

# Glaucoma

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a conversation guide to help people with glaucoma (and those at risk) receive high-quality care





Task Force

Health Quality Ontario is committed to helping patients, health care providers, and organizations improve the quality of health care in Ontario.

We know that not everyone across the province receives the right care, every time.

So, to help address gaps in care, we produce quality standards, which outline **what quality care looks like** for specific conditions, such as glaucoma. Quality standards are **based on current best evidence and input from patients, caregivers, and health care providers.** 

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Glaucoma <sub>Care for Adults</sub>

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<u>Download</u> Health Quality Ontario's quality standard for glaucoma, developed in partnership with the Provincial Vision Task Force, to read more.

Health Quality Ontario

# The following pages contain questions to help you and your health care providers work together on a care plan for your glaucoma.

This patient guide is based on information from Health Quality Ontario's quality standard *Glaucoma: Care for Adults*. It is not meant to be a complete guide to glaucoma but a tool to help you talk with your health care providers about the topics that matter to you.

Our goal: to empower you to ask for and receive the best quality care.



# What is glaucoma?

Glaucoma is an eye disease that damages the optic nerve—which is responsible for vision—in one or both eyes. This guide is about primary open-angle glaucoma, the most common type of glaucoma in North America.

In its early stages, primary open-angle glaucoma has no symptoms; you won't have pain or notice vision changes. But it gradually causes permanent damage to the optic nerve, resulting in worsening eyesight and sometimes blindness. The best way to know if you have glaucoma is through routine eye exams with your eye care provider.

Although there is no cure for glaucoma, you and your eye care providers can slow down or stop further vision loss with regular eye exams and treatment. Currently, the only treatment for primary open-angle glaucoma is to lower the pressure in the eye (known as intraocular pressure) through medication, laser therapy, or surgery.

## Learn more

There's a lot of information out there about glaucoma, but it can be challenging to know what's reliable. The patients, caregivers, and clinicians we spoke with to put this guide together told us these are resources they find useful:

- <u>Canadian Ophthalmological Society</u>
- <u>CNIB Foundation</u>
- Glaucoma Research Society of Canada
- Ontario Association of Optometrists

Though these resources may not always say the same thing as what's in the quality standard for glaucoma, you may also find them useful.

# Who treats glaucoma?

Your family doctor or nurse practitioner might be the first person to suspect you have glaucoma, and they may refer you to an eye care provider to get your eyes checked.

There are two groups of eye care providers in Ontario:

- Optometrists: Licensed health professionals trained to provide primary vision care. They perform eye exams, prescribe and dispense eyeglasses or contact lenses, and also diagnose, treat, and manage specific eye conditions. You don't need a referral from your family doctor or nurse practitioner to visit an optometrist.
- **Ophthalmologists**: Medical doctors who specialize in the medical and surgical treatment of eye diseases and disorders. You typically need a referral from your optometrist, family doctor, or nurse practitioner to see an ophthalmologist.

Glaucoma care is complex and may involve an optometrist, ophthalmologist, or both working together. Your eye care providers should share any changes in your condition and treatment with your family doctor or nurse practitioner since they play an important role in your overall health and well-being.

If you have questions about glaucoma, talk with your eye care provider, family doctor, or nurse practitioner.



# Start talking

If you have glaucoma or you're at risk of getting it, you might have a lot of questions. You might be scared that you could lose your eyesight and be worried about how that could change your life.

You can ease some of your concerns by discussing them with your eye care providers. Use the topics outlined below to guide your conversations with them as you work together to create the best treatment plan for you:

- Risks for glaucoma
- Eye exams
- Treatments (medications, laser therapy, and surgery)

There are many topics to cover here—there may be more you'd like to add, and you may decide that some are particularly important to you. They may not all be addressed in a single visit or by a single provider, but you can adjust them and refer to them over time. It's OK to ask lots of questions and to get advice from a range of health care providers.

# Write it down

It may help you to write down your experience if you have symptoms. Having written details on hand when you talk to your care providers will help you give a more complete description of your experience.

Consider making your notes right in this electronic file, or in a printed copy, and use this guide each time you visit and review your care plan with your eye care providers.



### Start talking: Risks for glaucoma

Since it's painless, about half of people with glaucoma don't know they have it—by the time people notice that something is wrong with their vision, their glaucoma has already caused quite a lot of damage to the optic nerve.

Anyone can develop glaucoma, but people at higher risk include those who:

- Are over 50 years old
- Have a family member with glaucoma
- Are of African or Hispanic ethnicity
- Are nearsighted
- Have had a past eye injury or surgery
- Have taken steroid medications, particularly as eye drops
- Have high pressure in their eye
- Have a thin central cornea (the eye's outermost layer)
- Have an optic nerve with an abnormal appearance

If you aren't sure whether you're at risk for glaucoma, talk with your family doctor, nurse practitioner, or eye care provider.

It's particularly important to get your eyes checked regularly if any of the above risks are true for you. Early detection and treatment can often slow down or stop vision loss.

### Here are some questions you may want to ask:

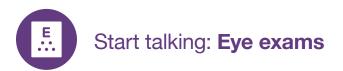
Am I at risk for developing glaucoma?



Continued from the previous page	
How often should I get my eyes tested?	Ø
Will I have to pay out of pocket for these tests?	Ø
Are there any symptoms I should watch for?	Ø
Should my family members get tested for glaucoma?	<b>/</b> /



You don't need a referral from your family doctor or nurse practitioner to get your eyes checked. You can make an appointment with a local optometrist directly.



If you have glaucoma, your eye care provider will want to see you regularly. They will let you know how often your exams should be—this depends on the severity and stage of your glaucoma—so they can monitor your treatment and help prevent further vision loss.

Just like any aspect of your health, it's important to be involved in your eye care. Ask plenty of questions at your eye exams to ensure you understand your condition and what you can do to help it. If you like, involve your family and caregivers for extra support.

Here are some questions you may want to ask your eye care provider:

What type of glaucoma do I have?

Is my glaucoma getting worse?

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Will I go blind?



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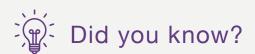
How often do I need to have my eyes checked?

Are there any lifestyle changes I can make to help improve my eye health?

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Which treatment should we try first?



Some tests and treatments for glaucoma are not paid for by the province through the Ontario Health Insurance Plan (OHIP). For these, you may have to pay out of pocket or submit a claim to your insurance company.

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### Start talking: Treatments

Glaucoma treatments are designed to prevent your vision from getting worse and to give you the best possible quality of life. Three common treatments can help treat glaucoma by lowering eye pressure: medications (prescription eye drops), laser therapy, and surgery. There are pros and cons with each, and you may have to try different approaches to find the right one for you—sometimes a combination of treatments is best.

### 1. Medication: Prescription eye drops

Prescription eye drops are usually the first treatment your eye care provider will recommend.

Using eye drops can be tricky. Ask your eye care provider or pharmacist to show you how to make sure that the medication gets into your eyes. To make sure your technique stays correct, feel free to ask them to show you again at any time. I thought I was [putting the eye drops 7 in] correctly; but over the years, having had discussions with other patients and pharmacists, I realized I wasn't doing the best job. It was all explained at the beginning, but a follow-up discussion six months to a year later would be beneficial.

PERSON WITH GLAUCOMA

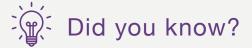
Here are some key questions you may want to ask your eye care provider:

How do eye drops help?

Are there any risks to taking eye drops?



Continued from the previous page	
How do I put them in?	Ø
Is it necessary for me to take my prescription eye drops?	Ø
If I have to put two drops into one eye, do I need to pause between the drops?	Ø
How should I store my eye drops?	Ø
How will we know if the eye drops are working?	



Eye drops to treat glaucoma are only available by prescription and are different from the eye drops you can buy over the counter. Your eye care provider will work with you to find the best kind of prescription eye drops for you.



### 2. Laser therapy

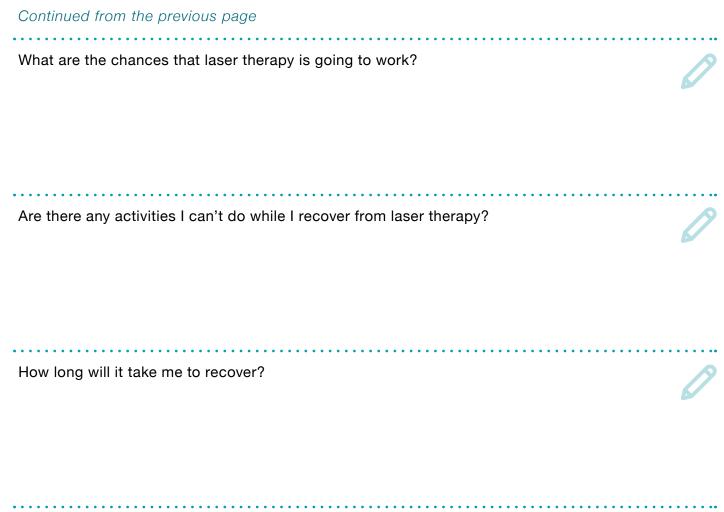
Laser therapy works to lower eye pressure by helping the fluid drain away. The results may not last, but laser therapy can often delay the need for surgery and may reduce the need for eye drops. While it won't improve your eyesight, laser therapy can help prevent further vision loss.

Your eye care provider might suggest using laser therapy first, in combination with eye drops, or if you can't tolerate the eye drops (for example, if you're having trouble putting them in, or if you're experiencing unpleasant side effects).

Here are some key questions you may want to ask your eye care provider:	
Why is laser therapy a good choice for me now?	Ø
What does laser therapy involve?	<i>/</i> /

What are the benefits and risks of laser therapy?





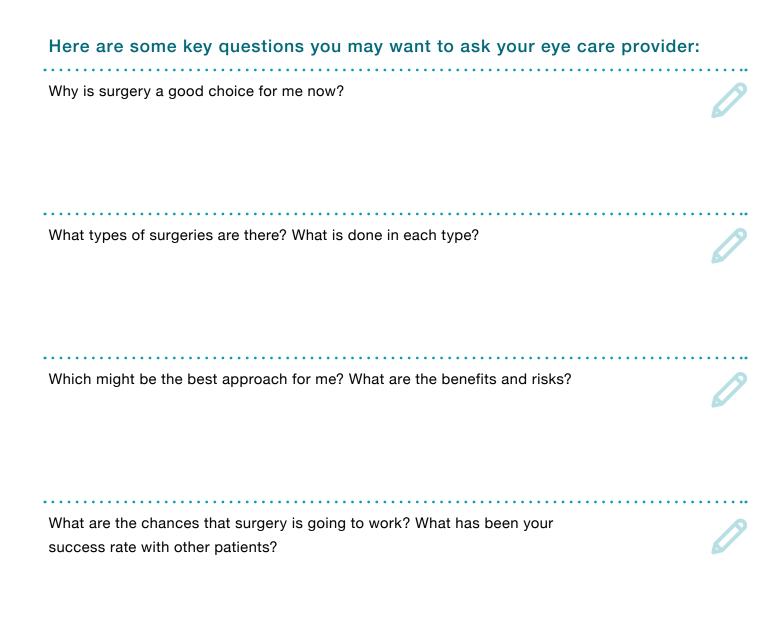
What follow-up is needed?





### 3. Surgery

In some cases, your eye care provider may suggest surgery. It won't cure the disease or improve your vision, but it can help lower the pressure in your eyes so your vision doesn't get worse.





# Continued from the previous page Are there any activities I can't do while I recover from surgery?

How long will it take me to recover?

What kind of follow-up is needed?

14 A CONVERSATION GUIDE TO HELP PEOPLE WITH GLAUCOMA

# What's next?

### Remember, everybody is different.

The treatment plan you develop with your eye care provider and the support you require will be unique to you.

### This conversation guide is meant only as a starting point.

You may have other topics you want to cover with your eye care provider, family doctor, or nurse practitioner. It's important to speak to them about any other questions or concerns.

### **Need more information?**

If you have any questions or feedback about this guide, please contact us at qualitystandards@hqontario.ca or 1-866-623-6868.

For more reading on glaucoma, read the quality standard at: <u>hqontario.ca/qualitystandards</u>



# For your reference: The quality standard in brief

The quality standard for glaucoma is a document for eye care providers that outlines what quality care looks like for this condition. It is based on the best evidence and input from clinicians, patients, and their caregivers.

Below is a summary of the quality standard. For further reading, download the full version online.

### Routine Eye Examination and Comprehensive Glaucoma Assessment

People at risk for glaucoma receive a routine eye examination. People suspected of having glaucoma, based on the routine eye examination, receive a comprehensive glaucoma assessment.

### Monitoring

People with glaucoma or at risk for glaucoma are monitored on an appropriate reassessment schedule, according to their current stage of disease and risk of progression to vision impairment.

### What this means for you

Usually, glaucoma has no symptoms in its early stages. The best way to know if you have glaucoma is to get a routine eye examination by an eye care provider. Your eye care provider should ask you about your vision and your health and check for signs of glaucoma. If your eye care provider thinks you might have glaucoma, they will recommend additional testing.

#### What this means for you

Your eye care provider should check your eyes regularly to see if your eye condition is getting worse. If so, it should be treated promptly to try to slow down or prevent further vision loss.

#### Information

Eye care providers speak with people with glaucoma or at risk for glaucoma about their diagnosis, prognosis, and management, and offer them relevant and accessible information about their condition at initial and subsequent visits.

#### What this means for you

Your eye care provider should give you information about glaucoma. They should tell you about how the disease is likely to progress, what you can do to help manage it, how often to get your eyes tested, and your treatment options. This information should be available for you in a variety of ways, including verbal, written, or electronic (such as websites). If you give permission, your family should also be given this information.

You should be involved in all decisions made about your care and have the opportunity to discuss your condition and treatment with your eye care provider.

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### Referral and Timely Access to an Ophthalmologist

People with glaucoma are referred to and have timely access to an ophthalmologist for consultation, when clinically indicated.

#### What this means for you

Your eye care provider may refer you to an ophthalmologist for testing and/or treatment. If you are referred to the ophthalmologist, they should see you within 6 months. You may see the ophthalmologist once or on an ongoing basis.

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#### Medications and Laser Therapy

People with glaucoma or at risk for glaucoma are offered medications or laser therapy when clinically indicated.

#### What this means for you

There is no cure for glaucoma, but there are treatments that aim to preserve your eyesight. Three common options to treat glaucoma by lowering eye pressure are medications (prescription eye drops), laser therapy, and surgery (see "Incisional Surgery," below). Your eye care provider should discuss with you the potential benefits and harms, side effects, and out-of-pocket costs (if any) of the available treatment options so that you can make informed decisions about your care together. If you want to, include family members in these discussions.

Medications are an important part of managing glaucoma. It is important to use your prescription eye drops correctly. Your eye care provider should explain how and when to take your medications and should ask you to show them how you administer your eye drops. This way, you can both be sure you can administer the drops correctly.

Your eye care provider may recommend laser therapy to help open your eye's natural drainage system; this reduces the pressure in your eye. Laser therapy may be used as an initial treatment or in addition to prescription eye drops.

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#### **Incisional Surgery**

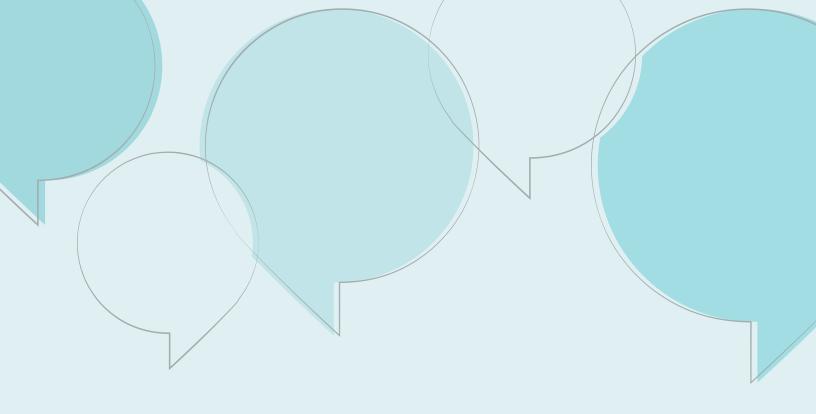
People with glaucoma who are at risk of progressing to sight loss despite maximum tolerated medical therapy and laser therapy are offered incisional surgery.

#### What this means for you

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If medications and laser therapy do not lower your eye pressure enough, or if you cannot tolerate the side effects of the medication, your eye care provider may recommend surgery. Surgery is done to try to preserve your vision; it doesn't cure glaucoma, and you won't regain the vision you have already lost.

Your eye surgeon should discuss surgery options with you, including potential risks and benefits, side effects, and recovery time, so that you can make informed decisions about your care together. If you have family or others involved in your care, they should also receive this information.



For more information, please visit: hqontario.ca

Ontario Health Quality Ontario

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