

TALKING TO YOUR DOCTOR

If you are not seizure-free after trying two different anti-seizure drugs, it is recommended that you talk to your doctor about other treatment options. Sometimes it can be hard to discuss this topic with your doctor. You may be worried that your doctor may feel insulted or get upset with you. But try to remember that your doctor is there to help you find the right treatment.

BEFORE YOUR APPOINTMENT:

It's a good idea to have a goal in mind for your appointment. Would you like to talk about changing your medication? About doing further testing? Would you like to talk about surgery? Write down your questions and bring them to your appointment.

STARTING THE CONVERSATION:

This is sometimes the most difficult part. If you are unsure about how to explore different treatment options, you could start by asking:

"So I have been taking these medications for (# of) years and they don't seem to be working. Could we discuss other treatment options?"

OR

"I've been experiencing a lot of side effects from my medication. I'd like to talk about other possible treatments."

If your doctor says that your seizures are under control, remember that the goal of epilepsy treatment is having no seizures and minimal side effects. If you are still having seizures once a month, or once a year, you are not seizure-free.

If you would like to talk about a specific treatment, such as surgery, you can ask:

"I'd like to talk about epilepsy surgery. I know it works for some people. Do you think I might be a candidate for surgery?"

If your doctor says that brain surgery is too risky or is a last resort, say that you would like information on both the risks and benefits so that you can discuss the decision with your friends and family.

If you have established that you would like a referral to a specialty centre, ask what the next step is.



Your doctor may be unaware that these guidelines exist. If this is the case, they may be unaware of your right to be referred to a specialty centre. You can approach this by saying (for example): *“The new epilepsy guidelines in Ontario say that if I’m not seizure-free after trying two different medications, I should be referred to a specialty centre. Does this apply to me?”*

DURING YOUR APPOINTMENT:

Here are some questions you can ask your doctor to find out if another treatment might be right for you. You may already know the answers to some of these, but if not, you can start at the beginning.

- ◆ *What type of seizures do I have?*
- ◆ *What is the cause of my seizures?*
- ◆ *Do the side effects of taking seizure medication outweigh the benefits for me?*
- ◆ *Do I have drug-resistant epilepsy?*
- ◆ *Should I visit an epilepsy center to see if other treatments might work for me?*
- ◆ *Is it possible that I have the kind of seizures that can be treated with surgery?*
- ◆ *If I try another treatment, how will it affect my lifestyle?*
- ◆ *If I try another treatment, how will it affect my overall health?*

If you would like to discuss a specific treatment, some questions that might be useful are:

- ◆ *How effective is this treatment?*
- ◆ *Would this treatment work for me (or my child)?*
- ◆ *What are the risks of this treatment?*
- ◆ *Where can I go for more information?*

TIPS:

- ✓ It’s a good idea to write down the information your doctor gives you, but it can be difficult to follow the conversation at the same time. Consider bringing a friend or family member along who can take notes.
- ✓ Remember that there are no silly questions. You can keep asking any questions you have if there is anything you do not understand, or if something does not make sense to you.
- ✓ Many doctors book very short appointments. If there is not enough time to ask your questions, tell your doctor that you would like another appointment so you can continue the discussion.
- ✓ Most doctors will listen to your concerns and try to help. If your doctor does not answer your questions to your satisfaction, you have a right to ask for a second opinion. You can ask your family doctor for a referral to another specialist, or you can find another family doctor. The Ontario government offers a service called Health Care Connect to assist you with finding a family doctor. Call 1-800-445-1822 for more information.