



How to be an Advocate for Yourself or Your Loved One

Over time, liver disease can lead to liver scarring as well as more serious complications, like cirrhosis. Cirrhosis occurs when healthy liver tissue is replaced with scar tissue, due to persistent inflammation and swelling. Cirrhosis can eventually progress to a more advanced stage – decompensated cirrhosis – and if left untreated, patients can experience further complications, including ascites (fluid buildup which causes painful swelling), enlarged veins, gallstones or an enlarged spleen. It can also lead to hepatic encephalopathy (HE), which is believed to be a result of a buildup of toxins in the brain.

That is why it is important to speak to your doctor to understand the risk of developing serious complications like HE (and if you/your loved one has already been diagnosed with HE, how best to manage it).

You play a vital role in the management of your/your loved one's diagnosis. The following are a few things to help you feel empowered to take action and help get the care you/your loved one needs and deserves.



GUIDELINES FOR HE

HE management doesn't have to be confusing. There are guideline-recommended therapies, but not all doctors are aware of them. In fact, 56% of doctors are not sure how to translate the guideline information into daily practice.

The *Hepatic Encephalopathy in Chronic Liver Disease: 2014 Practice Guideline* was published by The American Association for the Study of Liver Diseases (AASLD) and was created to provide doctors with evidence-based recommendations for managing HE. This guideline is recognized as the standard of care for the management of HE.

Ask your doctor:

- Am I/Is my loved one on guideline-recommended HE therapy? If so, which medications are involved? Is there a point in time we'd add another therapy?
- What can I/my loved one do to minimize recurrence of HE in addition to adhering to medications?
- How do you recommend best monitoring my/my loved one's symptoms to understand if the medication is working?
- What do I do if I think I've had/my loved one has had another HE episode?
- How often should I/my loved one come in for visits?



PRIOR AUTHORIZATION

Often your doctor needs to complete extra paperwork to submit to your health insurance to cover a portion or all of the cost of a prescription.

This extra paperwork is known as a prior authorization (PA) and is needed for a number of conditions. Once properly completed by your doctor, the PA will document why the treatment is medically necessary for you/your loved one. Once your insurance company confirms, it will typically cover some or all of the cost of prescription medication.

Ask your doctor:

- Did you complete a prior authorization form?
- Is there anything else you can provide to submit to the insurance provider for my/my loved one's HE medication?
- Is there anything else I need to know about possible access to guideline-recommended therapy?

Learn more about insurance intricacies by checking out our [Patient Health Insurance Roadmap](#).



SOCIAL STIGMA

44% of doctors agree that patients often feel social stigma related to their liver disease. Some feel stigma due to misconceptions around how their disease occurred, even when speaking with their doctor.

You and your loved one's doctor are a team in helping secure and maintain optimal care and outcomes, and it should be a trusting, two-way relationship. Provide honest and complete information about what you/they are implementing (or not) and experiencing, and come prepared with a list of questions to get the most out of the visit.



PATIENT ADHERENCE

It might surprise you to learn that 87% of doctors state patient nonadherence is the top factor that limits the duration of treatment for the prevention of an HE recurrence.

Adherence means taking your medication as directed by your doctor. If you or your loved one is having trouble "sticking to" taking medication as instructed, you are not alone. Talk to a nurse or doctor if you are having difficulty taking your medicine consistently. They may be able to help ensure you're able to take your medicine as prescribed to get the optimal treatment.

Additionally, find support by connecting with others in the HE community. Advocacy and support groups are a great way to learn more about the disease and connect with other patients/caregivers going through similar experiences. Having access to a network can help remind you that you are not alone.

For more information check out our [patient resources](#) and [caregiver resources](#).