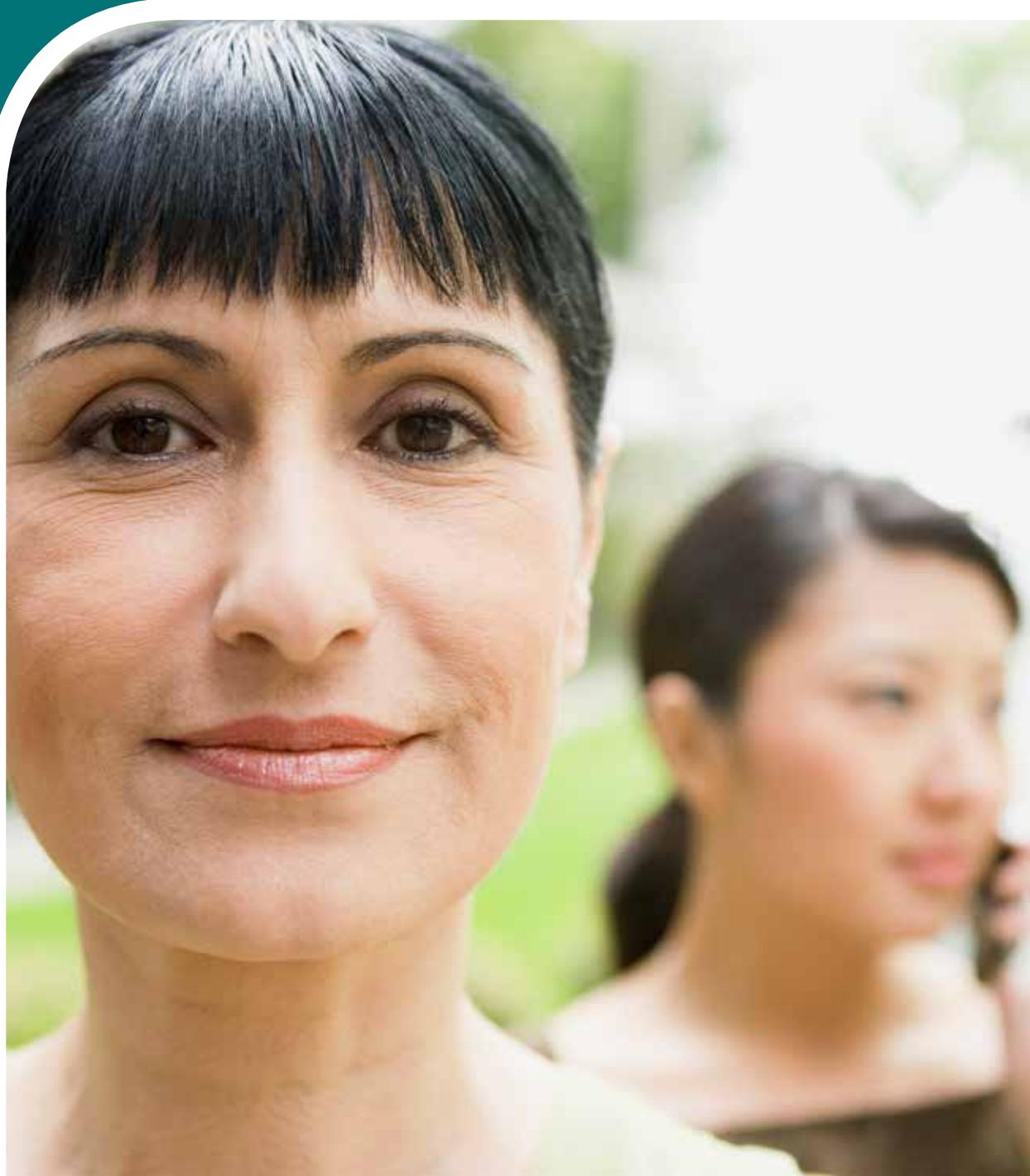


Your Guide to
**Diabetic
Retinopathy**



Welcome

Welcome to “Your Guide to Diabetic Retinopathy”, a helpful new resource designed to give you a better understanding of diabetic retinopathy – what it is, how it’s diagnosed, how it can be treated, as well as how you can reduce your risk of developing diabetic retinopathy if you haven’t already been diagnosed. This guide also provides helpful information and tips to assist you in managing your diabetes if you’ve experienced vision loss.

Just as importantly, this guide is designed to show you that if you’ve experienced vision loss, **you’re not alone**. CNIB has a range of services available to help you adjust to vision loss and lead a full, independent life.

Learn more online

In addition to this guide, we’ve also developed a comprehensive web portal to support you as you adapt to diabetic retinopathy – and discover that a fulfilling, independent life is absolutely within your reach.

At **cnib.ca/dr**, you’ll find the information you need to understand your condition, the skills to live independently and the confidence to keep doing the things you love.

You’ll also get more information about how others with diabetic retinopathy have overcome the challenges of sight loss, how to find helpful CNIB services in your area and how to get the most out of your remaining vision.

Visit us today at **cnib.ca/dr**. Help is just a click away.

What is Diabetic Retinopathy?

Affecting 500,000 Canadians, diabetic retinopathy is an eye condition where elevated blood sugar levels cause blood vessels in the eye to swell and leak in the retina.



Normal Vision*

Without treatment, the condition can result in uncorrectable vision loss or even blindness. But with regular, comprehensive eye exams by an eye doctor, diabetic retinopathy can be detected early and treated.



Vision with Diabetic Retinopathy*

Did you know?

Diabetic retinopathy is the leading cause of blindness and partial sightedness in Canadians under the age of 50.

Nearly all patients with Type 1 diabetes and 60 percent of those with Type 2 diabetes develop some form of diabetic retinopathy in the first 20 years after the onset of diabetes.

Types of Diabetic Retinopathy

There are four stages of diabetic retinopathy, ranging from mild to severe:

Stage 1: Mild non-proliferative retinopathy

Tiny blood vessels swell in the retina, which may cause some early leakage.

Stage 2: Moderate non-proliferative retinopathy

Some blood vessels that feed the retina become leaky or blocked.

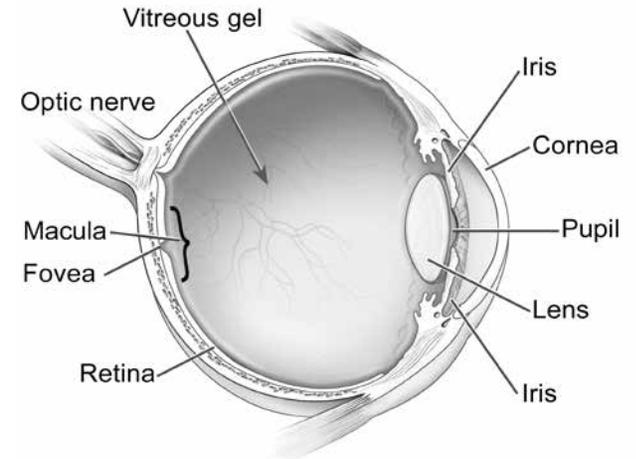
Stage 3: Severe non-proliferative retinopathy

More blood vessels are being blocked and other areas of the retina are affected as a result.

Stage 4: Proliferative retinopathy

New abnormal blood vessels grow along the retina and the clear, vitreous gel inside the eye. These vessels have thin, fragile walls that leak easily, causing blurred vision, severe vision loss or blindness. Vision loss can occur quickly at this stage.

Macular edema – where blood and fluid leaks into the macula – may also occur at any stage, causing vision loss in the central retina.



The Human Eye

Symptoms

In the early stages of diabetic retinopathy, there are often no symptoms and your vision may not be affected.

People with proliferative retinopathy or macular edema may experience vision loss when blood from leaking blood vessels blocks the field of vision. At this stage, it's still possible to have no noticeable symptoms, or for symptoms to occur suddenly and without apparent warning.

That's why it's critical for people living with diabetes to see their eye doctor regularly for comprehensive eye exams. The earlier diabetic retinopathy is detected, the better the chance that it can be effectively treated and further vision loss prevented.

Visit your eye doctor right away if you notice:

- Dark spots in your visual field.
- Blurred, distorted or double vision.
- Large "floaters" – specks in the form of dots, circles, lines or cobwebs that move across your field of vision.

It's critical for people living with diabetes to see their eye doctor regularly for comprehensive eye exams.



Prevention and Risk Factors

Everyone with diabetes is at risk of developing diabetic retinopathy, but there are certain factors that increase this risk. Some of these risk factors can be controlled, but others can't.

Uncontrollable risk factors:

- **Type of diabetes:** People with Type 1 diabetes are more likely to experience vision loss sooner.
- **Ethnicity:** Aboriginal Canadians are three to five times more likely than the general population to develop Type 2 diabetes, placing them at a much higher risk of developing vision problems related to diabetes.

Controllable risk factors:

- **High blood sugar:** Target ranges for blood sugar levels vary depending on age, medical condition and other risk factors. Ask your doctor or diabetes educator what your levels should be.
- **Smoking:** When you have diabetes, smoking increases your risk of vision loss, it also increases blood pressure and blood sugar levels, making it harder to control diabetes.
- **High blood pressure and cholesterol:** If you have diabetes and you also have high blood pressure and/or high lipid (fat) levels, you're more likely to develop diabetic retinopathy.



High Risk Groups

Reducing Your Risk

Fortunately, there are ways that people living with diabetes can proactively reduce their risk of experiencing vision loss due to diabetic retinopathy.

- **Maintaining blood sugar levels**

Blood sugar levels are measured with a blood sugar monitor. Your diabetes educator can help determine which monitor is right for you and provide you with training on how to use it. Maintaining a proper diet and exercising regularly also helps achieve target blood sugar levels.

- **Healthy eating**

A balanced meal plan typically includes three meals per day at regular times (spaced no more than six hours apart) and healthy snacks. Limit sugars and high-fat foods, and eat more high-fibre foods. Talk to your family doctor or

endocrinologist about referring you to a registered dietitian and diabetes education program for healthy eating support.

- **Physical activity**

Staying active with aerobic exercise (like walking or cycling) and weight training can reduce your risk of developing complications from diabetes. Exercise can affect blood sugar and sensitivity to insulin so make sure to speak with your doctor before beginning any type of exercise program.

- **Regular eye exams**

It's important for people with diabetes to have their eyes examined regularly. With regular eye exams, your eye doctor can provide you with an early diagnosis if you have diabetic retinopathy, as well as treatment

options that may prevent future vision loss. Your eye doctor will recommend how often you should have your eyes checked.



Visiting Your Eye Doctor

If you don't already visit an eye doctor regularly, make an appointment immediately with an optometrist to have your eyes tested for any signs of eye disease, including diabetic retinopathy.

Depending on your vision health history, risk factors and symptoms, your optometrist may refer you to an ophthalmologist or retinal specialist for further medical care.

When booking your appointment with an eye doctor:

- Ask if your vision will be temporarily affected by any tests.
- Ask if your province's health plan or private insurance will cover the cost of the exam.

Before an eye exam, make notes about:

- Any problems you've noticed with your vision. For example, blurred vision, dark spots or floaters in your visual field.
- Any recent eye injuries or eye surgeries you've had. Include dates, doctors' names and the names of hospitals where you were treated.
- All current and previous significant medical conditions or operations you've had, whether they relate to your vision or not. Don't forget to include any diagnosed eye conditions (glaucoma,

blood pressure or chronic health problems.

- Your family's current and previous history of significant medical conditions.

When you get to the exam, bring the following with you:

- Your notes from above.
- Your glasses, contact lenses, sample bottles of your current prescription and over-the-counter medications, and your health insurance card.
- Any low vision aids or devices that you've been using (magnifiers, reading glasses, etc.).

Don't have an eye doctor?

Visit cnib.ca/findanoptometrist or call the CNIB Helpline at **1-800-563-2642** to find one in your area today.

Diagnostic Tests

Your eye doctor might want to conduct one or more of the following tests to diagnose diabetic retinopathy:

- **Visual acuity test:** This is the standard measurement of a person's ability to see, using an eye chart.
- **Dilated eye exam:** In this test, drops are placed in the eye to widen (dilate) the pupils to allow a direct view of the inside of your eye, including the retina. This test may temporarily blur your vision for one to two hours, so you will want to bring a friend or family member with you to help you get home.
- **Tonometry:** This is a test that measures pressure inside the eye.



- **Optical coherence tomography (OCT):** In this test, a diagnostic imaging device is used to detect retinal disease.
- **Fundus photography:** This test involves taking colour photographs of both the central and peripheral retina, which allows your eye doctor to monitor changes in your retina and document the extent and stage of any diabetic retinopathy.
- **Fluorescein angiogram:** Your optometrist may refer you to an ophthalmologist for this test, where a dye is injected into a vein and then circulated within the eye. Photographs are then taken of any abnormal blood vessels.

If You've Been Diagnosed with Diabetic Retinopathy...

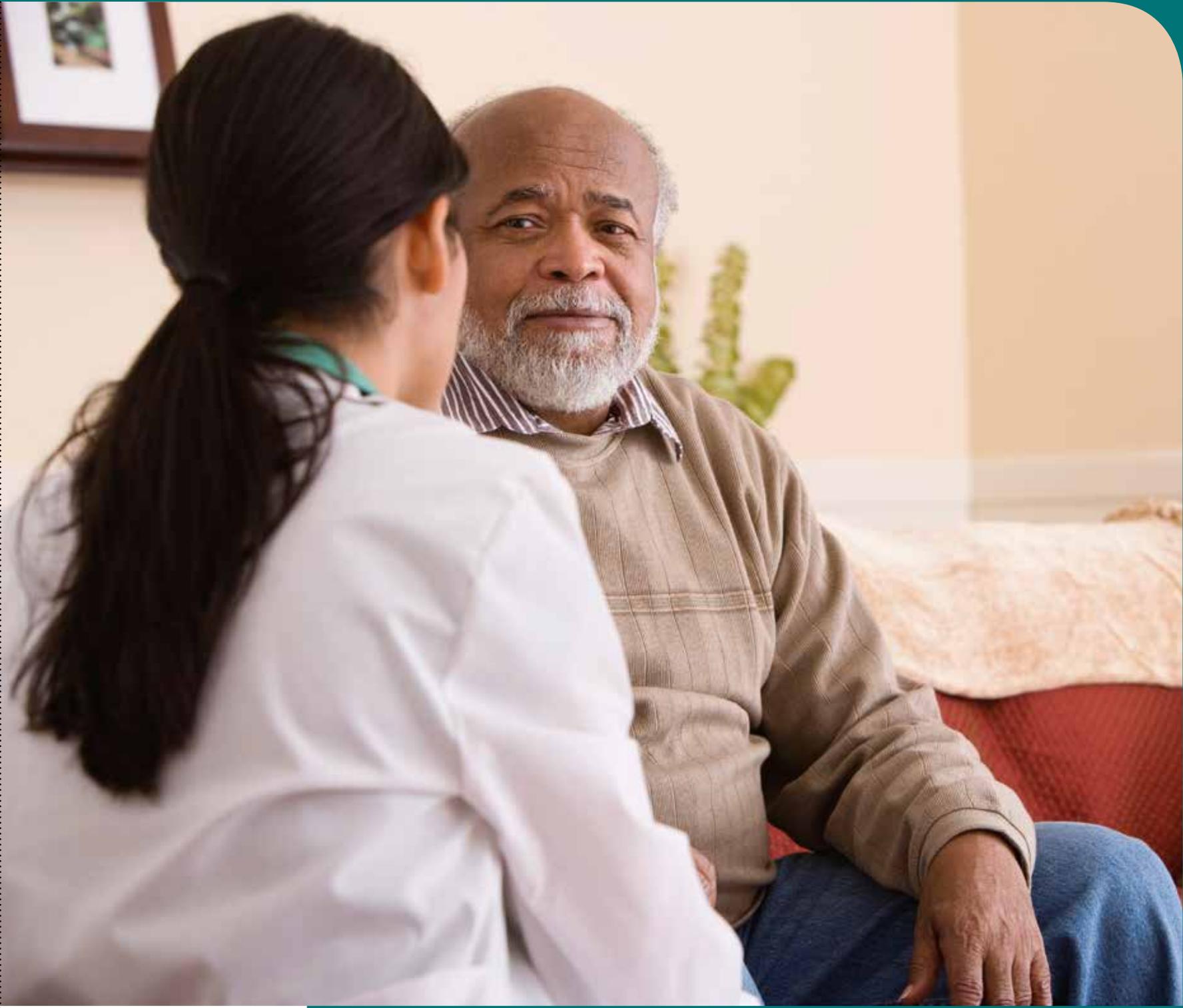
...take heart. You may be feeling overwhelmed or afraid, but knowledge is your best tool to help you overcome those feelings and take an active role in managing your diabetic retinopathy in the future.

Questions for your eye doctor

If you've recently developed diabetic retinopathy, understanding what's happening to your vision will help you make confident, informed decisions as you move forward.

Sit down with your eye doctor and have an open conversation about how diabetic retinopathy is affecting your eyes and what you can do to help preserve or make the most of your remaining sight. The following questions may help you start that conversation:

- What is my exact diagnosis?
- What are the risks and side effects?
- What is the typical progression for someone with this disease?
- Do you know how my vision will be affected in the near and distant future? Do you know if my vision will get worse?
- Are there any signs or symptoms that I should watch for and notify you about?
- How often should I get my eyes examined?
- If my diabetic retinopathy can be treated, what are your recommendations, the risks, benefits and costs involved?
- What can I do to protect or prolong my vision?
- Can I make any lifestyle changes to try to prevent further vision loss?

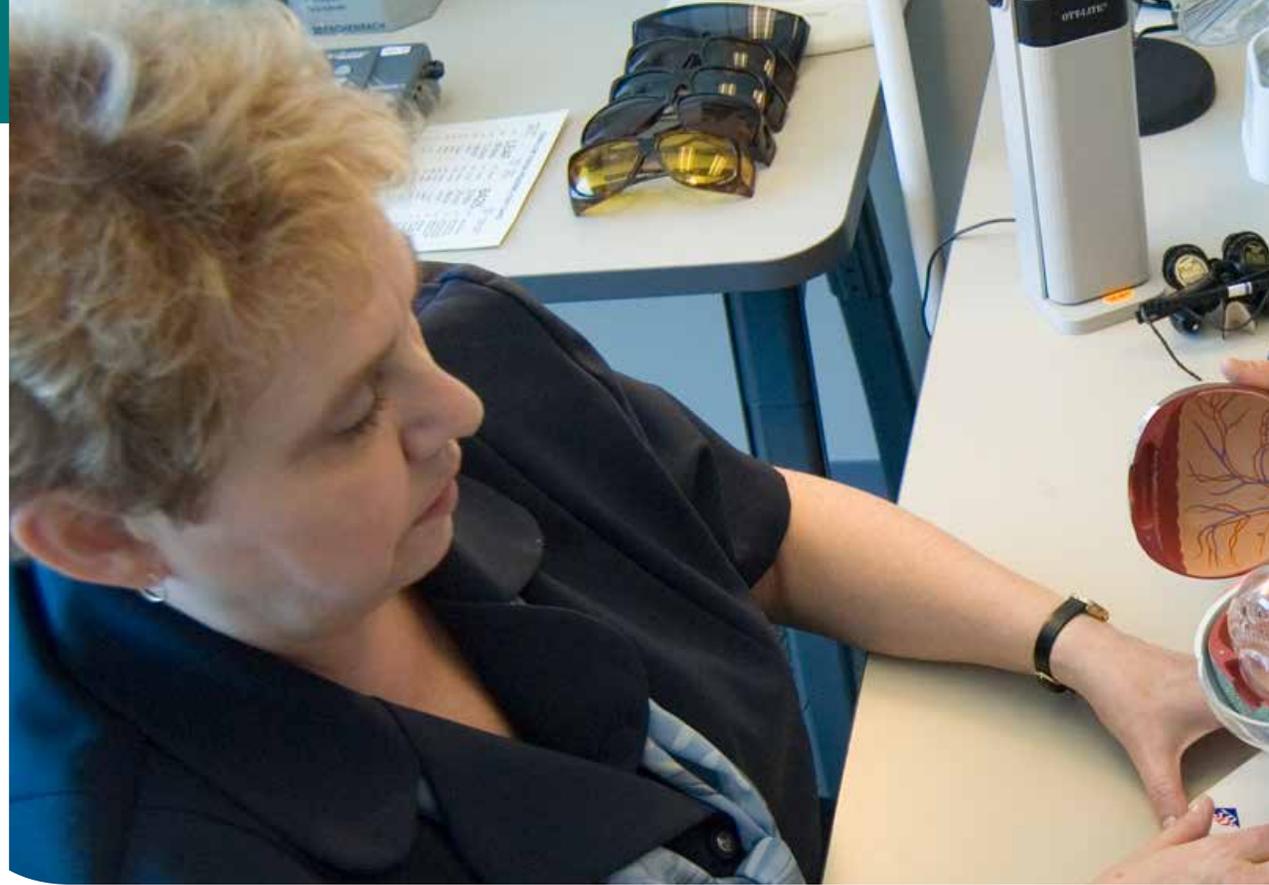


Treatment

Although lost vision from diabetic retinopathy can't be restored, early treatment is often successful and can prevent vision from getting worse.

Treatment options for proliferative retinopathy and macular edema are described below. Discuss your options with your eye doctor to determine which is right for you.

- **Scatter laser treatment:** This treatment uses a large number of microscopic thermal laser burns in the retina to shrink abnormal blood vessels.
- **Vitrectomy:** If blood has leaked into the centre of the eye, the vitreous gel must be removed. A tiny incision is made in the eye, and the vitreous gel is replaced with a salt solution that mimics the normal fluids of the eye.



- **Intraocular (anti-VEGF) injections:** In this treatment, anti-angiogenic drugs are injected into your eyes, sometimes for two years or longer, to stop the growth of abnormal blood vessels and treat macular edema.

The only anti-angiogenic therapy approved by Health Canada for the treatment of macular edema associated with diabetic retinopathy is Ranibizumab (Lucentis).

New treatments for diabetic retinopathy are constantly evolving so it's important to consult regularly with an eye doctor and visit cnib.ca/dr.



Macular edema is treated by:

- **Focal laser treatment:** In this treatment, microscopic thermal laser burns are made around the macula, which slows the leaking from the blood vessels. This treatment can reduce the risk of further vision loss by 50 per cent and may improve vision for a small number of people.
- **Intraocular anti-inflammatory injections:** This short procedure involves an injection used to reduce inflammation inside the eye. In some severe cases, several treatments may be required. Side effects may include the development of cataracts or glaucoma.

In the more advanced stages of diabetic retinopathy, other eye complications, such as a retinal detachment, may need to be treated.

Managing Diabetes with Vision Loss

The onset of vision loss may make it more challenging for you to manage your diabetes, but your health care team and CNIB are here to help you learn new ways of adjusting to and managing diabetes with vision loss.

Testing blood sugar levels

Blood sugar testing is done with a small portable device called a blood sugar monitor. Regular blood sugar testing helps you to know if your blood sugar is at target.

If you're unable to see well enough to read a monitor or measure dosages, testing your blood sugar and taking medication or insulin can be challenging. Your family doctor, diabetes educator and local CNIB specialist can support you with techniques for managing your diabetes effectively.

Talking blood sugar monitors (glucometers)

Your diabetes educator and CNIB can also show you how to use a talking blood sugar monitor, which lets you hear as well as see your sugar levels. **For more information on talking glucometers, visit the Canadian Diabetes Association website at diabetes.ca.**



Adaptive techniques for managing your diabetes

- Lighting:** You may find it helpful to bring a light closer to your blood glucose monitor (a headlamp or illuminated magnifier) or bring the monitor closer to the light (an adjustable task lamp) in order to better see what you're doing.
- Organization:** Checking your blood sugar within a confined space with only essential monitoring supplies can make organization much easier. A tray with a lip to hold monitoring equipment can also make it easier to locate items and prevent items from scattering.
- Tactile cues:** Having notched, cut-out, raised or recessed areas on your blood sugar monitor can help you with orientation and placement. If you're having trouble

with sensation in your fingers, bringing your finger to your lip to search for the sensation of wetness can help you locate the blood sample on your finger.

- **Landmarks:** Using landmarks on your fingertip – such as the top, middle and bottom of the fingernail and the first joint of the finger – may help you locate the blood sample more easily.
- **Writing aids:** If you have low vision, thick-line or large-print paper and fibre tip pens (gel pens, 20/20 pens, Sharpie pens) are just a few of the writing aids you can use to help keep track of your blood sugar. For more information on writing aids, visit the CNIB online store at cnib.ca/shop.
- **Managing medications:** Oral medications are often prescribed to help manage diabetes. Take them as directed

by your doctor and talk with your diabetes educator to ensure proper management is in place. A CNIB specialist can help you identify and mark your medications with high-contrast or tactile markings.

- **Taking insulin:** If you have Type 1 diabetes, or if you have Type 2 diabetes and your blood sugar levels can't be kept at target with diet, exercise and oral medications, it may be necessary to take insulin. A CNIB specialist can work with your diabetes educator to determine the adaptive techniques that will best help you to take your insulin.
- **Foot care:** Diabetes can lead to reduced sensation in the feet, and vision loss may prevent you from feeling or noticing blisters or cuts that, if untreated, can become infected and lead to

serious complications. It's important for you or someone else to examine your feet daily, and to have your feet checked regularly by your health care provider.

For a detailed daily foot care regimen and more information on adaptive techniques for managing diabetes, visit cnib.ca/dr.

Living with Diabetic Retinopathy

The life you want is still in sight

For many people, adjusting to vision loss can be extremely challenging, and it's not uncommon to feel scared or overwhelmed after being diagnosed with an eye disease.

But there is help available to you.

You don't have to be totally blind to come to CNIB for support (in fact, nine out of 10 people we help have some degree of vision), and you don't need a referral of any kind.

How CNIB can help you

If you've experienced a loss of sight because of diabetic retinopathy – or for any other reason – the CNIB team is always here to help. Our community-based services can help you build the skills and confidence to lead a full, active life with vision loss.

Our caring specialists will speak to you about your specific challenges and needs, and develop a plan to get you back on the road to independence – whether that means learning to cook again after a loss of vision, being able to read the newspaper again, travelling with confidence, or getting the emotional support you need to move forward.

If you need us, all you have to do is call the toll-free CNIB Helpline at 1-800-563-2642 or visit cnib.ca.

Adjusting to vision loss

If you're living with vision loss, CNIB's services can teach you new ways to perform your daily activities independently and with confidence, from learning how to do common household tasks to getting around safely at home, at work or in your community.

Maintaining your love of reading

Home to more than 80,000 accessible materials in formats like braille and audio, the CNIB Library is Canada's largest library for people who are unable to read traditional print. If you'd like help finding a book, movie or other library material, call 1-800-268-8818 or email library@cnib.ca.

Living independently with low vision

If you've experienced a partial loss of vision, learning to maximize your remaining sight can be life-changing. Our low vision specialists can give you a specialized vision assessment, teach you to use helpful tools, and show you special tricks and techniques to make the most of your remaining sight.

Connecting with people who understand

Adapting to life with vision loss can be challenging, but peer support can help you build friendships and share experiences with other people who understand the impact of vision loss on everyday life. If you feel that you or your family could benefit from additional support, speak to your doctor about being referred to a counsellor, therapist or psychologist.

Accessing support and information for family and friends

Watching a loved one experience vision loss can be very difficult for friends and family members as well, but there is help available. Call the CNIB Helpline at 1-800-563-2642 to learn more.



Services for Québec Residents

In Québec, many vital services for people living with vision loss - such as mobility and life skills training - are funded by the provincial government and available through a network of locally-based agencies and rehabilitation centres.

If you've experienced a loss of sight, our caring specialists can help you learn to navigate Québec's health care system and refer you to rehabilitation services in your community. And to complement those services, CNIB offers other helpful forms of support to make life with vision loss easier, including:

- Telephone counseling and peer support
- Specialized computer training for people who are blind or partially sighted
- Access to the CNIB Library and its bilingual collection
- A wide range of innovative assistive products

Call the CNIB Helpline at 1-800-563-2642 or visit cnib.ca to learn more about the support services available to you.

CNIB helps people in every province across Canada, and we deliver our services right where you need them – over the phone, online, or in your own home, community or local CNIB office.



CNIB Resources Online

- CNIB's Eye Connect: Diabetic retinopathy online portal - cnib.ca/dr
- CNIB's main website, where you'll find vision health publications, forums with experts, blogs, news, support - cnib.ca
- The CNIB Library, home to more than 80,000 books, magazines, newspapers and other materials in alternative formats like braille and audio - cniblibrary.ca
- The CNIB online store, offering hundreds of products that can make life with vision loss easier - cnib.ca/shop

Disclaimer

The content of this guide is for informational purposes only and is not intended to be a substitute for professional medical advice, diagnosis or treatment. Always see the advice of your doctor or another qualified health provider with any questions you may have regarding a medical condition.

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CNIB Helpline: 1-800-563-2642

cnib.ca

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