Talking to Your Doctor About Hepatitis C Treatment, Getting What's Best for You

November 28, 2016 By Lucinda K. Porter RN

The newest hepatitis C medications are changing lives, are easier to take, and curing nearly everyone. There is a menu of choices, and wading through the ins and outs of each can be daunting. In a perfect world, your medical provider will evaluate your condition and make a recommendation about the best course of treatment for you.

Unfortunately, the world is not perfect. The price of the newest hepatitis C drugs is making it difficult to get hep C treatment from some private and government insurance plans. Many people have successfully fought these denials. However, there is one obstacle that is hard to get around—your own provider. What can you do if your doctor won't prescribe hepatitis C treatment, or wants to prescribe an older regimen, when clearly there are newer ones available?

I've seen a fair amount of data showing the percentages of denials by insurance companies for treatment of chronic hepatitis C viral infection (HCV); I've seen none about denials of treatment by providers. When a person contacts me because their insurer has denied treatment, I can provide resources to help them appeal the denial. When a person is offered an inferior or no hep C treatment, the only suggestion I have is, "Find a new doctor." Not everyone can, particularly if they live in an area where there are few medical specialists, or their choices are restricted by their health plan.

If your doctor isn't going to treat you, good luck changing his or her mind. However, that doesn't mean it isn't worth trying. We are talking about your health, and you are worth fighting for. Some medical providers are open-minded, and are genuinely happy to learn new information. You have little to lose by speaking up on your own behalf.

If you don't get the response you want from your doctor, here are some suggestions:

- Document every exchange you have with your doctor, insurance company, and other involved parties. Write down who you talked to, what you talked about, and when the conversation occurred.

- Ask your doctor to explain her recommendations. Understanding your doctor's reasoning will help you to determine what to do next. For instance, your doctor may want to hold off treating you because he knows that a new drug is about to be approved. Or, she may have had terrible experience with your insurance plan and knows you will be denied. Perhaps your doctor is misinformed about the current qualifications for treatment.
- Bring an advocate to your appointment. Sometimes a friend or family member can make your case for you better than you can.
- Join a support group. Fighting for your health can be frustrating. A support group can help keep you fortified and focused.
- Be a source of information. You need to know what the latest hepatitis C treatment recommendations are in order to know if your doctor knows them. The HCV Guidelines are provided by the American Association for the Study of Liver Diseases (AASLD) and the Infectious Diseases Society of America (IDSA), in collaboration with the International Antiviral Society–USA (IAS–USA). The guidelines state that nearly everyone can be treated, "Treatment is recommended for all patients with chronic HCV infection (emphasis mine), except those with short life expectancies that cannot be remediated by treating HCV, by transplantation, or by other directed therapy. Patients with short life expectancies owing to liver disease should be managed in consultation with an expert." In addition to knowing that you have the right to treatment, know which regimens the HCV Guidelines recommend for you.
- Be armed with resources. Your doctor may be feeling discouraged by repeated insurance denials. His staff may be burned out, and your doctor must pay the staff for their time, which isn't reimbursed by insurance. If your doctor doesn't work with a specialty pharmacy or patient assistance program (PAP), ask her if she'd like the name of one. The HCV Advocate provides a resource list with reliable PAPs. My current favorite is the Patient Advocate Foundation's Hepatitis C CareLine. They offer case management services to providers, as well as to consumers.
- Stay flexible. Your doctor may suggest a regimen that isn't your first choice, but maybe it is a good enough choice. For instance, there are six different treatment recommendations for

genotype 1 patients without cirrhosis, none using peginterferon or ribavirin. Perhaps you wanted the newest HCV treatment, but the others may be as good or better.

- Enlist help. Find a doctor to advocate for you by asking her to reach out to your doctor and community. Some physicians are writing letters to community physicians and providing continuing education seminars to bring the latest practice guidelines to busy clinicians. Ask your support network, Help4Hep, and the National Viral Hepatitis Roundtable's (NVHR) for any leads. NVHR's Hepatitis C Treatment Access page provides templates for letters of appeal that your provider can use, as well as links to helpful resources.

If the treatment your doctor prescribed for you isn't on your plan's formulary, consider changing insurance plans during the next open enrollment period. The Patient Advocate Foundation's Hepatitis C CareLine keeps track of formulary changes, and will provide information to you.

File a complaint. There are multiple websites where you can review and rate your medical provider, such as Healthgrades or Vitals.

Consider travel or telemedicine. Some physicians see their patients using web-based services, and prescribe lab tests and treatment accordingly. Click here for information about accessing generic hepatitis C drugs.

Speak up. Talk to advocacy groups such as NVHR and Help4Hep (877Help-4-Hep/877-435-7443). If you have trouble accessing treatment through your state Medicaid program, report this to NVHR.

Don't despair. Despair serves no one. It will steal all the life out of you and will not help you get your hepatitis C medications. The "system" may deny your hepatitis C treatment, but don't let them also have your precious joy.

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