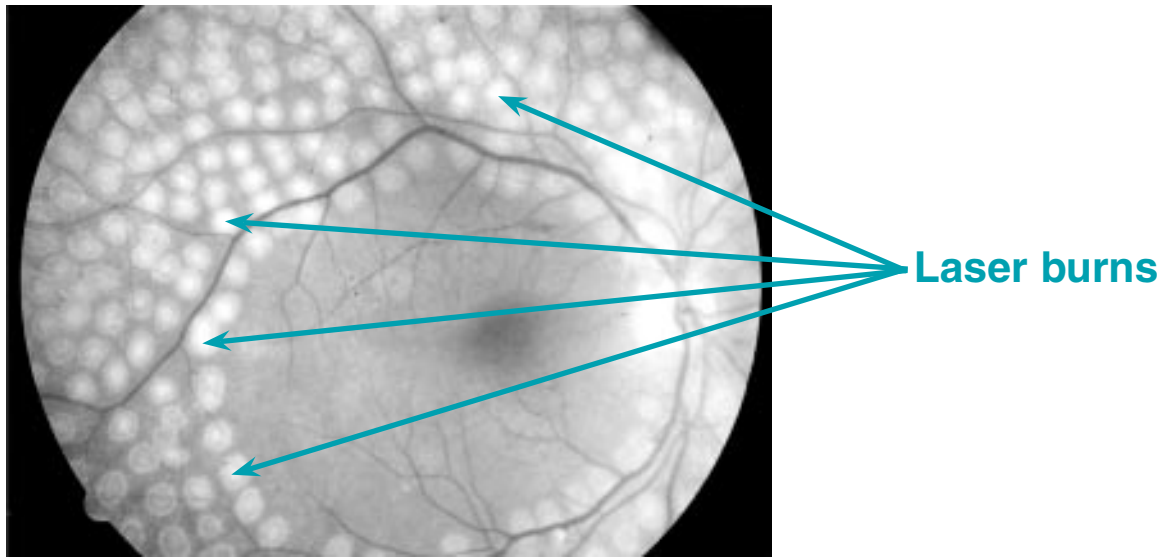
Focal laser treatment stabilizes vision. In fact, focal laser treatment reduces the risk of vision loss by 50 percent. In a small number of cases, if vision is lost, it can be improved. Contact your eye care professional if you have vision loss.

How is diabetic retinopathy treated?

During the first three stages of diabetic retinopathy, no treatment is needed, unless you have macular edema. To prevent progression of diabetic retinopathy, people with diabetes should control their levels of blood sugar, blood pressure, and blood cholesterol.

Proliferative retinopathy is treated with laser surgery. This procedure is called scatter laser treatment. Scatter laser treatment helps to shrink the abnormal blood vessels. Your doctor places 1,000 to 2,000 laser burns in the areas of the retina away from the macula, causing the abnormal blood vessels to shrink. Because a high number of laser burns are necessary, two or more sessions usually are required to complete treatment. Although you may notice some loss of your side vision, scatter laser treatment can save the rest of your sight. Scatter laser treatment may slightly reduce your color vision and night vision.

Scatter laser treatment works better before the fragile, new blood vessels have started to bleed. That is why it is important to have regular, comprehensive dilated eye exams. Even if bleeding has started, scatter laser treatment may still be possible, depending on the amount of bleeding.



Scatter laser treatment

If the bleeding is severe, you may need a surgical procedure called a vitrectomy (described on the next page). During a vitrectomy, blood is removed from the center of your eye.

What happens during laser treatment?

Both focal and scatter laser treatment are performed in your doctor's office or eye clinic. Before the surgery, your doctor will dilate your pupil and apply drops to numb the eye. The area behind your eye also may be numbed to prevent discomfort.

The lights in the office will be dim. As you sit facing the laser machine, your doctor will hold a special lens to your eye. During the procedure, you may see flashes of light. These flashes eventually may create a stinging sensation that can be uncomfortable.

You will need someone to drive you home after surgery. Because your pupil will remain dilated for a few hours, you should bring a pair of sunglasses.

For the rest of the day, your vision will probably be a little blurry. If your eye hurts, your doctor can suggest treatment.

What is a vitrectomy?

If you have a lot of blood in the center of the eye (vitreous gel), you may need a vitrectomy to restore your sight. If you need vitrectomies in both eyes, they are usually done several weeks apart.

A vitrectomy is performed under either local or general anesthesia. Your doctor makes a tiny incision in your eye. Next, a small instrument is used to remove the vitreous gel that is clouded with blood. The vitreous gel is replaced with a salt solution. Because the vitreous gel is mostly water, you will notice no change between the salt solution and the original vitreous gel.

You will probably be able to return home after the vitrectomy. Some people stay in the hospital overnight. Your eye will be red and sensitive. You will need to wear an eye patch for a few days or weeks to protect your eye. You also will need to use medicated eyedrops to protect against infection.

Are scatter laser treatment and vitrectomy effective in treating proliferative retinopathy?

Yes. Both treatments are very effective in reducing vision loss. People with proliferative retinopathy have less than a five percent chance of becoming blind within five years when they get timely and appropriate treatment. Although both treatments have high success rates, they do **not** cure diabetic retinopathy.

Once you have proliferative retinopathy, you always will be at risk for new bleeding. You may need treatment more than once to protect your sight.

What can I do if I already have lost some vision from diabetic retinopathy?

If you have lost some sight from diabetic retinopathy, ask your eye care professional about low vision services and devices that may help you make the most of your remaining vision. Ask for a referral to a specialist in low vision. Many community organizations and agencies offer information about low vision counseling, training, and other special services for people with visual impairments. A nearby school of medicine or optometry may provide low vision services.

What research is being done?

The National Eye Institute (NEI) is conducting and supporting research that seeks better ways to detect, treat, and prevent vision

loss in people with diabetes. This research is conducted through studies in the laboratory and with patients.

For example, researchers are studying drugs that may stop the retina from sending signals to the body to grow new blood vessels. Someday, these drugs may help people control their diabetic retinopathy and reduce the need for laser surgery.

What can I do to protect my vision?

The NEI urges everyone with diabetes to have a comprehensive dilated eye exam at least once a year. If you have diabetic retinopathy, you may need an eye exam more often. People with proliferative retinopathy can reduce their risk of blindness by 95 percent with timely treatment and appropriate followup care.

A major study has shown that better control of blood sugar levels slows the onset and progression of retinopathy. The people with diabetes who kept their blood sugar levels as close to normal as possible also had much less kidney and nerve disease. Better control also reduces the need for sight-saving laser surgery.

This level of blood sugar control may not be best for everyone, including some elderly patients, children under age 13, or people with heart disease. Be sure to ask your doctor if such a control program is right for you.

Other studies have shown that controlling elevated blood pressure and cholesterol can reduce the risk of vision loss. Controlling these will help your overall health as well as help protect your vision.

What should I ask my eye care professional?

You can protect yourself against vision loss by working in partnership with your eye care professional. Ask questions and get the information you need to take care of yourself and your family.

What are some questions to ask?

About my eye disease or disorder...

- What is my diagnosis?
- What caused my condition?
- Can my condition be treated?
- How will this condition affect my vision now and in the future?
- Should I watch for any particular symptoms and notify you if they occur?
- Should I make any lifestyle changes?

About my treatment...

- What is the treatment for my condition?
- When will the treatment start and how long will it last?
- What are the benefits of this treatment and how successful is it?
- What are the risks and side effects associated with this treatment?

- Are there foods, drugs, or activities I should avoid while I'm on this treatment?
- If my treatment includes taking medicine, what should I do if I miss a dose?
- Are other treatments available?

About my tests...

- What kinds of tests will I have?
- What can I expect to find out from these tests?
- When will I know the results?
- Do I have to do anything special to prepare for any of the tests?
- Do these tests have any side effects or risks?
- Will I need more tests later?

Other suggestions

- If you don't understand your eye care professional's responses, ask questions until you do understand.
- Take notes or get a friend or family member to take notes for you. Or, bring a tape recorder to help you remember the discussion.
- Ask your eye care professional to write down his or her instructions to you.
- Ask your eye care professional for printed material about your condition.

- If you still have trouble understanding your eye care professional's answers, ask where you can go for more information.
- Other members of your health care team, such as nurses and pharmacists, can be good sources of information. Talk to them, too.

Today, patients take an active role in their health care. Be an active patient about your eye care.

Remember...

If you have diabetes, get a comprehensive dilated eye exam **at least once a year**.

- Proliferative retinopathy can develop without symptoms. At this advanced stage, you are at high risk for vision loss.
- Macular edema can develop without symptoms at any of the four stages of diabetic retinopathy.
- You can develop both proliferative retinopathy **and** macular edema and still see fine. However, you are at high risk for vision loss.

Your eye care professional can tell if you have macular edema or any stage of diabetic retinopathy. Whether or not you have symptoms, early detection and timely treatment can prevent vision loss.

Where can I get more information?

For more information about diabetic retinopathy or diabetes, you may wish to contact:

American Academy of Ophthalmology*

P.O. Box 7424

San Francisco, CA 94120–7424

415–561–8500

www.aao.org

American Optometric Association*

243 North Lindbergh Boulevard

St. Louis, MO 63141–7851

314–991–4100

www.aoa.org

American Diabetes Association

1701 North Beauregard Street

Alexandria, VA 22311–1717

1–800–342–2383 (National Headquarters)

1–888–342–2383 (Local Offices)

703–549–1500

E-mail: AskADA@diabetes.org

www.diabetes.org

Juvenile Diabetes Research Foundation International

120 Wall Street
New York, NY 10005-4001
1-800-533-CURE (2873)
E-mail: info@jdrf.org
www.jdrf.org

National Diabetes Information Clearinghouse

1 Information Way
Bethesda, MD 20892-3560
1-800-860-8747
301-654-3327
E-mail: ndic@info.niddk.nih.gov
www.niddk.nih.gov

National Eye Institute*

National Institutes of Health
2020 Vision Place
Bethesda, MD 20892-3655
301-496-5248
E-mail: 2020@nei.nih.gov
www.nei.nih.gov

Prevent Blindness America*

211 West Wacker Drive, 17th Floor
Chicago, IL 60606
1-800-331-2020; ext. 6026
312-363-6026
E-mail: info@preventblindness.org
www.preventblindness.org

* These organizations also provide information on low vision.

For more information about low vision programs, you may wish to contact:

American Foundation for the Blind

11 Penn Plaza, Suite 300
New York, NY 10001–2006
1–800–232–5463
212–502–7600
E-mail: afbinfo@afb.net
www.afb.org

Council of Citizens with Low Vision International

1–800–733–2258

Lighthouse International

111 East 59th Street
New York, NY 10022–1202
1–800–334–5497
1–800–829–0500
212–821–9200
212–821–9713 (TDD)
E-mail: info@lighthouse.org
www.lighthouse.org

National Association for Visually Handicapped

22 West 21st Street, 6th Floor
New York, NY 10010–6493
212–889–3141
www.navh.org

