

The burden of liver disease in Europe



The case of Hepatic Encephalopathy

Key facts and figures

The world is facing a veritable liver disease crisis.¹ More than **844 million** people worldwide suffer from chronic liver disease (CLD).²

With a mortality rate of **two million deaths per year**, liver disease is comparable to other major public health epidemics, such as diabetes and pulmonary diseases. Europe has the largest burden of liver disease worldwide.³ **500,000 EU citizens** are estimated to be living with **advanced chronic liver disease**.⁴

Hepatic encephalopathy (HE) is a serious complication of advanced chronic liver disease characterised by a loss of brain function, which occurs when the liver fails to remove sufficient toxins from the blood. As per the joint EASL and AASLD guidelines, **up to 80% of people with cirrhosis will develop minimal or covert symptoms of HE** during their clinical course, with up to **40% suffering from fully symptomatic overt HE**.⁵ HE equals increases in hospitalisations, healthcare costs and mortality.⁶ In Europe, HE is estimated to affect up to **200,000 people**.⁷ However, the exact incidence of HE remains unknown.⁹

Liver disease is comparable to other major public health epidemics

Liver disease²



844 million worldwide
2 million deaths

Pulmonary diseases²



650 million worldwide
6.17 million deaths

Diabetes²



422 million worldwide
1.6 million deaths

HE is a serious complication of advanced chronic liver disease...

...and is estimated to affect up to **200,000 people in Europe**⁷



ICD-11 code for HE

Since the *Time To DeLiver: Getting a grip on HE* report (2015), some progress has been made, notably the inclusion of HE under the forthcoming 11th revision of the World Health Organization's International Classification of Disease (ICD) code, known as ICD-11.

Next step: This milestone, if implemented in a timely manner, could support better diagnosis and treatment of HE by improving data on prevalence, cost and HE burden.



HE on the agenda of MEPs

Following ELPA's 2018 stakeholder engagement Round, a parliamentary question to the European Commission posed by Nessa Childers MEP, supported by other leading MEPs, focused on what is being to done to overcome the key challenges facing people with HE.

Next step: The answer from the European Commission reflects a growing recognition of HE as an area where further research and action is needed.

HE from the patient's perspective⁵

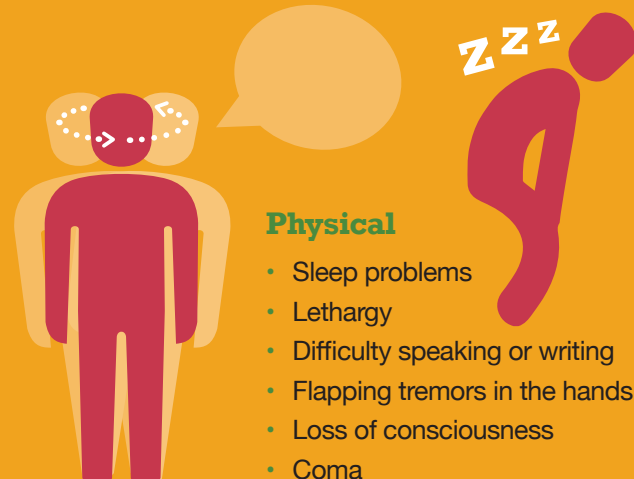
Mental

- Forgetfulness
- Reduced ability to concentrate
- Disorientation and confusion
- Personality change
- Hallucinations



Physical

- Sleep problems
- Lethargy
- Difficulty speaking or writing
- Flapping tremors in the hands
- Loss of consciousness
- Coma



Challenges still remain

Underdiagnosis and undertreatment, data gaps and unequal access to diagnosis and treatment are key issues when it comes to tackling HE, as per ELPA's new policy white paper on HE.



Key advocacy opportunities:

2019 European elections and the next EU legislative period: 2019-2024

Key problems and solutions

Underdiagnosis and undertreatment of HE



HE remains underdiagnosed and undertreated, resulting in poor quality of life for patients and their carers. The symptoms of HE are often subtle and easily missed, meaning that the condition is generally underdiagnosed. HE, and liver disorders more broadly, carry a heavy stigma owing to the false assumption of alcohol abuse, which stops patients seeking the help that they need.

Policy recommendations

- MEPs and patient organisations to support national HE awareness and education campaigns in order to raise awareness and dispel myths on HE among patients, policymakers, carers and medical professionals
- MEPs, patient organisations and medical societies to call for the systematic implementation of existing EASL guidelines in Europe

Closing the data gaps in HE



Limited data on the epidemiology, triggers, burden and treatment of HE continues to stunt the European community in measuring, benchmarking and improving outcomes for patients.

Policy recommendations

- MEPs, patient organisations and medical societies to support the timely implementation of ICD-11
- MEPs, patient organisations and medical societies to collaborate in the generation and sharing of robust data on HE, including on patient reported outcomes (perceived quality of life) and the burden of HE on patients, society and healthcare systems as well as employment and work issues

Ensuring better and equal access to treatment for HE



Available treatments for HE are effective, improve patient outcomes and reduce the burden of HE. The most important aspect of HE management is prompt recognition and immediate initiation of treatment, as progression of HE is often rapid. Many symptoms can be successfully managed if such measures are taken.

Policy recommendations

- MEPs and patient organisations to support the reform of value assessment methods and pricing and reimbursement systems to recognise the expected savings from HE treatments that can counteract the costs of care and hospitalisation across the care pathway
- MEPs and patient organisations to advocate for sufficient national and regional budgets to support the reimbursement of approved therapies for an optimal treatment duration for patients, treatment follow-up (including post diagnostic clinics), support and the funding of carers for people with HE