

Draft—do not cite. Report is a work in progress and could change following public consultation.

Glaucoma

a conversation guide to help people with
glaucoma receive high-quality care

September 2018

DRAFT FOR INPUT ONLY

As the provincial advisor on the quality of health care, Health Quality Ontario is committed to helping health care providers and organizations improve the quality of health care for patients.

To help address the gaps and unnecessary variations in care for specific conditions—glaucoma and others—we produce quality standards. A quality standard is a reference document that outlines **what quality care looks like** for a given condition, and it **is based on the best evidence and input from clinicians, patients, and caregivers**.

We've used the information from [Health Quality Ontario's](#) quality standard for glaucoma, which was developed in partnership with [the Provincial Vision Task Force](#), to create this conversation guide for patients. It focuses on care for adults with glaucoma or who are at risk for glaucoma. It is not meant to be a complete guide to glaucoma but, rather, a tool – based on what is in the standard – to enable you to have informed discussions with your eye care providers (your optometrist or ophthalmologist) to help ensure you receive the best quality care.

[Download Health Quality Ontario's quality standard for glaucoma to read more.](#)

DRAFT FOR INPUT

WHAT IS THIS GUIDE?

This conversation guide is designed to help you play an active role in getting the best possible care. We know that in Ontario, not every adult with glaucoma receives the same care—evidence shows there are variations in care that can be improved.

This guide is designed to highlight the conversations that may be missed between patients and eye care providers as people are screened and treated for glaucoma.

Inside this guide you will find:

- Starting points for important conversations
- Thoughtful questions you may want to ask your eye care providers as you work together to make a plan for your care

DRAFT FOR INPUT ONLY

WHAT IS GLAUCOMA?

Glaucoma is a group of eye diseases. This guide addresses the most common type of glaucoma, called primary open-angle glaucoma. With this kind of glaucoma, the fluid in one or both eyes doesn't drain properly. Instead, it builds up (see the illustration below), increasing pressure (known as intraocular pressure) and damaging a nerve in one or both eyes.

At first, primary open-angle glaucoma is painless and causes no vision changes, but it gradually begins to affect eyesight, causing permanent damage. Left untreated, glaucoma can result in worsening eyesight and blindness. The best way to know if you have glaucoma is through a routine eye exam 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 checkups and treatment.

[Note: Here, the guide will include an illustration that shows how primary open-angle glaucoma develops.]

Who treats glaucoma?

There are three types of eye care providers in Ontario. Depending on your condition and the treatments you need, you may see different providers – including an optometrist, an ophthalmologist or an ophthalmologist who specializes in glaucoma – and you may even move back and forth between them.

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 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 (eye drops, laser therapy and surgery)

There are many topics to cover here—and you may have more you'd like to add. They may not all be addressed at once or in a single visit, 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 eye care providers.

Write it down

Feel free to write down your notes (either in a printed copy or right into this electronic version) and use this guide many times as you review your treatment plan with your eye care providers. We recommend you do this at each visit with them.

Start talking: Risks for glaucoma

Since it's painless, about half of people with glaucoma don't know they have it – they often don't notice until their eyesight begins to deteriorate.

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

- Are over 50 years old
- Have a family member with glaucoma
- Are of African or Hispanic ethnicity
- Are very nearsighted
- Have high eye pressure
- Have thin central cornea (the eye's outermost layer)
- Have thinning of the optic nerve

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

If you aren't sure whether you are at risk for glaucoma, talk with your family doctor, nurse practitioner or your eye care provider. If your family doctor or nurse practitioner thinks you might be at risk for glaucoma, they should refer you to an eye care provider for an eye exam.

Here are some questions you may want to ask:

Am I at risk for developing glaucoma?

How often should I get my eyes tested?

Are there any symptoms I should watch for?

Should my family members get tested for glaucoma?

Did you know?

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

Start talking: Eye exams

If you have glaucoma, your eye care provider will want to see you regularly. They will let you know how often your checkups should be – it 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 checkups 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 stable?*

Will I go blind?*

**Eye care providers say these are priority topics to discuss*

How often do I need to have my eyes checked?

What can I do to stop my glaucoma from getting worse?

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

Did you know?

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 (if you have additional health coverage). If you have concerns about paying for a particular test or treatment, ask your eye care provider if there are low- or no-cost options.

Start talking: Treatment

Glaucoma has no cure, but there are treatments that can prevent your vision from getting worse and give you the best possible quality of life. Three common treatments can help lower the eye pressure associated with glaucoma: 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.

As you begin discussing treatments with your eye care provider, here are some questions you may want to ask:

What can I do to stop my glaucoma from getting worse?*

**Eye care providers say this is a priority topic to discuss*

Which treatment should we try first?

What are the possible benefits and risks of each treatment option?

DRAFT FOR INPUT ONLY

1. Medication: Prescription eye drops

Prescription eye drops are often the first line of treatment eye care providers will recommend, and the most commonly used for glaucoma. Your eye care provider will work with you to find the best kind of prescription eye drops for you.

Using eye drops can be tricky—ask your eye care provider or pharmacist to show you how to do it, as it's important the medication goes into your eyes. If you ever feel like you need a refresher, ask them again to make sure your technique stays correct.

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

How do eye drops help?

How do I put them in?

How should I store my eye drops?

How will we know if the eye drops are working?

“I thought I was [putting the eye drops 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

Did you know?

Eye drops to treat glaucoma are only available by prescription and are different from the eye drops that you can buy over the counter.

2. Laser therapy

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

Your eye care provider might suggest using laser first, using it in combination with eye drops, or trying it 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?

What are the types of laser therapy? What is done in each type?

Which might be the best approach for me? Why?

How long will it take me to recover?

What follow-up is needed?

3. Surgery

If the pressure in your eyes hasn't eased with eye drops and laser therapy, or if you can't tolerate eye drops, 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.

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

Why is surgery a good choice for me now?

What types of surgeries are there? What is done in each type?

Which might be the best approach for me? Why?

How long will it take me to recover?

What kind of follow-up is needed?

DRAFT FOR INPUT ONLY

WHAT'S NEXT?

Remember, everybody is different.

The treatment plan you develop with your eye care providers 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 providers. It's important to speak with them should any questions or concerns come up.

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: hqontario.ca/qualitystandards

DRAFT FOR INPUT ONLY

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 findings from the routine eye examination, receive a comprehensive glaucoma assessment.

What this means for you

Usually, glaucoma has no symptoms in its early stages. The best way to know if you have glaucoma is through routine eye exams with your eye care provider. Your eye care provider should ask about your vision and overall health and check for signs of glaucoma. If your eye care provider thinks you might have glaucoma, they should do additional tests.

Monitoring

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

What this means for you

Your eye care provider should check your eyes on a regular basis to see if your condition is worsening. If so, it should be treated promptly 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 and their condition's prognosis and management, and offer them relevant and accessible information about glaucoma at initial and subsequent visits.

What this means for you

Your eye care provider should give you information about glaucoma. They should explain 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 verbally, written down, or in a video. If you give permission, your family should also be given this information too.

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

Referral for Consultation

People with glaucoma are referred for consultation, when clinically indicated, to the appropriate level of eye care provider for their needs.

What this means for you

Depending on your condition and the treatments you need, you may see different eye care providers – including an optometrist, an ophthalmologist or an ophthalmologist who specializes in glaucoma – and you may even move back and forth between them.

Pharmacotherapy and Laser Therapy

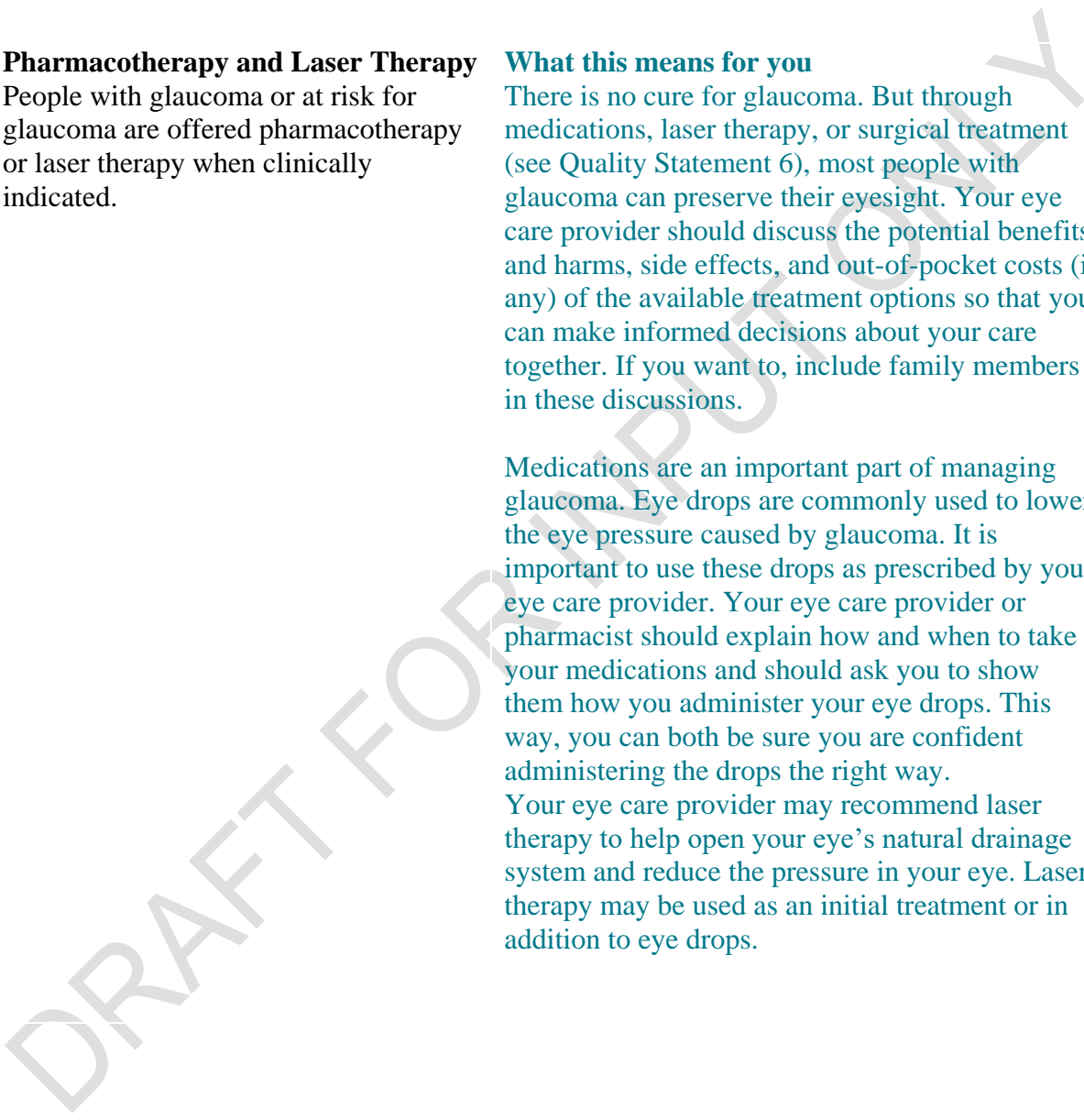
People with glaucoma or at risk for glaucoma are offered pharmacotherapy or laser therapy when clinically indicated.

What this means for you

There is no cure for glaucoma. But through medications, laser therapy, or surgical treatment (see Quality Statement 6), most people with glaucoma can preserve their eyesight. Your eye care provider should discuss 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. Eye drops are commonly used to lower the eye pressure caused by glaucoma. It is important to use these drops as prescribed by your eye care provider. Your eye care provider or pharmacist 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 are confident administering the drops the right way.

Your eye care provider may recommend laser therapy to help open your eye’s natural drainage system and reduce the pressure in your eye. Laser therapy may be used as an initial treatment or in addition to eye drops.



Incisional Surgery

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

What this means for you

If eye drops and laser therapy do not adequately lower your eye pressure, or if you cannot tolerate the side effects of the medication, your eye care provider may recommend surgery. Surgery is done 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.

DRAFT FOR INPUT ONLY

Draft—do not cite. Report is a work in progress and could change following public consultation.

FOR MORE INFORMATION,

PLEASE VISIT:

Health Quality Ontario: hqontario.ca

ISBN TBA (Print)

ISBN TBA (PDF)

© Queen's Printer for Ontario, 2018

DRAFT FOR INPUT ONLY