

Hepatic encephalopathy



European Liver Patients Association

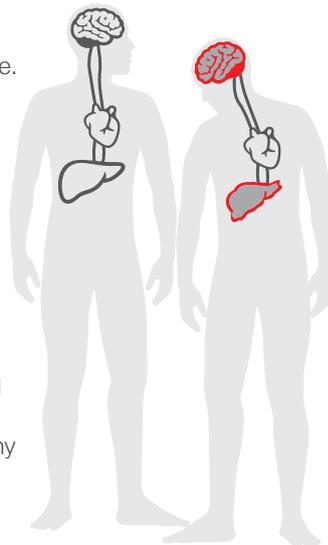


The European Liver Patients Association (ELPA) is undertaking a pan-European campaign, *Time to DeLiver*, to raise awareness of and change attitudes to hepatic encephalopathy (HE), a serious complication of cirrhosis. We are working with stakeholders including politicians, professional groups and national patient groups to help raise the standard of care for people with HE. This paper highlights the burden of HE, our calls for action, and the barriers that still need to be overcome to improve the lives of people living with HE.

The burden of hepatic encephalopathy

Cirrhosis (advanced chronic liver disease) refers to end stage liver disease where the damage to the organ has become irreversible. The condition prevents the liver from fully functioning and can become so extensive that it results in liver failure. It is estimated that 500,000 EU citizens currently live with cirrhosis.¹

HE is a serious complication of cirrhosis. HE is a potentially fatal liver-related brain disorder, which presents itself when the liver is no longer able to remove toxins from the blood. The symptoms of HE range from mild to extremely severe. In serious cases it can lead to coma. HE is thought to affect as many as 200,000 EU citizens.² It may ultimately lead to death.



HE is associated with **poor health outcomes, frequent hospitalisations and high management costs.** People with liver disease who develop HE are twice as likely to die, when compared with liver disease patients without the condition over the same time period.³ They are also more likely to be admitted into hospital,⁴ placing considerable financial strain on European health systems.

While effective management can help prevent HE episodes and avert many of the costs associated with hospitalisation,⁵ the treatment of people with HE in Europe can be below optimal standards. The barriers to high quality care for people with HE can include **stigma, late and inaccurate diagnosis and restrictions on clinician's freedom to prescribe.**

Hepatic encephalopathy in numbers

HE is a major burden on European health systems. This burden is likely to grow, if urgent action is not taken to improve the management of HE.

High prevalence

It is estimated that **500,000** EU citizens are living with advanced chronic liver disease¹



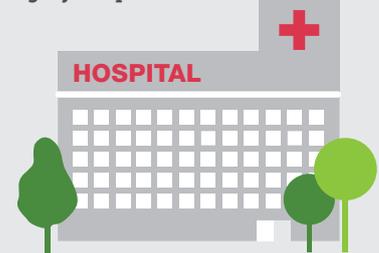
Severe health burden

Advanced chronic liver disease results in an estimated **170,000** deaths per year in Europe¹



Financial strain

People with HE **often require frequent and lengthy hospitalisation**²



HE affects up to 40% of people with advanced chronic liver disease, suggesting that as many as **200,000** people in the EU are likely to be affected by HE²



Up to **64%** of patients with HE will die within one year of diagnosis⁶



Liver disease patients with HE are **admitted to hospital three times more often** for illnesses directly related to their liver disease than patients without HE⁴



What can be done to improve care for people with HE?

ELPA calls on stakeholders to join our campaign and help ensure that people with advanced liver disease receive care of the highest possible quality. Here are suggestions of how stakeholders from different backgrounds can do their bit:

Politicians and policymakers:

- Work together with healthcare professionals, patients and carers to develop a standard of care for managing HE and apply it at a national level
- Make resources available to provide comprehensive training and education in the management of advanced liver disease for health professionals
- Ensure that healthcare professionals have the freedom to prescribe treatments that are most appropriate for individual patients

Healthcare professionals:

- Work with peers and their professional associations to develop simplified guidelines defining the best practice care and support for people with HE
- Ensure that they are confident in identifying symptoms suggestive of HE and taking appropriate action
- Provide their patients with easy-to-interpret information on HE and a point of contact who can offer advice and organise interventions at an early stage

Patient groups:

- Develop accessible and easy-to-interpret patient information and ensure its dissemination to people who might be at risk of HE, their carers and their families
- Survey their members to better identify what support patients and carers could benefit from
- Provide tools to campaign for better health services on HE

What barriers need to be overcome?

1. Stigma



People affected with advanced liver disease can encounter stigma arising from the false assumption that their condition is self-inflicted and a result of alcohol misuse. This stigma can prevent patients and their caregivers from accessing healthcare and support services. In order to enable European health systems to effectively identify, treat and support people with HE, public and health professional misconceptions need to be urgently addressed.

2. Late and inaccurate diagnosis



HE is characterised by relatively non-specific signs and symptoms such as personality changes, confusion, slurred speech, lethargy, trembling hands, poor co-ordination and bad breath. These symptoms are often subtle and may be incorrectly attributed to other causes. They can be easily missed, leading to late or inaccurate diagnosis. The problem of late and inaccurate diagnosis of HE is worsened by the fact that there is no agreed standard diagnostic test or procedure.

3. Freedom to prescribe



Liver disease can at times be under-prioritised by European health systems, leading to undue restrictions on prescribing appropriate treatments on the basis of cost. Real-world data from 295 patients treated in the UK reported that the introduction of appropriate treatment was associated with a significant decrease in one-year hospital admissions, duration of stay, and costs.⁵ In order to provide people with HE with optimal care and support, their clinicians must have the freedom to prescribe treatments which are most appropriate for the individual patient.

References

- 1 European association for the study of the liver, The burden of liver disease in Europe: A review of available epidemiological data, 2013
- 2 ELPA, Time to DeLiver: Getting a Grip on HE, 2015
- 3 Morgan, C.LI et al, Mortality associated with hepatic encephalopathy in patients with severe liver disease, International Liver Congress 2014, Abstract P452
- 4 Orr, J.G et al, Resource use associated with hepatic encephalopathy in patients with liver disease, International Liver Congress 2014, Abstract P478
- 5 Orr JG, et al. Liver Int. 2016; doi: 10.1111/liv.13111. [Epub ahead of print]
- 6 Jepsen P, et al, Clinical course of alcoholic liver cirrhosis: a Danish population-based cohort study, Hepatology, 51(5), 2010

Where can I find more information?

In 2015, ELPA published its Time to DeLiver: Getting a Grip on HE report, seeking to drive the change in the perception of HE and to improve the identification and management of the condition. The report can be accessed here: http://www.elpa-info.org/tl_files/elpa_news/elpa/2015/ELPA-Time-to-DeLiver-Getting-a-Grip-on-HE-Report.pdf

For more information about ELPA's campaign please contact: contact@elpa-info.org