

Caring for a Loved One With Hepatic Encephalopathy (HE)

American Liver Foundation Support Guide



Your Liver. Your Life.

The American Liver Foundation’s mission is to facilitate, advocate, and promote education, support, and research for the prevention, treatment, and cure of liver disease.

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Caring for a Loved One With Hepatic Encephalopathy (HE)

If your loved one develops hepatic encephalopathy (HE), you may be stepping into a new role as a caregiver. You may have a lot of questions about what is involved and what to expect when caring for a person with chronic liver disease. You may want to know where you begin to find answers and what resources are available to you.

The American Liver Foundation (ALF) is here to help. This guide contains information on the roles of a caregiver, the nature and progression of chronic liver disease and HE, how to care for your loved one and yourself, how to effectively communicate with individuals involved in your loved one's care, and how to utilize available resources.

Visit www.he123.liverfoundation.org for more information on hepatic encephalopathy.

Caregiving and You

Who is a caregiver?

A caregiver is someone who is committed to providing care for someone with a short-term or long-term health condition. A caregiver can be a spouse, partner, sibling, parent, family member, or friend.

What roles do caregivers have?

A caregiver serves in many important roles and capacities. A caregiver's roles may be determined by their loved one's needs and his/her own strengths, ability, or situation. No two caregivers are identical. Some of the common roles caregivers serve include:

Listener – someone who listens to a loved one and understands what he/she is going through

Advocate – someone who is committed to improving a loved one's quality of life and looks for information and resources

Caretaker – someone who takes care of household activities (for example, cooking nutritious meals, doing laundry, washing dishes, cleaning, paying bills, or picking up mail)

Navigator – someone who takes a loved one to appointments and visits (for example, to the doctor, diagnostic lab, benefits enrollment office, barber, or shops)

Communicator (or sometimes an interpreter) – someone who communicates with healthcare and social service providers on behalf of a loved one or with a loved one on behalf of healthcare and social service providers

Observer – someone who closely observes a loved one's health condition

You may take on one, some, or all of the roles listed above, and the roles may change as time goes on. It is okay if your loved one does not need someone to fill all of these roles or you are not able to take on all the roles your loved one needs.

You may have other responsibilities or demands, such as a job or parenting. Think about ways you can realistically assist your loved one and who else may be able to assist. Talk to your family and close friends about their ability to assist periodically or regularly with tasks, such as driving your loved one to the pharmacy, preparing a meal, or doing chores around the house. Assistance from others will help provide balance and support for you.

What Is HE?

HE is a condition that occurs in people with cirrhosis who have a damaged liver. The damaged liver cannot remove toxins as a healthy liver normally would. These toxins travel through the body until they reach the brain. They can then damage the brain and cause HE.

How will you know if your loved one has HE?

The symptoms of HE can be different for each person. Symptoms can depend on how bad your loved one's liver disease is and how well they are able to eliminate toxins. People with HE may get confused about who or where they are. It may seem like they are not themselves, and they may not be aware of what they are doing. HE also changes people's sleep patterns, causing them to stay awake at night and sleep all day.

But with continuous treatment, HE can be controlled and sometimes even stopped. So it's very important that people with HE are taken care of and continue treatment to keep HE symptoms from returning.

If you think a loved one may have HE, talk to a doctor right away.



“During nearly 8 years as a caregiver while my husband was waiting for a liver transplant, HE was by far the most difficult side effect of liver disease to deal with. The first symptoms were confusion and an inability for him to speak for short periods. He would go into strange catatonic phases and then snap out of it just as quickly. Two days after the first episodes, he started on lactulose. He was good about taking it, and I nagged constantly. Three and a half years later, he is in outstanding health, working hard, playing golf, and life is wonderful.”

***Story by Tracey Nettell
(Caregiver for husband with HE)***



How Are HE and Liver Disease Connected?

In a healthy person, the liver filters everything that enters the body—food, drink, and medicine. After the intestines break these down into basic substances, the liver separates the toxins from the useful substances. Then, the body gets rid of the toxins, while the liver sends the nutrients and vitamins into the bloodstream for the body to use.

If the liver is damaged, it can't filter out everything it's supposed to. That means that toxins can build up and get into the brain. The buildup of these toxins can lead to HE.

What Are the Signs of HE?

HE starts slowly. At first, people with HE may not even know they have it. To them, things seem fine. But things may not seem fine to family or friends.

People with worse HE may not be able to drive a car or work a steady job. They may also need to rely on a caregiver to take care of them. In serious cases, hospitalization, coma, and even death can occur.

Knowing the signs of HE can help slow it down before it gets worse. Let a doctor know right away if a loved one is beginning to show any of these signs or has shown them before.

Mental symptoms of HE

- Forgetfulness, mild confusion
- Poor judgment
- Being extra nervous or excited
- Not knowing where he/she is or where he/she is going
- Inappropriate behavior or personality changes

Physical symptoms of HE

- Breath with a musty or sweet odor
- Change in sleep patterns (often awake at night, sleeping during the day)
- Worsening of handwriting or loss of other small hand movements
- Shaking of hands or arms
- Slurred speech
- Slowed or sluggish movement



What Are the Stages of HE?

Stage 1: Mild HE

Patients may have sleep problems and trouble concentrating. They may have mood swings.

Stage 2: Moderate HE

Patients may not have much energy. They keep forgetting things and have problems with basic math. They may behave strangely and slur their speech. Their hands might shake, and they may have difficulty writing.

Stage 3: Severe HE

Patients are very sleepy and sometimes pass out. They can't do basic math at all. They act strange and can be very fearful and jumpy.

Stage 4: Coma

The final stage of HE is coma—the patient is unconscious.

What Can Cause HE to Get Worse?

When HE symptoms return and get bad, it's also known as an "HE recurrence." It is not known for certain why some people experience HE recurrences, but several possible triggers are listed below:

- Dehydration—not getting enough water
- Low levels of salt in the blood (this can happen when someone is dehydrated)
- Bleeding in the stomach and intestines
- Infections
- Constipation
- Drugs that can act on the central nervous system, such as antidepressants, opiates, etc
- Lack of potassium
- Kidney failure
- Blocked urinary tract
- Hepatic portal shunt—this is a tube that is placed in a vein near the liver to relieve pressure
- Surgery
- Liver injury from disease or drugs
- Liver cancer
- Excessive intake of animal protein



"Although HE is difficult for the patient, it is terribly challenging for caregivers. Every day you have to find the strength to face another day and have no idea what to expect. You feel so much pressure to ensure your loved one is safe, getting the best medical care, taking their medications properly, managing medication refills and doctor appointments, taking care of their finances. You have to learn

your loved one's HE symptoms and try to catch it before it gets worse. Ultimately, your loved one's life is in your hands."

**Story by Angie Merryman
(Caregiver for brother with HE)**



How Important Is It to Treat HE?

It is unlikely that your loved one's HE episode will get better without treatment. Tell the doctor about any warning signs as soon as you notice them.

The doctor may give your loved one medicine for his/her HE. If so, it's very important to make sure your loved one is taking it exactly as prescribed for as long as the doctor instructs.

How is HE treated?

The doctor may have your loved one:

- Take a medication that can help remove toxins
- Follow specific instructions to carefully raise his/her sodium and potassium levels
- Get treatment for certain infections
- Stop taking certain drugs
- Get treatment for any urinary blockages

Your loved one may also have to change his/her diet. If he/she is eating too much protein, the instruction may be to eat less protein that comes from meat. It may be better to get protein through fruits and vegetables instead.

What Medications Are Used to Treat HE?

There are 2 types of medicine that are used most often to treat HE: lactulose and antibiotics.

Lactulose

Lactulose is a kind of sugar. It works by causing a person to have more bowel movements. This will help flush toxins out of the system. Lactulose may also help reduce the amount of toxins that are made in the intestines.

Lactulose has been shown to help during HE recurrences and also to make them less likely to happen. But sometimes lactulose can cause dehydration. This may actually trigger an HE recurrence. In addition, some people find lactulose to have an unpleasantly sweet taste. Others get gassy and bloated, and some get diarrhea when they use it.

Antibiotics

Antibiotics stop the growth of certain bacteria that create toxins as food is digested. By reducing bacteria, antibiotics reduce the amount of toxins.

There are a few different antibiotics that are used to treat HE. Your loved one's doctor will choose the one that is best for him/her. Antibiotics may make episodes less likely to occur. As with any medication, your loved one may experience side effects while taking antibiotics. Talk to your loved one's doctor about whether antibiotics may be right for managing his/her HE.

8 Things You Should Remember About HE

- 1 HE mainly happens to people who have cirrhosis or other types of liver damage.
- 2 HE is caused by toxins that build up in the blood and reach the brain.
- 3 Symptoms of HE can be both mental and physical.
- 4 HE can start slowly. Symptoms of HE may not be noticed at first.
- 5 HE will not get better on its own. Symptoms will likely get worse without continuous treatment.
- 6 Treatments for HE aim to control the disease and keep people out of the hospital. Hospital stays for HE can be lengthy and costly.
- 7 Lactulose and antibiotics are used to treat HE and prevent toxins from building up.
- 8 With timely and proper treatment, the progression of HE can be slowed and sometimes stopped.

"I did not know anything about HE until my wife was on her deathbed due to liver failure beginning in October 2012, and her doctor asked me about certain symptoms, observed her physical condition, and provided a diagnosis. Part of my grieving is dealing with the fact that we did not recognize these symptoms sooner and possibly could have done something about it. I learned too late that liver failure and HE produce deceptive symptoms that you don't necessarily connect to the liver."

Story by Jeremiah Burton
(Caregiver to wife with HE)

Caring for Your Loved One

Being a caregiver can sometimes feel like running in a three-legged race with your loved one. You cannot run alone, and neither can your loved one. You as a caregiver and your loved one need to be a team. It is important for both of you to understand your roles and what each of you can do in order to be an effective team member. Open and honest communication is a key aspect of teamwork. Working as a team may involve making compromises that require shifting around previous roles and responsibilities to meet the clinical needs of your loved one. Similar to running a three-legged race, it takes time and practice to run successfully.

Coping with emotions

Coping with a chronic disease can be difficult. It can feel overwhelming. Your loved one may feel sad or angry. There may be things your loved one can no longer do or enjoy, such as eating a favorite food, drinking wine, playing sports, or taking trips. Your loved one also may have fears of pain, loneliness, death, or being a burden to his/her family. Listening to your loved one and talking through the concerns that you both may have can help. Your loved one may find talking to a professional counselor/therapist helpful to cope with emotions and stress from having chronic liver disease.

Diet modifications

A healthy diet can play a key role in your loved one's well-being and help maintain a level of liver health or minimize further liver damage. It is important for your loved one to be informed about nutritious foods and to talk to his/her doctor about specific diet recommendations. A certified dietitian/nutritionist also can provide personalized diet recommendations for your loved one.

For people with liver disease, doctors recommend avoiding alcohol. Alcohol can damage or destroy liver cells, and even a small amount of alcohol can be harmful.

Having HE may require your loved one to take medications. Medications can include over-the-counter and prescription medicines, vitamins, dietary supplements, and alternative medicines. Medicines can help your loved one feel better; however, they can cause liver damage when they are taken incorrectly (by taking too much or the wrong type or by mixing). Mixing alcohol and medicines can be harmful, even if they are not taken at the same time. It is important for your loved one to talk to his/her healthcare provider before taking any new medications or dietary supplements.

Caring for Your Loved One *(continued)*

Lifestyle modifications

HE may cause your loved one to change how he/she lives. These changes can impact your loved one's personal relationships, professional life, family budget, and more. Common questions that a caregiver has about a loved one's lifestyle modifications include:

- Will my loved one need to take medications on a daily basis?
- Will my loved one have diet restrictions?
- Will my loved one need to exercise more or less often?
- Will my loved one need to leave his/her job?
- Is my loved one allowed to drive/travel alone to his/her appointments?
- What are activities that my loved one can no longer do alone?

Being a caregiver may require you and your family to make lifestyle modifications as well. These changes can affect your personal relationships, professional life, and family budget. Common questions that caregivers have about their own lifestyle modifications include:

- Can I continue to work while I provide care to my loved one? Can I work full-time or part-time?
- How does my loved one's chronic condition affect my family's budget/finances?
- Is my house/apartment equipped for my loved one who has a chronic disease? Do I need to make any modifications to my house/apartment?
- Can my family assist with my personal responsibilities when I am not able to do so?



Caring for Yourself

HE is an unpredictable condition, and caring for a patient who suffers from it can put a lot of stress on you. This can leave you feeling burned out, if you're not careful. It's very important for you as a caregiver to take steps to avoid burnout. Many caregivers initially think they can—or should—handle everything themselves. They may start to neglect their own needs, both emotional and physical, and the strain begins to take a toll. Taking care of yourself is always a top priority. Good physical and mental health are essential to adjust to new circumstances and responsibilities. There may be periods of time where a responsibility occupies a significant portion of your time or an emotion occupies your thoughts constantly. But you still need to find ways to share your emotions, rest, balance your personal life, and communicate.

Coping with emotions

It can be challenging to accept that a loved one is chronically ill. It is okay to feel sad or frustrated. It is important to be able to express your feelings. Below are some ways to cope with your emotions:

Share your experience – Talk to others about your experience and learn from other caregivers' experiences. There may be support groups for caregivers in your area, or you may find an online community/support group that you can join.

Speak to a professional listener – Express your emotions and thoughts to a professional who may be able to help you. Many people find it helpful to speak to a counselor or therapist when they are facing a new issue or are unsure of how to cope with emotions. Professionals who provide counseling include social workers, mental health counselors, therapists, and psychologists. Ask your insurance provider or your doctor for a referral to a counseling professional. Some social service organizations and faith-based organizations may also provide this service.

Caring for Yourself *(continued)*

Rest and find balance in your life

Be sure to make time for rest and activities that do not involve caregiving. Integrate breaks into your caregiving role. Try to find balance between your role as a caregiver and your personal life.

Take care of yourself – Many of the healthy habits that are good for your loved one, such as eating nutritious meals, exercising, and getting regular check-ups are good for you as well.

Sleep tight – Adequate amount of sleep is important for your health. Lack of sleep can slow you down and affect your mood. Also, not getting enough sleep is associated with many serious health conditions, including diabetes, cardiovascular disease, obesity, and depression.

Relax – Find ways to relax and make time for yourself. Some people enjoy listening to music, drinking a cup of tea, walking, reading a book, or getting a massage.

Be yourself – While you may have additional responsibilities now, continue to participate in your regular activities and hobbies, such as playing basketball, gardening, or spending time with friends.

Communicate

It is important for you to communicate your needs as a caregiver to those who care about you.

Let yourself be heard – Share your feelings and thoughts with your family members and friends. They can provide support and helpful advice.

Ask for help – If you need an additional set of hands, ask your family members and friends. Also, know where to call and where to go for assistance when you need it. The resources at the end of this guide will provide information on organizations and services that you as a caregiver can benefit from.

Write it down – Write things down to help you remember and stay organized.

Getting to Know the Healthcare Team

Who is involved in HE management?

A team of healthcare professionals works closely to support a person's healthcare needs. Learn about these important individuals and their roles.

Primary Care Physicians (PCPs), also referred to as family physicians or internists, provide preventive care and disease management.

Liver Specialists

Gastroenterologists (GIs) are physicians who specialize in the treatment and/or study of digestive organs, including the liver.

Hepatologists are physicians who specialize in the treatment and/or study of the liver.

Physician Assistants (PAs) practice medicine under the supervision of physicians. PAs provide diagnostic screenings, take medical histories, order and interpret test results, prescribe medications, perform medical procedures, provide education to patients on how to manage conditions, and make referrals to other healthcare professionals as needed.

Nurse Practitioners (NPs) provide diagnostic screenings, take medical histories, order and interpret test results, prescribe medications, provide education to patients on how to manage conditions, and make referrals to other healthcare professionals as needed.

Registered Nurses (RNs) take medical histories, assist with diagnostic screenings and medical procedures, provide education to patients, administer medications and treatment, and provide administrative support, such as scheduling appointments and addressing billing and insurance issues.

Getting to Know the Healthcare Team *(continued)*

Patient Representatives or Patient Assistants assist with scheduling appointments, billing, and insurance issues. They also help contact insurance providers and pharmacies to verify information and assist with prescription refills.

Medical Assistants provide similar administrative support and technical support, such as recording vital signs and drawing blood.

Pharmacists dispense and provide education on prescribed medications, including potential interactions with other medications and their side effects.

Registered Dietitians and Nutritionists specialize in nutrition and healthy diets and can provide counseling on nutrition and meal plans.

Patient Advocates, Case Workers, Case Managers, and/or Social Workers provide assistance with accessing eligible services and improving the patient's quality of care. They assess the patient's needs and eligibility for benefits and services, such as Medicaid, Medicare, disability, and financial assistance.

Therapists and Counselors assist individuals in coping with conditions that can affect their physical and mental health, such as stress, anxiety, depression, substance abuse, addiction, self-esteem, and trauma.

Other Providers for people with chronic liver disease include radiology technicians for CT scan (imaging method that uses x-rays to get detailed pictures of the body), medical sonographers for ultrasound (imaging technique that uses waves to get inside views of the body), and phlebotomists for drawing blood and other specimen collections (ie, urine).

"I am a volunteer at a nursing home and am familiar with the residents who have dementia. My mother's HE episodes came as a complete shock to me. She was only 66, and there I was comparing her to an older person. Only a matter of days before her first episode I was able to interact with her and never saw this coming."

**Story by Melissa Jugeat
(Caregiver for mother with HE)**

Resources

The following resources and organizations can be valuable sources of information on HE, patient assistance, and caring for a patient with a chronic condition.

ALF Support Services

www.LiverFoundation.org

E-mail: info@liverfoundation.org

National HelpLine: 1-800-GO-LIVER (800-465-4837)

Online information and education materials: LiverFoundation.org

Online support communities: www.inspire.com/groups/american-liver-foundation

ALF provides education and support services for all those affected by liver disease.

National Organization for Rare Disorders (NORD)

www.rarediseases.org

E-mail: orphan@rarediseases.org

Phone: 1-203-744-0100

NORD provides information about rare diseases, patient assistance programs, and related resources for patients and their families, medical professionals, and the public.

American Gastroenterological Association (AGA)

www.gastro.org

E-mail: member@gastro.org

Phone: 1-301-654-2055

The public section of this Web site offers a digestive health resource, a gastroenterologist locator service, and various helpful Web links.

American College of Gastroenterology (ACG)

www.acg.gi.org

E-mail: info@acg.gi.org

Phone: 1-301-263-9000

ACG provides consumer guides on various gastroenterological disorders and common problems, offers digestive health tips, and has a physician locator to find an ACG member in your area.

Caregiver.com

www.caregiver.com

E-mail: info@caregiver.com

Phone: 1-800-829-2734

This site provides information for, about, and by caregivers. In addition to being one of the most visited caregiver Web sites, they also publish Today's Caregiver, a bimonthly magazine, and provide links to many caregiver resources, including both government and nonprofit agencies.

Resources *(continued)*

National Family Caregivers Association

www.nfcacares.org

E-mail: info@thefamilycaregiver.org

Phone: 1-800-896-3650

This association educates, supports, and empowers more than 65 million Americans who care for loved ones with a chronic illness or disability. Free member benefits include a subscription to their TAKE CARE! quarterly newsletter.

The Well Spouse Association

www.wellspouse.org

E-mail: info@wellspouse.org

Phone: 1-800-838-0879

This group advocates for and addresses the needs of individuals caring for a chronically ill and/or disabled spouse or partner. They publish Mainstay, a quarterly newsletter, and also facilitate networking and access to local support groups.





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www.LiverFoundation.org

1-800-GO-LIVER

*Visit www.he123.liverfoundation.org for more
information on hepatic encephalopathy.*

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