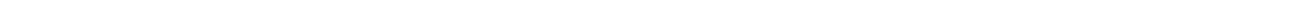




TIME TO DELIVER

Time to DeLiver: Getting a Grip on HE

October 2015



A message from ELPA President, **Tatjana Reic**

Hepatic encephalopathy (HE) is a debilitating condition that affects up to 40% of patients across Europe who suffer from advanced chronic liver disease.¹ Despite the severity of hepatic encephalopathy, it remains under-diagnosed and under-treated, resulting in poor quality of life for patients and their carers. To address this challenge, the Time to DeLiver campaign was formed with the aims of driving change in the perception of hepatic encephalopathy among the public, healthcare professionals, payers and policy makers, and to improve the identification and management of this debilitating condition. It is ELPA's hope that this will ultimately benefit both patients and carers, as well as healthcare systems and policy makers.

The objectives of our campaign are to ensure the specific inclusion of hepatic encephalopathy within public-facing information, to improve the provision of quality care for patients and to ensure the patient's voice is heard on a national and European level.

We hope you find the following report both interesting and impactful, and you will commit to working with us as we strive to develop strategies for overcoming the immense burden hepatic encephalopathy places on patients, their families and caregivers.

Yours sincerely,

Tatjana Reic

European Liver Patients Association (ELPA)
President



Executive Summary

Chronic advanced liver disease (often called cirrhosis) results from long-term injury to the liver with hepatic encephalopathy being a significant complication. Hepatic encephalopathy occurs in up to 40% of people with advanced chronic liver disease¹ and affects up to 200,000 people in Europe. What's more, hepatic encephalopathy is associated with a poor prognosis and large numbers of people will die from the condition. The symptoms of hepatic encephalopathy are often subtle and easily missed, meaning that the condition is generally under-diagnosed. Healthcare providers who are not specialists in liver disease may only occasionally encounter patients with advanced chronic liver disease or hepatic encephalopathy. Furthermore, they may not identify hepatic encephalopathy as a possible cause of symptoms.

Hepatic encephalopathy interferes with the way a person interacts socially, their sense of well-being and many report feeling stigmatised by their disease. This may lead to an unintentional barrier preventing patients and their caregivers accessing healthcare and support services. It is for this reason that this report makes a number of calls to action, including simplified guidelines which define what care and support for people with hepatic encephalopathy should look like. The guidance has to be easily applicable and useable in clinical practice by a range of healthcare professionals. Addressing these barriers would not only improve the lives of patients, but also those of their families and caregivers. Importantly, effective diagnosis and treatment of hepatic encephalopathy can improve outcomes by maintaining remission

and reducing the risk of hospitalisation. Guidelines from The European Association for the Study of the Liver (EASL) and the American Association for the Study of Liver Diseases (AASLD) underline the need for coordinated care, so that everyone involved can understand how best to manage hepatic encephalopathy in patients and prevent them being forced to stay in hospital unnecessarily. There are 10 calls to action in total in this report, ranging from a call on healthcare providers, policy makers and patient organisations to work together to properly assess the impact of hepatic encephalopathy on patients and others, to calling for comprehensive training and education to ensure healthcare professionals can identify the symptoms of hepatic encephalopathy and take appropriate action.



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What is Hepatic Encephalopathy?

Advanced Chronic Liver Disease

- Hepatic encephalopathy is a significant complication of advanced chronic liver disease¹ and occurs in up to 40% of patients² or as many as 200,000 people in Europe.
- Advanced chronic liver disease (cirrhosis) results from long-term injury to the liver.^{3,4}
- It has been suggested that 0.1%, or 500,000, EU citizens may be living with advanced chronic liver disease.⁵
- According to the UK General Practice Research Database (GPRD), the prevalence of advanced chronic liver disease in the UK almost doubled between 1992 and 2001 to 76.3 per 100,000 persons.⁶

Advanced chronic liver disease results in an estimated 170,000 deaths per year in Europe⁵

The most common causes of advanced chronic liver disease are alcohol-related liver disease and chronic infection with the hepatitis C or hepatitis B virus.^{7,8} Non-alcoholic related fatty liver disease (NAFLD)/ non-alcohol related steatohepatitis (NASH) is becoming a more common cause as it is associated with obesity.⁹ Other conditions that can lead to advanced chronic liver disease include primary biliary cholangitis (PBC), primary sclerosing cholangitis (PSC) and drug-induced liver injury.⁵

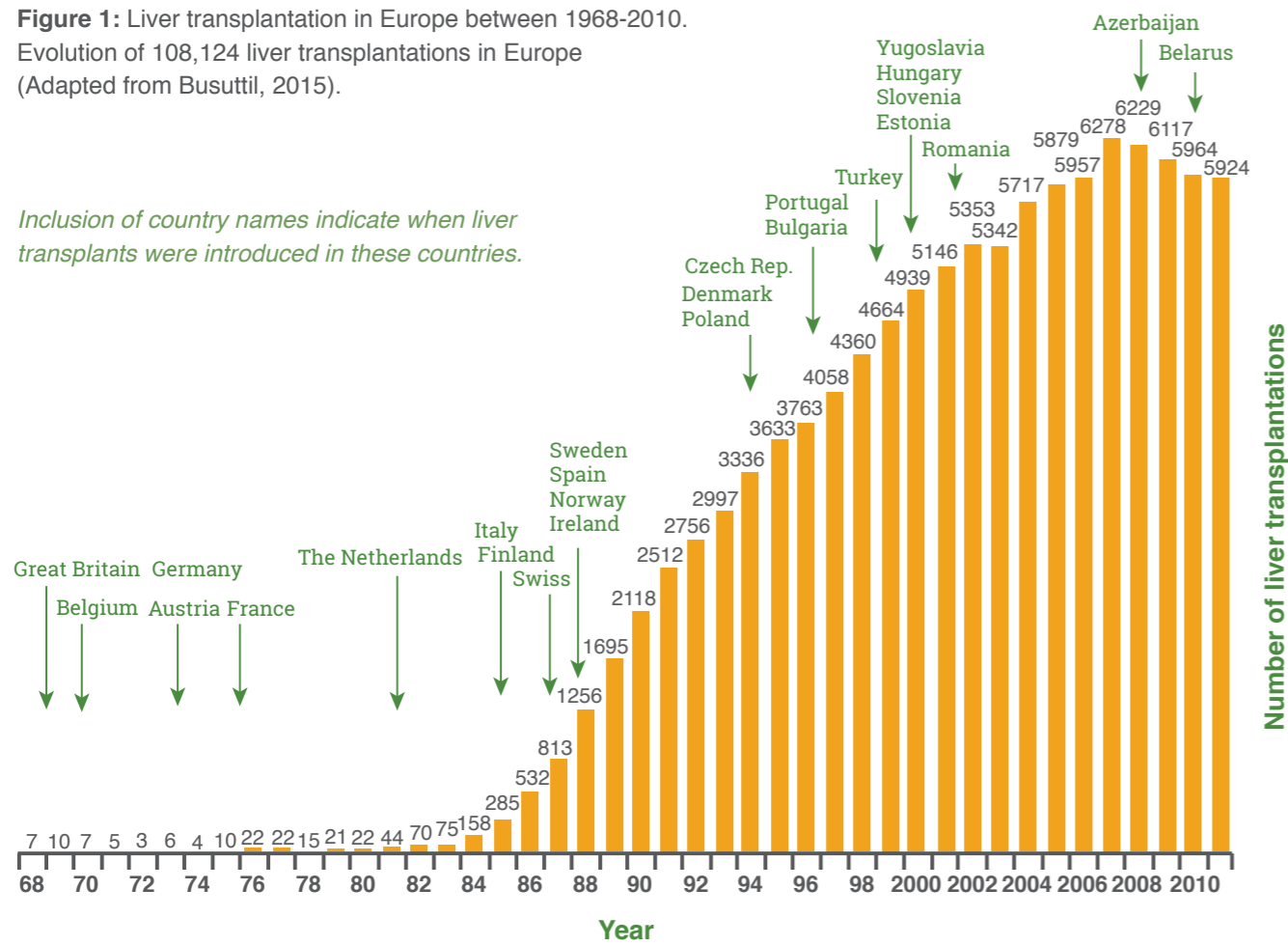
Patients with advanced chronic liver disease may not develop any noticeable symptoms until the damage to the liver is very advanced. This is referred to as compensated advanced chronic liver disease and can be managed with careful monitoring. Despite this, the only 'cure' for advanced chronic liver disease is transplantation, however each year in Europe only 6,000 transplants are performed (Figure 1, page 8).^{5,10} Given the substantial and increasing population with advanced chronic liver disease, the number of patients waiting for a liver transplant continues to increase, and the gap between those requiring transplantation and the number of livers available is growing.¹⁰

Patients with advanced chronic liver disease are also at risk of acute liver failure or liver cancer, both of which have low survival rates.^{3,4}

Continued...

Figure 1: Liver transplantation in Europe between 1968-2010. Evolution of 108,124 liver transplantations in Europe (Adapted from Busuttil, 2015).

Inclusion of country names indicate when liver transplants were introduced in these countries.



Hepatic Encephalopathy is a significant complication of Advanced Chronic Liver Disease

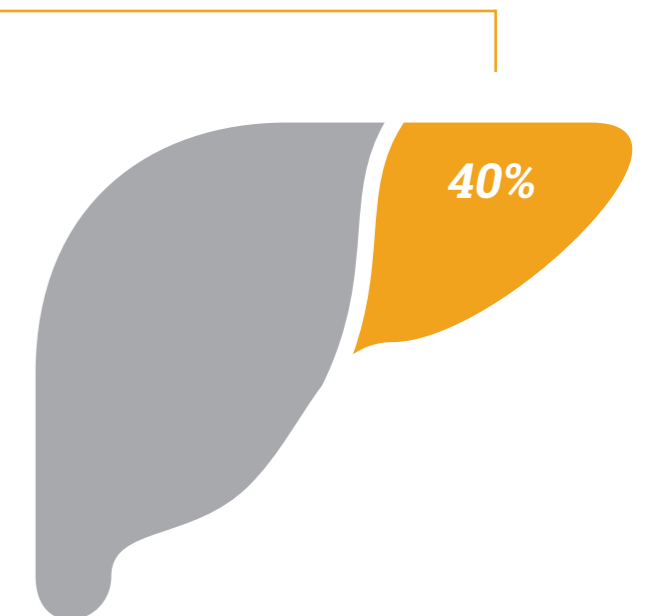
- Hepatic encephalopathy manifests as a wide spectrum of neurological and psychological abnormalities including personality changes, such as apathy and irritability, disorientation, inappropriate behaviour, confusion and asterix (flapping tremor in the hands). Furthermore, patients may have problems with their sleep/waking pattern.^{1,11}
- Cognition may also be affected, for example the ability to concentrate, undertake calculations, read or watch the television.^{1,11}

- In severe cases, patients can become agitated, suffer hallucinations and lose consciousness.³
- National hospital in-patient data from Portugal confirms that hepatic encephalopathy is an important cause of hospitalisation.¹² 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.¹³

Liver failure and portosystemic shunting (where circulating blood bypasses the liver) are required for the development of hepatic encephalopathy.¹⁴ This allows absorbed products that would otherwise be detoxified to enter the systemic circulation. As a result, excessive amounts of toxins including ammonia and bacterial products are able to reach the brain causing significant alterations in neuronal function.^{14,15}

Some, but not all, episodes of hepatic encephalopathy can be triggered by a number of factors, including, most commonly, infection, gastrointestinal bleeding, constipation and dehydration. Collectively these are known as precipitating factors.¹⁵

Up to 40% of advanced chronic liver disease patients (200,000 European citizens) develop hepatic encephalopathy during their disease course²



CASE STUDY

Tanya* is a 36-year-old professional and mother of an 11-year-old daughter.

Tanya was born with Biliary Atresia and underwent the Kasai operation (a procedure where blocked bile ducts and the gall bladder are removed and replaced with a small section of the small intestine) at six weeks old.

As a result, Tanya was later diagnosed with oesophageal varices, enlarged spleen, osteoporosis, irritable bowel syndrome, advanced chronic liver disease, and most recently, has been showing symptoms of hepatic encephalopathy.

She began experiencing changes in her general well-being, including feeling 'on edge' and extremely fatigued as her sleep patterns were disturbed. These symptoms slowly progressed and her ability to concentrate on simple day-to-day tasks became increasingly difficult as she became forgetful and confused by basic communication and tasks. Tanya found this period scary and frustrating as she felt her normal mental abilities and retention were diminishing.

Ultimately, these symptoms began to have an impact on both Tanya and her family. She was exhausted and frequently contracted bacterial and viral infections, which are more severe for liver disease patients. This situation resulted in increased prescriptions of antibiotics, time-off work and decreased ability to function as a mother and wife. Tanya's performance at work was also drastically impacted as she was arriving late and leaving early due to fatigue, resulting in her contracted hours being cut. Tanya's usually excellent attention to detail, her ability to provide solid business advice, and her understanding of new information all deteriorated, affecting her self-confidence and enthusiasm. Unfortunately during this time her daughter also suffered as Tanya was unable to care for her as well as usual.

Tanya recently started medical treatment for hepatic encephalopathy and after a few months, noticed a significant improvement in her physical and mental state. Her sleeping patterns have gradually returned to normal and her ability to understand and carry out daily tasks has improved, resulting in increased motivation and an improved work-life balance. Most importantly, Tanya has managed to repair and strengthen her relationships with her family.

**Tanya's real name has been omitted at her request.*



SECTION 2

The stigma of Hepatic Encephalopathy and Advanced Chronic Liver Disease

- Many patients with advanced chronic liver disease report feeling stigmatised by their disease. In one survey, 89% indicated they felt stigmatised in at least one aspect of their lives.¹⁶
- Patients with higher levels of perceived stigma had less social support, were less likely to seek medical care, suffered higher rates of depression and had a worse quality of life.¹⁶
- Hepatic encephalopathy interferes with patients' functioning, social interaction and sense of well-being.¹⁷ Caregivers also report effects on their ability to work, feeling a sense of entrapment and suffering poor personal health.¹⁸
- Data from the USA confirm the negative effect of hepatic encephalopathy on employment and income.¹⁸ There is no comparable European data.

Isolation and stigma add to the impact of hepatic encephalopathy on the quality of life of both the patient and their family and/or caregiver^{14,17,18}

Feelings of isolation and stigma result in part from public misunderstanding about hepatic encephalopathy and advanced chronic liver disease. In addition, both the public and some healthcare professionals may make judgements based on perceptions and past experience. This can lead to an unintentional barrier preventing patients and their caregivers accessing healthcare and support services. In turn, this is one of the underlying causes of low rates of diagnosis and effective treatment experienced by many patients and their families. Addressing these barriers will not only improve individual patient's lives, but also those of their family and caregivers.



Calls to action

- Healthcare professionals, patient associations and governments need to recognise and address potential barriers caused by the stigma associated with hepatic encephalopathy and advanced chronic liver disease.
- Local, national and the European government should work together to raise awareness of hepatic encephalopathy and advanced chronic liver disease in order to define patient-focused initiatives.

CASE STUDY

Charlie is a 47-year-old hotel owner.

Prior to receiving a diagnosis for primary biliary cirrhosis (an autoimmune disease), Charlie began exhibiting behavioural changes that his wife, Angie, was concerned may be the initial symptoms of dementia. He was increasingly impatient and quite easily confused and often complained of feeling tired and lethargic.



Charlie became increasingly difficult to live with as he was argumentative, unwilling to talk to the hotel guests and struggled with daily activities and processes, such as the hotel's reservation system. Following a diagnosis from his GP of liver problems, Charlie was referred to see a hospital consultant in a specialist liver unit. The initial diagnosis did not refer to hepatic encephalopathy, despite his GP noting his dementia-like symptoms on his medical records. While waiting for this referral appointment, Charlie's symptoms worsened and he became increasingly aggressive and confused. Through internet research, Angie found out about hepatic encephalopathy, however Charlie's GP maintained that his symptoms were a reaction to the diagnosis of liver problems.

Eventually Charlie was diagnosed with primary biliary cirrhosis, prescribed therapy for his severe hepatic encephalopathy and placed on the liver transplant waiting list. Unfortunately whilst awaiting a transplant, Charlie suffered a fall and was admitted to hospital where he became extremely agitated and upset forcing the hospital staff to call security and eventually the police. As a result of this incident, Charlie was summoned to appear in court and despite supportive letters from his liver specialist, the Community Health Council and patient associations the case was not dropped until after Charlie's transplant.

Fortunately, Charlie received a liver transplant nine months ago and although his symptoms worsened immediately after, his quality of life has since significantly improved. However, both Charlie and Angie have noticed that he still gets confused and sometimes struggles with daily tasks and communication.

SECTION 3

The true burden of Hepatic Encephalopathy: A hidden complication of Advanced Chronic Liver Disease

- Symptomatic hepatic encephalopathy is a common complication of advanced chronic liver disease. Approximately 10% of patients have hepatic encephalopathy upon diagnosis with advanced chronic liver disease.^{19,20}
- In addition, up to 40% of patients are thought to develop hepatic encephalopathy during their disease course.²
- European data estimate that approximately 0.1% of the European population have advanced chronic liver disease,⁵ therefore it can be suggested that up to 200,000 patients will suffer with hepatic encephalopathy at some point.

An important gap in our understanding of hepatic encephalopathy and a barrier to fully appreciating the impact it has on patients and healthcare systems, is the relative lack of European data reporting on the epidemiology of hepatic encephalopathy or resulting hospital admissions. As a result, hepatic encephalopathy can be considered a hidden complication of advanced chronic liver disease.

A UK-based hepatic encephalopathy patient survey commissioned in 2014 by the British Liver Trust and Liver4Life (supported by Norgine), found that half of the respondents had been hospitalised, or seen their loved one hospitalised due to a hepatic encephalopathy episode. A third of patients had been hospitalised on more than one occasion, some more than six times in one year. On average, 70% of patients spent up to 10 days in hospital, although some (12%) patients were in hospital for a month or more.^{21,22}

One in three patients are hospitalised with hepatic encephalopathy on more than one occasion, some even more than six times in one year²¹



Continued...

Common symptoms described by 80% of patients include irregular sleep patterns, forgetfulness and poor concentration. More than half of the respondents reported personality or mood changes, difficulty speaking or writing, and memory loss.^{21,22}

"These findings really drive home the crushing impact of hepatic encephalopathy on patients, families and the healthcare system. The results tell us that we have to get better at detecting and diagnosing the disease, and managing and preventing further episodes, which we can do through better awareness and treatment."

- Dr Richard Aspinall, consultant hepatologist, Trustee and medical advisor to Liver4Life.

An important barrier to the collection of this information is the lack of a specific International Classification of Diseases (ICD) code for hepatic encephalopathy. The ICD code is a diagnostic tool used to monitor the incidence and prevalence of diseases for health management and clinical purposes²³. Previously there was a specific code for hepatic encephalopathy and the re-introduction of this in the ICD-10 update would facilitate the measurement of prevalence, cost and disease burden.²⁴

All of the patients mentioned in this report experienced symptoms that significantly affected their day-to-day lives. They felt unable to cope, confused, fatigued and their families often described them as difficult to live with as they were not themselves.



Calls to action

- An ICD code for hepatic encephalopathy should be reintroduced as a priority into the ICD-10 revision to allow this information to be more easily collected and analysed.
- Healthcare providers, policy makers and patient organisations should work together to properly assess the impact of hepatic encephalopathy on patients, caregivers and healthcare resources.

CASE STUDY



Jane*, a 65-year-old mother and medical secretary.

Jane's husband, Tony, was frequently away for work so over many years she was regularly left to manage the household and her career. Over time, it was clear to Jane's family that she was not well. For example, she loved crosswords, yet eventually she could not even read the paper or magazines, let alone complete a crossword. Although Jane was being monitored by her gastroenterologist, her symptoms worsened over a two year period until eventually she was unable to follow television programmes, and Tony had to take on more of the day-to-day running of their home. In addition, Tony felt like Jane was becoming increasingly depressed.

Jane's symptoms eventually became so severe that she needed a walking stick and Tony frequently had to help her in and out of the bath and bed. When one day she became so ill that she was unable to walk, did not know where she was and became very upset; Tony called an ambulance. Jane was admitted to hospital where she became even more confused, disorientated and suffered from hallucinations. Jane remained in hospital for an extended period, and while her symptoms did improve a little, she still did not receive a diagnosis until a doctor recognised the signs of cirrhosis and hepatic encephalopathy and referred her to a liver specialist.

After meeting the liver specialist, Jane was diagnosed with hepatic encephalopathy and prescribed medical treatment. She is now feeling much more herself and her symptoms have improved. She is able to watch television, read magazines, help with some household tasks and she has even taken up yoga.

**Jane's real name has been omitted at her request.*

Delays in identifying patients with Hepatic Encephalopathy: Impact on patient outcomes

- Hepatic encephalopathy is characterised by relatively non-specific signs and symptoms such as personality changes, sleep disorders, confusion, depression, slurred speech, lethargy, trembling hands, poor co-ordination and bad breath. These symptoms are often subtle and easily missed, meaning that the condition is generally under-diagnosed. There are also other causes of similar symptoms that may present in patients with advanced chronic liver disease.^{1,11,14}
- In addition to feelings of isolation and stigma that can result in patients not seeking health or social support services, patients may also experience barriers to receiving a diagnosis.
- Healthcare providers who are not specialists in liver disease may only infrequently encounter patients with advanced chronic liver disease or hepatic encephalopathy, and may not identify hepatic encephalopathy as a possible cause of symptoms.
- A number of techniques and tests are used to diagnose hepatic encephalopathy, many of which require expertise in administration or interpretation.^{1,14,15} However, there is a lack of an agreed standard diagnostic test or procedure.¹⁴

Hepatic encephalopathy is associated with significant morbidity and mortality^{20,25,26}

The correct diagnosis of Hepatic Encephalopathy is essential

Hepatic encephalopathy is associated with a poor prognosis, and significant morbidity and mortality (between 50% and 64% of patients die within one year of diagnosis), which may be improved with more effective treatment.^{20,25,26} In addition, a prior episode of hepatic encephalopathy is associated with an increased risk of subsequent episodes.^{2,26} In one study, around half of patients with at least one prior hepatic encephalopathy episode suffered recurrence within one year, despite being treated with lactulose.²⁷ In another study, 46% of those patients with at least two prior episodes (most of whom were taking lactulose) suffered recurrence within six months.²⁸ Given these data it is perhaps not surprising that patients are frequently readmitted for repeat hepatic encephalopathy episodes.^{21,27,28}

Adequate diagnosis and treatment of hepatic encephalopathy can improve outcomes by maintaining remission and reducing the risk of hospitalisation.²⁸

Continued...

All of the patients described in our case studies have experienced significant delays in their diagnosis of hepatic encephalopathy. For Charlie, this had devastating consequences resulting in him being arrested while in the local hospital Emergency Department. Another patient was hospitalised and was unconscious for several weeks.



Calls to action

- Healthcare providers with an interest in hepatic encephalopathy should use any opportunity to raise the profile of the condition amongst their peers and in professional organisations.
- Patients, and in particular, carers should be made aware of the signs and symptoms of hepatic encephalopathy and its common causes. The Hepatic Encephalopathy patient information publication (available at: www.britishlivertrust.org.uk/liver-information/liver-conditions/hepatic-encephalopathy/), for example, provides useful information for patients, families and carers.
- Patients and carers should have access to an informed point of contact who can provide advice and organise interventions at an early stage.
- All healthcare professionals should be capable of identifying symptoms suggestive of hepatic encephalopathy and taking appropriate action. Comprehensive training and education should be provided to ensure this is possible.
- There is a need for short and simplified guidelines defining the best practice care and support for people with hepatic encephalopathy, which is easily applicable and useable in clinical practice by a range of healthcare providers.
- Policy makers should work together with healthcare professionals, patients and carers to develop a best practice/standard of care for managing hepatic encephalopathy and apply it at a national level.

CASE STUDY

Sheila, 57-year-old with non-alcohol-related fatty liver disease.

Sheila has long-standing type 2 diabetes and for 20 years she did not feel herself and was eventually diagnosed by her GP as suffering from depression.

During this time, her symptoms worsened and Sheila's daughters and grandchildren felt they had lost her. Her husband, Steve, dreaded phone calls from home while he was at work and became increasingly frustrated by her behaviour - she could no longer manage routine daily tasks and was very forgetful.

Eventually, Sheila's symptoms dramatically worsened and she was admitted to hospital. Whilst there, Sheila slipped into unconsciousness and the staff were concerned that she would not recover. After several weeks, Sheila regained consciousness but started suffering frightening hallucinations. It was during the recovery from this episode that Sheila was diagnosed with non-alcohol-related fatty liver disease, which had progressed to liver cirrhosis, and the cause of her symptoms became clear. Her specialist told her that her liver function had been abnormal for 10 years and her misdiagnosis of depression was in fact unidentified hepatic encephalopathy. Sheila continued to suffer post-diagnosis, experiencing difficulties with everyday tasks and requiring home visits from carers.

Sheila was fortunate to receive a liver transplant and has since almost returned to her normal self. She now plays an active role in running local patient groups for people with advanced liver disease and says her experience helps her understand the fear that others feel about losing themselves to hepatic encephalopathy.



SECTION 5

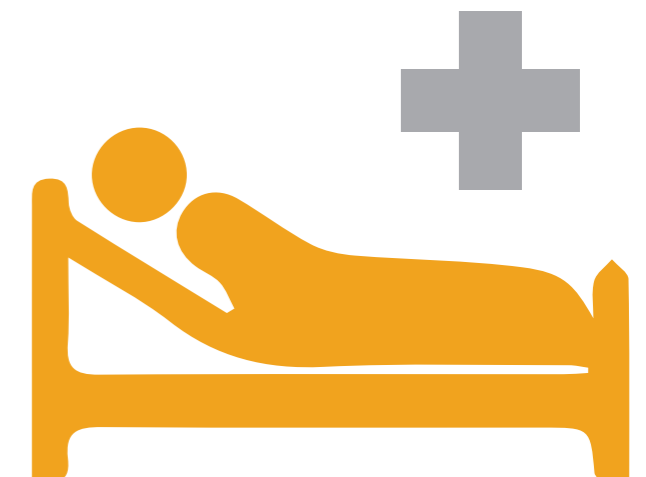
Ensuring access to therapies for Hepatic Encephalopathy

- Substantial direct costs are attributable to hospitalisations for hepatic encephalopathy, in addition to indirect costs.¹
- Long hospital stays for these patients increase resource utilisation.¹
- European prevalence data for hospitalisations due to hepatic encephalopathy are currently unknown, however they are likely to be consistent with USA figures where approximately 110,000 hospitalisations each year are due to hepatic encephalopathy.¹
- 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.¹³

Treatments for hepatic encephalopathy are available which improve patient outcomes (Figure 2).^{1,27,28} The most important aspect of hepatic encephalopathy management is prompt recognition and treatment of precipitating factors; many patients can be successfully managed with correction of the precipitating factor.^{1,15} Unfortunately, not all treatments are available and/or reimbursed in all European countries.

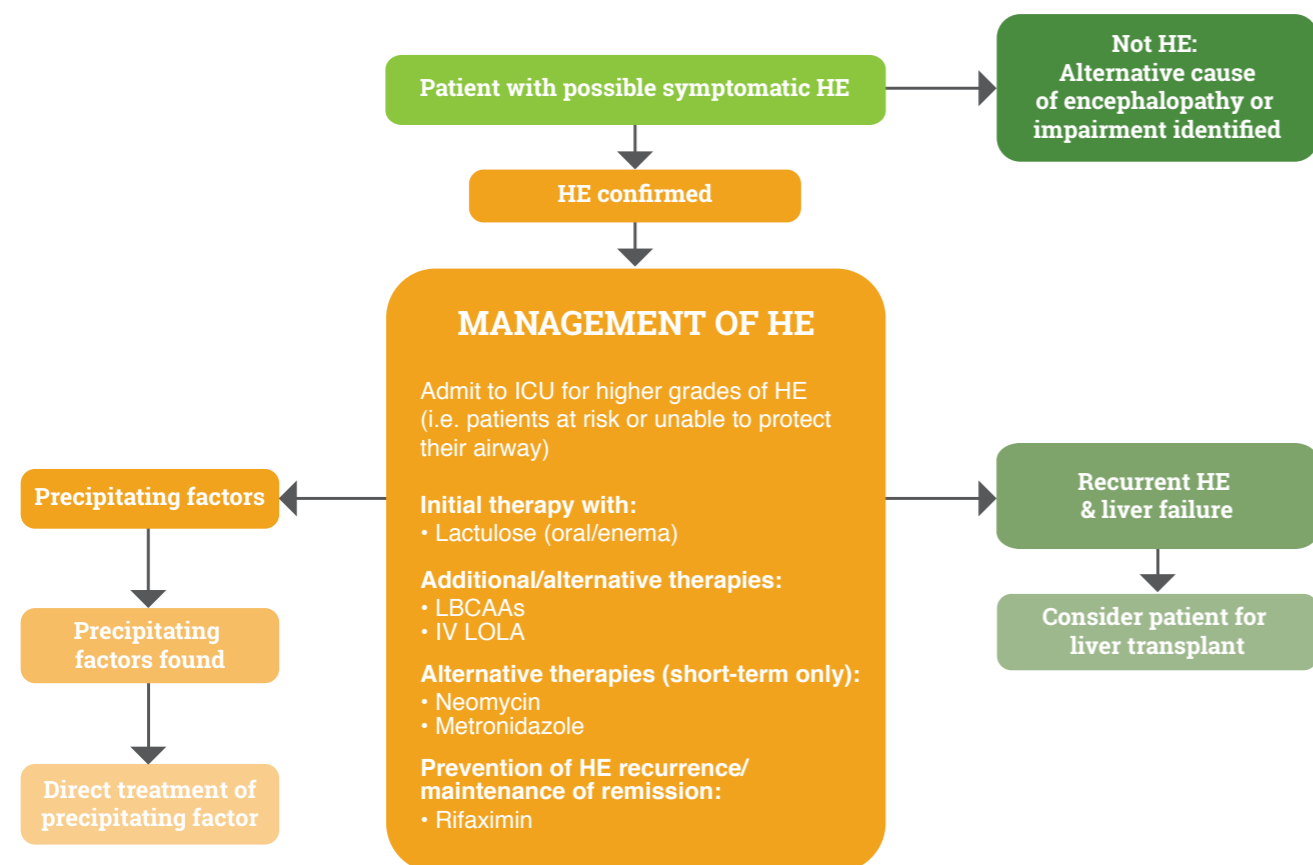
After initial delays in diagnosis, Tanya and Jane responded well to treatment and have noticed real changes in their day-to-day lives. After receiving her liver transplant, Sheila is almost back to her original self.

Treatment options for hepatic encephalopathy are available which reduce the risk of recurrence and subsequent hospitalisation^{1,27,28}



Continued...

Figure 2: Recommended treatment pathway for symptomatic hepatic encephalopathy (EASL/AASLD, 2014)
 BCCAs, branched-chain amino acids; hepatic encephalopathy; ICU, intensive care unit; IV LOLA, intravenous L-ornithine L-aspartate



! Calls to action

- Healthcare professionals should have the freedom to prescribe treatments to improve the quality of life of their patients with hepatic encephalopathy through a flexible approach to suit individual patients.
- Reimbursement for approved therapies is a priority to allow individualised care and support, and to remove any financial barriers to accessing these treatments.

Integrating multi-disciplinary care: An opportunity to improve patient experience

- Advanced chronic liver disease patients and their carers/family are frequently not part of an integrated, multi-disciplinary care team.²⁹
- Patients who eventually manage to see a liver specialist often receive fragmented care that is inadequately coordinated.²⁹
- Fragmented care generally occurs between inpatient and outpatient settings, primary care providers and liver specialists.²⁹
- The EASL/AASLD guidelines (2014) underline the need for a close liaison between the patient's family, the general practitioner and other caregivers in the primary health service.¹

Advanced chronic liver disease patients and their carers/family are frequently not part of an integrated, multi-disciplinary care team²⁹

A survey commissioned by the British Liver Trust of liver services in Scotland identified a general lack of liver specialists, which may adversely affect management of liver disease. Furthermore, there was a lack of on-site facilities or clear referral pathways to deal with emergency bleeding varices, which represents a major clinical risk.³⁰

A more coordinated care approach increases patient attendance at outpatient centres and quality of care, compared with advanced chronic liver disease patients who do not receive appropriate care management.³¹

The EASL/AASLD guidelines underline the need for a close liaison between the patient's family, the general practitioner, and other caregivers in the primary health service, so that all parties involved understand how best to manage hepatic encephalopathy and prevent recurrent hospitalisations.¹

! Calls to action

- Liver patient organisations should survey their members to better identify what support patients and carers would like/benefit from, and then either provide them or campaign for health services to provide them accordingly.
- Healthcare providers should identify how to improve care pathways for hepatic encephalopathy through joint working and a shared voice scheme.



Getting a Grip on HE: Calls to action

- 1.** Healthcare professionals, patient associations and governments need to recognise and address potential barriers caused by the stigma associated with advanced chronic liver disease and to raise awareness of advanced chronic liver disease and hepatic encephalopathy among the general public and healthcare professionals.
- 2.** Healthcare providers, policy makers and patient organisations should work together to properly assess the impact of hepatic encephalopathy on patients and caregivers, and on healthcare resources. We call for the ICD-10 revision to re-instate the code for hepatic encephalopathy to facilitate this.
- 3.** Patients, and in particular, carers, should be made aware of the signs and symptoms of hepatic encephalopathy and its common precipitants. The Hepatic Encephalopathy patient information publication (available at: www.britishlivertrust.org.uk/liver-information/liver-conditions/hepatic-encephalopathy/), for example, provides useful information for patients, families and carers.
- 4.** Patients and carers must have access to an informed point of contact who can provide advice and organise interventions at an early stage.
- 5.** All healthcare professionals should be capable of identifying symptoms suggestive of hepatic encephalopathy and taking appropriate action. We call for comprehensive training and education to be provided to ensure this is possible.



Getting a Grip on HE: Calls to action

- 6.** There is a need for short simplified guidelines defining the best practice care and support for people with hepatic encephalopathy, which is easily applicable and usable in clinical practice by a range of healthcare professionals.
- 7.** Healthcare professionals should have the freedom to prescribe treatments to improve the quality of life of their patients with hepatic encephalopathy through a flexible approach to suit individual patients.
- 8.** Reimbursement for approved therapies is a priority to allow individualised care and support and to remove any financial barriers to accessing these treatments.
- 9.** Liver patient organisations should survey their members to better identify what support patients and carers would like/benefit from and then either provide them or campaign for health services to provide them accordingly. Healthcare providers should identify how to improve care pathways for hepatic encephalopathy through joint working and a shared voice scheme.
- 10.** Policy makers should work together with healthcare professionals, patients and carers to develop a best practice/standard of care for managing hepatic encephalopathy and apply at a national level.

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