

Questions to ask your Eye Doctor (Pediatric Ophthalmologist or Glaucoma Specialist)

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Available at www.gl-foundation.org

Get a blank spiral bound notebook and bring it to all doctor appointments. Record the instructions your doctor gives you (e.g. medication schedule), terminology you want to look up, etc. Keep a record of your questions & the answers in the notebook so that you remember what you want to ask at each appointment. The answers to some of these questions may change as your child grows older, or as your child's response to therapy becomes known or changes over time.

1. Do you specialize in pediatric glaucoma? How many children with glaucoma do see each week? How many glaucoma surgeries do you do on children?
2. What type of glaucoma does my child have? Is it related to other problems with my child's eyes and overall health problems?
3. Should I have my current and future children checked for this condition? If so, when?
4. Is my child's glaucoma stable? Will it get better? Will it get worse?
5. Are there other possible problems that will develop with my child's eyes related to the glaucoma or its treatment?
6. If my child needs treatment, what are the options? Risks/benefits?
7. What can I do to make treatment less stressful for my child?
8. What kinds of tests will be done on my child? Will he need more tests later?
9. Do I have to do anything special to prepare for any of the tests or treatments?
10. What type of equipment do you have to check pressures?
11. What are the signs of increased pressure/what should I watch for at home?
12. What precautions should I take? Any restrictions for my child (at home, in school, recreation)?
13. Do I need to be concerned about pink eye/eye infection?
14. How will glaucoma affect my child's vision now and in the future?
15. What tests will be done to check if my child has any vision problems?
16. Does my child have discomfort from his/her glaucoma or the treatments for it?
17. How will I know if my child needs glasses?
18. Will my child develop lazy eye(s)? Who should I see to have this assessed and when?
19. Will my child be able to wear contacts?
20. Will my child be able to drive?

If you have concerns or questions about raising a child with a chronic condition, or have concerns about access to care, insurance, or financial issues don't be afraid to ask for help. Resources and programs will vary by state/province and country. Most hospitals have social services staff to help answer these questions, and direct you to organizations that can help. Your eye doctor should be able to help connect you with a social worker. Also get your child's pediatrician involved. He/she is a key quarterback in making sure everything about your child is looked after.

Other parents of children with glaucoma are a very helpful source of information & support. Go to the website section called "Connect with Others" to find links to parent groups.

If you don't understand your eye doctor's responses, ask questions until you do. If you still have trouble understanding your doctor's answers, ask where you can go for more information. Other members of your healthcare team, such as nurses, can also be good sources of information. If your doctor is not communicating well, consider changing doctors.

Helping the Doctor - Good Things to Ask

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1. Helping the Doctor to Get to Know You.

Remember that the eye doctor may need some "warm up" time with you and your child, and feel free to provide a clue or two that may help put your child at ease with the doctor (or warnings if a particular activity has proven troublesome to your child before).

If you have come from another eye doctor let the new doctor know generally why you have come (second opinion, unhappy with some aspect of care, insurance change, etc.).

If you are coming for another opinion, or have been seen elsewhere in the past, try to get/bring records with you, or even ask to have them sent ahead of your visit with the new doctor (and good to bring a back-up copy with you, too). It's okay to take notes or ask the doctor to write down a complicated diagnosis, if you are not familiar with it, so you can share it with family, look up reading materials, etc.

2. Tips when using MEDICATIONS (for beginners).

Review the new schedule with your eye doctor, and ask how precisely the schedule should be followed and how far apart drops can be taken (especially if you are traveling, etc.).

Prepare a simple chart for yourself and care providers (if your doctor doesn't provide one to you).

Remind the doctor about other medications your child may be taking (especially those for asthma), to be sure they don't have interactions with the eye drops.

3. Tips when using MEDICATIONS (for patient established on medications).

Bring all of your medications to each and every visit! Note ahead of the visit whether you will need refill prescriptions at that visit, so that you don't run out in between visits.

Do volunteer any (possible) side effects that you have noticed that have occurred if a new medication was added at the last visit. Remind the doctor to keep the schedule of medications as simple as possible, and feel free to take notes if you don't get written instructions during the visit.

Provide the doctor with school medication forms if they will be needed for a drop or to during the school day. Ask for an extra prescription for the drops that you'll use more than twice daily, so you don't run out, or so that an extra bottle can be designated for school use if needed.

If you are asked how well you are administering the drops, be honest if you or others are missing drops. Discuss with your doctor if and when it is okay for your older child to self-administer medications.

4. The Doctor – Patient Relationship and dealing with Uncomfortable Issues.

If you are not comfortable, or sense that the doctor is not comfortable with how things are going, feel free to ask the doctor whether there are other resources, including other doctors, who could provide further advice or suggestions to both of you.

Your honesty will be much easier on the doctor than the tension that exists when one/both of you are not comfortable. Share frustration with a failed surgery or bad outcome – the doctor is feeling it, too! If things are not going well, feel free to ask whether there is anything you could do differently.