

Nurses are increasingly likely to encounter patients with advanced liver disease and have a vital role in improving end-of-life care for this group

LIVER DISEASE: PART 1 OF 2

Nursing care for end-stage liver disease

In this article...

► Why mortality from liver disease is increasing

► Case history of end-stage liver disease

► Role of the nurse

5 key points

1 Liver disease is the fifth most common cause of mortality in England and Wales

2 The average age of death from liver disease is 59 – much younger than other causes of death nationally

3 The most common causes of liver disease – obesity, undiagnosed viral infection with hepatitis B or C, and harmful drinking – are avoidable

4 70% of people with end-stage liver disease die in hospital, compared with 55% of the general population

5 End-stage liver disease involves gradual decline, punctuated with episodes of acute deterioration and some recovery

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Abstract Clements A, Greenslade L (2014) Liver disease 1: Nursing care for end-stage liver disease. *Nursing Times*; 110: 29, 16-19. Nurses are seeing more and more patients with liver disease, many of whom are under 65. Most common causes are avoidable and, as liver disease may take up to 30 years to develop, identifying those at risk is key. Patients with liver disease often have a fluctuating course of complications that needs a team approach to care. Improving end-of-life care can also reduce the number of these patients who die in hospital. This article, the first in a two-part series, explores some common complications of liver disease and best practice for nurses treating patients with end-stage liver disease.

Liver disease is the fifth major cause of mortality in England and Wales, and one of the few causes of premature death that is increasing (Fig 1), yet the most common causes – obesity, undiagnosed viral infection with hepatitis B and C, and harmful drinking – are avoidable. Rates of chronic liver disease (CLD) and cirrhosis in people aged under 65 years have increased by around 20% over the last 10 years in the UK, but many European countries have seen cases of CLD fall in the same period (Davies, 2012).

As there is no national strategy to improve the detection and treatment of liver disease, the All-Party Parliamentary

Hepatology Group (2014) has recommended 20 actions to do this. The National Confidential Enquiry into Patient Outcome and Death's (2013) report on hospital deaths from alcohol-related liver disease revealed a wide range of missed opportunities when caring for these patients:

- » Death was considered avoidable in 10% of the cases reviewed;
- » Care was rated as less than good in more than half of patients admitted.

Nurses from all areas of practice must be able to offer health information and education to patients to raise awareness of liver disease and promote healthy-living strategies. As the mortality and morbidity associated with CLD and cirrhosis increase, nurses need to develop their knowledge and skills in caring for people who have advanced liver disease. The Royal College of Nursing has developed a competency framework for caring for people with liver disease (RCN, 2013).

Table 1 lists common causes of liver disease, and some of the tests and investigations used to confirm its presence (British Liver Trust, 2007). Ultrasound imaging may be used to assess the size and shape of the liver and surrounding organs, detect the presence of ascites, observe the direction of blood flow through the portal vein and detect focal abnormalities indicative of hepatocellular carcinoma. More imaging with computerised tomography or magnetic resonance imaging may be required.

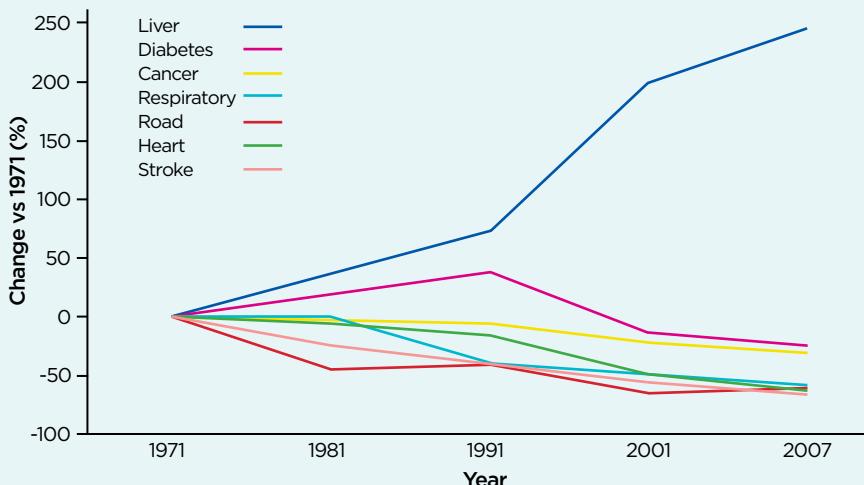
Non-alcohol related steatohepatitis (NASH)

NASH is the accumulation of fat – mainly triglyceride, cholesterol and phospholipids



Liver disease is a leading cause of death but the risk of developing it can be minimised

FIG 1. DEATHS PER MILLION OF POPULATION



Source: Office for National Statistics (2008)

– over 5-10% of liver weight. The term “non-alcohol related fatty liver disease” was introduced to explain the varying degree of severity of liver fibrosis in patients not exposed to alcohol. NASH is the more severe form and can progress over years to cirrhosis; it now accounts for 10-20% of all cases of cirrhosis (Dooley et al, 2011). NASH is part of a metabolic syndrome that includes obesity (although not all patients are obese), diabetes mellitus, hypertension and cardiovascular disease; these comorbidities may complicate care.

Treatment of NASH is aimed at weight loss and dietary intake, tight control of blood glucose in patients with diabetes, and management of hyperlipidaemia and hypertension. A multiprofessional team approach, with dietitians, diabetes specialist nurses and NASH pathways between primary and secondary care, optimises treatment outcomes.

End-stage liver disease (ELD)

Liver cirrhosis occurs as a result of any CLD. Repeated damage to the hepatocytes results in the development of fibrosis and nodular tissue. This alters the liver’s cellular structure, impedes function and affects the blood flow in and around the liver, leading to portal hypertension. Once cirrhosis has developed, it is usually irreversible and can lead to liver failure (Sargent, 2006).

The liver is a vital organ with many functions including: metabolising carbohydrates, fats and bilirubin; storing glycogen; and cleansing blood. The cirrhotic liver may be able to function adequately – termed a “compensated” liver – but once the functions start to deteriorate and complications of portal hypertension arise, it is “decompensated” and the patient has ELD.

Common presentations of decompensated cirrhosis are:

- » Jaundice (icterus);
- » Ascites;
- » Hepatic encephalopathy;
- » Variceal bleeding;
- » Sepsis, including spontaneous bacterial peritonitis, septicaemia, chest infection, urinary tract infection;
- » Lethargy or weakness;
- » Anaemia and chronic gastrointestinal blood loss;
- » Nausea and vomiting;
- » Pruritis (itching);
- » Malnutrition; and
- » Peripheral muscle loss.

Complications of ELD

Common complications of ELD include those experienced by Ms Brown (Box 1), such as ascites, hepatic encephalopathy, variceal bleeding and malnutrition.

Ascites

Ascites is fluid that collects in the peritoneal cavity. Many factors are involved in its development including increased pressure in the portal venous system resulting from cellular and blood-vessel changes in the cirrhotic liver (European Association for the Study of the Liver, 2010). Ascites occurs in 60% of patients with compensated cirrhosis within a 10-year period (EASL, 2010); it can cause abdominal discomfort, breathlessness and restricted mobility due to the large volume of fluid collected.

Initial treatment of ascites in patients with normal renal function is to use potassium-sparing diuretics such as spironolactone. Patients are encouraged to cut their sodium intake (not adding salt at the table or in cooking, and avoiding high-salt foods), and may need support with this. Spironolactone may be used with furosemide (Dooley et al, 2011). Renal and weight monitoring is vital to ensure symptom relief and early detection of diuretic side-effects such as electrolyte imbalance and dehydration.

In 10-15% of patients, ascites does not respond to diuretic therapy; these patients may need paracentesis (a drainage catheter is inserted into the peritoneal cavity). This may be required regularly and carries risks of infection, pain and bleeding. Patients who need regular paracentesis may be considered for transjugular intrahepatic porto-systemic shunt and stent (TIPSS), in which a stent is placed into the cirrhotic liver to facilitate portal blood returning to systemic circulation. However, TIPSS is contraindicated in patients who have developed hepatic encephalopathy (EASL, 2010).

Hepatic encephalopathy (HE)

HE is a complex and potentially reversible neuropsychiatric syndrome seen in patients

TABLE 1. TESTS FOR LIVER DISEASE

Alcohol-related liver disease	History/liver-function tests
Auto-immune hepatitis	Tests for autoantibodies such as anti-nuclear antibody and anti-smooth muscle antibody
Haemochromatosis	HFE gene analysis
Hepatitis A	Antibody test
Hepatitis B	Antibody, antigen tests/hepatitis B DNA
Hepatitis C	Antibody test/hepatitis C ribonucleic acid
Fatty liver disease, non-alcohol related fatty liver disease, NASH	History/liver-function tests, body mass index/ultrasound scan, liver biopsy
Primary biliary cirrhosis	Anti-mitochondrial antibody
Primary sclerosing cholangitis	Biopsy/bile-duct imaging (endoscopy)
Wilson's disease	Genetic analysis/copper studies, eye examination

HFE = haemochromatosis. NASH = non-alcohol related steatohepatitis. Source: British Liver Trust (2007)

BOX 1. CASE STUDY

Queenie Brown,* aged 58, requires abdominal paracentesis for diuretic-resistant ascites every 10 days. Diagnosed with non-alcohol related steatohepatitis cirrhosis, she was initially referred to the hepatology clinic for review of abdominal distension, fluctuating confusion and general physical deterioration. She is unsure how long she has "not felt herself", but is aware she cannot read the paper like she used to and that she often falls asleep during the day and wakes at night. She feels her memory is poor, and often forgets to take her tablets or eat regularly. She feels very tired and lacks motivation to look after herself.

Ms Brown's medical history is of type 2 diabetes, hypertension and hyperlipidaemia. She attends the GP practice "only if they call me in". Her current medications are metformin, gliclazide, ramipril, aspirin 75mg and simvastatin. Her mother died in her early 60s; she also had diabetes and "had a heart attack". Having cared for her until she died, Ms Brown now lives alone. She has no children and has been unemployed for the last five years. She does not drink alcohol and smokes up to 20 cigarettes a day. Physical examination reveals the following:

- Peripheral muscle mass loss
- Spider naevi on anterior/posterior chest wall
- Palmar erythema
- Bruising on lower legs and arms
- Asterixis (liver flap)
- Distended and uncomfortable abdomen
- Swollen ankles and calves (peripheral oedema)
- Body mass index: 34 (obese)

*Name has been changed

with ELD. It may be episodic and is a result of the cirrhotic liver's inability to break down nitrogen-based substances that arise from the bacteria in the gut and cross the blood-brain barrier (Dooley et al, 2011). Several tools are used to assess HE, including the West-Haven scale (Ortiz et al, 2007).

There may be precipitating factors in patients with cirrhosis (Box 2), which need to be identified and treated accordingly, although in 20–30% of patients no precipitating cause is found (Dooley et al, 2011). HE negatively affects quality of life and can be distressing for patients and their families. It also affects decision-making processes, so mental capacity needs to be assessed regularly.

Treatment of HE aims to cut ammonia levels in the gastrointestinal tract, using aperients such as lactulose, which assist with evacuating bowel contents. However, it can be difficult for patients to manage this, and side-effects can reduce adherence. Patients are advised to titrate the aperient dose so they aim to have at least two soft, bulky stools a day without developing diarrhoea. Rifaximin, a minimally absorbed, broad-spectrum antibiotic has been effective at treating HE and reducing hospital admissions (Felicilda-Reynaldo, 2012).

Variceal bleeding

Another potentially life-threatening complication, variceal bleeding, is the

presenting feature in >25% of patients with cirrhosis. Hypertension in the portal venous system can lead to oesophageal, gastric and duodenal varices (abnormally dilated blood vessels), which can rupture, resulting in haemorrhage. Although hospital mortality rates linked to variceal bleeding have fallen, the mortality rate in patients with ELD is around 30% (Ginès et al, 2012). Control of bleeding is achieved in 95% of patients using endoscopic banding; TIPSS may also be considered to reduce portal hypertension, as described earlier (European Association for the Study of the Liver, 2010).

Malnutrition

Malnutrition is often seen in patients with the complications of liver disease and becomes more marked in those with ELD, where muscle loss is evident – even in patients who are obese. In patients like Ms Brown, our case study in Box 1, the discomfort associated with large-volume ascites often results in loss of appetite. The dietitian's role is vital: nutritional intervention can improve survival rates and quality of life (Iwasa et al, 2013). For patients such as Ms Brown who have developed decompensated cirrhosis, liver transplantation may be the only long-term treatment option. Outcomes after liver transplant have improved significantly, with a 68–77% five-year survival rate (NHS Blood and Transplant, 2014a).

Several prognostic scoring systems can be used to identify patients who may be considered for a liver transplant. The UK uses the United Kingdom Model for End-Stage Liver Disease (UKELD), a scoring system combining blood tests for bilirubin, INR, creatinine and serum sodium (Asrani and Kim, 2010); patients with NASH cirrhosis would need a UKELD of >49 to be considered for the liver-transplant waiting list (NHSBT, 2014b). However, these scoring models do not reflect other adverse factors such as quality of life and difficult-to-treat variceal bleeding (Dooley et al, 2011). There are guidelines regarding eligibility for, and contraindications to, liver transplantation complications (NHSBT, 2014b). Ms Brown was considered for a transplant but did not fulfil the criteria due to cardiovascular comorbidities, which suggested she would not survive the arduous surgical procedure and potential post-operative complications.

End-of-life care in liver disease

Murray et al (2005) outlined three distinct illness trajectories for people with progressive chronic illness:

- » Steady progression with a clear terminal phase, for example in cancer;
- » Gradual decline punctuated with episodes of acute deterioration and some recovery, with more sudden – seemingly unexpected – death, for example in end-stage organ failure;
- » Prolonged gradual decline, for example in older people who are frail or in those who have dementia.

The illness trajectory of patients with end-stage organ failure may be more erratic and less predictable than for those with cancer. An episode of deterioration may improve with treatment or lifestyle change; quality of life may also improve. This makes it difficult to explain to patients about their life expectancy (Cox-North et al, 2013).

The National End of Life Care Intelligence Network (2012) highlighted that most patients (>70%) dying from liver disease do so in hospital due to their complex needs, compared with only 55% of the general population. It also highlighted missed opportunities to identify people with advanced liver disease and consider end-of-life care planning. This has been reinforced by the VOICES survey of bereaved people and their experiences of a relative's death (DH, 2012). Survey responses in relation to liver disease reflected differences in care, and some respondents reported poor coordination of care.

The DH has outlined a six-step approach to improving the care of all



"Nurses need to develop the confidence to take on new roles"

Garry Swann p26

people who are dying, regardless of diagnosis. Each step has been reviewed and adapted for the care of people with advanced liver disease (Kendrick, 2013). This end-of-life care pathway aims to improve the quality of care for patients and support health professionals.

There are several tools health professionals can use to prompt discussions about end-of-life issues. The Supportive and Palliative Care Indicators Tool (Hight et al, 2013) was developed to help identify patients at risk of deteriorating and dying with specific disease profiles. For those with liver disease there are triggers that should prompt consideration of end-of-life discussions and planning (Hight et al, 2013); these include patients with advanced cirrhosis for whom liver transplant is contraindicated, and who have experienced one or more of the following complications in the last year:

- » Diuretic-resistant ascites;
- » HE;
- » Hepatorenal syndrome;
- » Spontaneous bacterial peritonitis;
- » Recurrent variceal bleeds.

A review of the national end-of-life strategy describes the "surprise question" – namely health professionals asking themselves: "Would I be surprised if this patient were to die within the next year (or three months, or six months)?" (DH, 2010). If the answer is "no", this is another prompt to introduce end-of-life care and planning to the patient.

Ms Brown is presenting with several of the triggers for consideration for end-of-life care. Resources are available to help nurses and healthcare staff improve their confidence and skills in discussing these issues with patients. NHS Improving Quality, NHS Choices and Dying Matters can provide information and advice to support Ms Brown in her decisions and choices about her future care (NHSIQ, 2014).

A comprehensive assessment is needed for Ms Brown to ensure she has the right support when discharged from hospital. She may need dietetic, occupational therapy and physiotherapy assessment, and referral to social services. She may also need a package of care to ensure she can remain independent in her home if she wishes. Her discharge plan from hospital must ensure there is a clear management plan for when her condition deteriorates; close liaison with her GP is also important. This may be the time to consider referral to community palliative care and the long-term conditions teams. Some hospices now offer day-case paracentesis for patients with diuretic-resistant ascites.

The end-of-life care pathway emphasises the importance of the coordination of care and delivery of high-quality care in different settings. Nurses can ensure patients are entered onto an electronic palliative care coordination system if available. Ms Brown can now be given information to help her state her wishes for her future care and advanced care planning (NHSIQ, 2014). Advanced care planning can consider preferred priorities of care, advance decisions to refuse certain treatments, and lasting power of attorney. Several checklists available from NHS North East can help you write emergency health plans or advance decisions, particularly as HE can result in fluctuating mental capacity (tinyurl.com/NE-endoflife).

Conclusion

Increasing numbers of patients with liver disease are presenting in general practice and emergency departments. It is important that nurses understand the common causes and complications of liver disease and, as well as the complexities of patient management, they should be aware of the need to improve end-of-life care for people with ELD. Nurses have a vital role in developing and promoting high-quality coordinated care for the increasing numbers of people with advanced liver disease.

- The second article in this series, published next week, reports on the development of a liver-disease competency framework for nurses in all clinical settings. NT

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BOX 2. PRECIPITANTS OF HEPATIC ENCEPHALOPATHY

- Gastrointestinal bleeding
- Sepsis
- Electrolyte imbalance:
 - Hyponatraemia
 - Hypokalaemia
- Dehydration:
 - Fluid restriction
 - Excessive diuresis
 - Paracentesis
 - Diarrhoea/vomiting
- Constipation
- Excess protein load
- Alcohol
- Central nervous system-active drugs
- Transjugular intrahepatic portal-systemic shunt
- Surgery

Adapted from Dooley et al (2011)

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