

Expert Report to the Infected Blood Inquiry: Palliative Care in Advanced Liver Disease

February 2022

The logo for the Infected Blood Inquiry, consisting of a white circle containing the text "Infected Blood Inquiry" in a sans-serif font.

Infected
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Explanatory Note

Please note that the question numbers below relate to the numbered questions in the Letter of Instruction which was sent to the Hepatitis (Palliative Care in Advanced Liver Disease) Expert Group by the Infected Blood Inquiry.

Question 9: Is there a role for palliative care in advanced liver disease, and if so, how does it relate to end-of-life care?

The burden of advanced liver disease in the UK

There has been a dramatic increase in deaths caused by liver disease in the United Kingdom over the past 50 years, with mortality rates increasing four-fold since 1970. In 2012 it was reported that 60,000 people in England and Wales had a diagnosis of cirrhosis, representing a 40% increase in the number of patients given this diagnosis over a 10-year period. Liver disease is the fifth commonest cause of death in the UK and is set to overtake ischaemic heart disease (heart problems caused by narrowed heart arteries) as the primary cause of death in people of working age over the next decade.¹ Liver transplantation represents the only cure for advanced liver disease. However, strict listing criteria and a shortage of donor organs mean transplantation is available to a minority of patients. Even among patients listed for transplantation, 17% will die waiting for an organ to become available.²

Advanced liver disease causes a heavy burden of physical and psychological symptoms. Common physical complications of advanced liver disease include ascites, jaundice, hepatic encephalopathy and gastrointestinal bleeding. Ascites refers to the build-up of fluid within the abdominal cavity, which often requires repeated drainage procedures to control. Jaundice presents as yellowing of the skin and eyes and can cause significant itch and discomfort. Hepatic encephalopathy represents a neuro-psychiatric syndrome caused by the inability of the liver to metabolise toxic substances, which in turn affect the brain. It can happen gradually or suddenly, and may lead to a spectrum of symptoms, from confusion, forgetfulness, mood and personality changes, to slurred speech, unusual movements of the body, sleepiness, and even coma. It can be extremely distressing both for patients and carers, and often makes care at home difficult. Increased liver stiffness causes the formation of collateral blood vessels around the liver known as varices. If these vessels rupture, patients can experience life-threatening gastro-intestinal bleeding. Advanced liver disease is also the primary risk factor in the development of liver cancer (hepatocellular carcinoma), a risk which is accentuated when the cause of liver disease is viral hepatitis.

Treating the complications of advanced liver disease often requires hospitalisation. Therefore, the trajectory of advanced liver disease is typically punctuated with increasingly frequent, prolonged and costly hospital admissions. The inpatient mortality from each admission with advanced liver disease is approximately 20%, and over 70% of deaths from advanced liver disease occur during an unplanned hospital admission.³

Symptoms of advanced liver disease extend beyond its direct complications. Data from SUPPORT, a large prospective study of 9,105 seriously ill patients admitted to five United States teaching hospitals between 1989 and 1994, demonstrated that pain among patients who died from liver disease was comparable to that experienced in lung or colonic cancer.⁴ A retrospective analysis of medical records from patients declined for liver transplantation demonstrated the high prevalence of both physical (65% pain, 58% nausea, 49% lack of appetite, 48% shortness of breath) and psychological (36% anxiety, 10% clinical depression) symptoms.⁵ A recent systematic review found the prevalence of severe physical and

psychological symptoms (e.g. pain, breathlessness, fatigue, depression) to be comparable or worse in advanced liver disease than other common malignant and non-malignant life limiting conditions, with onset at a significantly younger age.⁶ Frailty, recurrent falls, poor sleep, malnutrition, muscle cramps and cognitive impairment also contribute to poor health related quality of life.⁷

Further to this considerable burden of physical and psychological symptoms, patients with advanced liver disease often face an array of social and economic difficulties. While we recognise the Inquiry’s focus on liver disease associated with contaminated blood and blood products, on a national level, chronic liver disease is often associated with ongoing alcohol and drug misuse. Many patients do not have existing relationships with primary care, making access to specialist services circuitous.⁸ Societal associations between liver disease and alcohol and drug use contribute to high levels of stigma. This is reported by patients and carers regardless of the cause of their liver disease or the presence of addiction.⁹

The principles of palliative care

The World Health Organisation (WHO) defines palliative care as:

“an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”¹⁰

The WHO further defines a set of principles that constitute appropriate palliative care, which are outlined in figure 1. The 2002 definition was updated from a 1990 version to encompass patients with non-malignant disease and remove any requirements for the underlying disease to be “non-responsive” to curative therapy, thereby encouraging palliative care to be utilised at an earlier stage in the disease trajectory. In 2014, the World Health Assembly further acknowledged the importance of palliative care by including it in the definition of universal health coverage and recommending its integration into the treatment of patients with any life-limiting condition.¹¹

Figure 1 – Principles as outlined by the World Health Organisation

Palliative Care:

- Provides relief from pain and other distressing symptoms.
- Affirms life and regards dying as a normal process.
- Intends neither to hasten or postpone death.
- Integrates the psychological and spiritual aspects of patient care.
- Offers a support system to help patients live as actively as possible until death.
- Offers a support system to help the family cope during the patient’s illness and in their own bereavement.
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated.
- Will enhance quality of life and may also positively influence the course of illness.
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

The terms ‘palliative care’ and ‘end of life care’ are frequently used interchangeably, however they are not synonymous. End of life care refers to care provided for patients in whom death in the short to medium term is almost inevitable. Whilst inclusive of end-of-life care, palliative care can also be provided in parallel to curative treatments when the prognosis is uncertain. This is with the aim of addressing common physical and psychological symptoms, optimising quality of life, and allowing the patient and their loved ones to plan for the possibility of death, so called “parallel planning”. An example would be in the provision of palliative care for patients on a liver transplant waiting list, in whom there is a considerable risk of death and a high burden of physical and psychological symptoms – but where hope for an ultimately curative outcome is maintained.

Specialist palliative care was established as an independent medical specialty in the UK in 1987. Specialists in palliative care provide expertise in managing symptoms of advanced disease which are difficult to control, and work with patients who have complex care needs. As a relatively small specialty, it is not able to be involved in the care of all patients with life limiting illnesses – and needs to reserve its expertise for cases of particular complexity. The responsibility for the provision of good palliative care therefore extends to all health-care professionals managing life-limiting disease. It should therefore represent a core skill of clinicians managing advanced liver disease. Palliative care provided by non-specialists is referred to as ‘core’ or ‘generalist’ palliative care, and is referred to as core palliative care in this document.

The role of palliative care and end of life care in advanced liver disease

Palliative care interventions can benefit patients with advanced liver disease and their carers, as well as providing wider value to healthcare systems. Various models of care have demonstrated evidence of benefit across a variety of clinical and community settings.

A prospective evaluation of a palliative care intervention delivered in parallel to assessment for liver transplantation demonstrated an improvement in 50% of moderate to severe symptoms among study participants after 3 months, with 43% of participants also demonstrating improvements in mood. The intervention consisted of a single consultation with a palliative care specialist focussing specifically on physical symptoms, mood, social well-being, and spiritual care. Patients with a higher initial symptom burden showed the greatest improvements.¹² In an outpatient and community setting, models of nurse-led supportive care have also been shown to improve quality of life, and to be acceptable to/valued by patients and carers.¹³ For patients presenting to services at the point of critical illness, Intensive Care Unit (ICU) based palliative care interventions have been studied. An ICU based intervention consisting of family support, a discussion around prognosis and patient preference, and discussion of cardio-pulmonary resuscitation and do not attempt resuscitation orders was prospectively evaluated as compared with a control group. Patients receiving the intervention had earlier documentation of resuscitation status. The time between do not attempt resuscitation decisions and death was increased, thereby potentially increasing the period where loved ones were aware of the gravity of the clinical situation, possibly allowing them to say goodbye. There was a decreased length of ICU stay, and a shorter time to withdrawal of organ support. Importantly there was no difference in mortality between the groups.¹⁴

Recurrent, unplanned hospital admissions are commonplace in advanced liver disease. Avoidance of hospitalisation has been shown to be highly valued by patients and their carers.¹⁵ A large, population based, study in Canada demonstrated that palliative care intervention was associated with reductions in emergency department visits, hospital admissions and ICU admissions within the last 6 months of life, and increased the probability that a patient would die in their own home. The magnitude of these associations was accentuated in patients

with liver disease when compared with other diseases.¹⁶ A pilot randomised controlled trial demonstrated that early palliative care intervention among hospitalised patients with liver disease resulted in an increased time to hospital readmission and a higher number of days outside the hospital – again, without adversely impacting mortality.¹⁷

Despite evidence of benefit, patients with advanced liver disease seldom receive palliative care. A study of patients dying from liver disease at a UK transplant centre reported that only 19% of patients received palliative care, on average only 4 days before death,¹⁸ a finding which has been broadly replicated by similar studies in the US and Canada. Palliative care used only at the very end of life can mean that opportunities to control symptoms, reduce suffering, and involve individuals in decisions around their future care are missed. The latter point is of particular pertinence in advanced liver disease, given the potential for hepatic encephalopathy to mentally incapacitate patients as their disease progresses.

In summary, advanced liver disease is characterised by a multitude of distressing physical and psychological symptoms, poor quality of life, frequent hospital admissions and a high caregiver burden. Palliative care, delivered across a variety of settings, can help alleviate distress and is of demonstrable benefit to patients and carers. Despite a growing body of evidence supporting the integration of palliative care in the management of advanced liver disease, at present it is not routinely used in this patient group.

Question 10: What are the hallmarks of effective palliative care for advanced liver disease?

Quality indicators in palliative care

Access to palliative care for those who need it is recognised as a fundamental human right.¹⁹ Improved and cost-effective palliative and end-of-life care has been identified by the World Health Organisation as an international policy priority.²⁰ The importance of equitable access to high quality palliative care is underlined by the vast number of people this affects. It is estimated that between 50% and 89% of those who are dying require palliative care.²¹ There is evidence that the palliative care needs of the global population are set to increase.²²

Palliative care is considered to be a complex intervention. It is comprehensive, holistic care for those with a life-limiting illness, tailored to each individual's needs, rather than one specific treatment. It straddles a myriad of care environments, including hospital, community and hospice settings, and is delivered by multiple different teams representing both health and social care. As such, objectively measuring and evaluating the quality of palliative care delivery is difficult.

High level strategic policy should establish standards and promote improvements in aspects of life that impact on society as a whole. The quality of palliative care service provision is one such example, where formulating robust policy may promote improvements in the quality of care. In a recent UK study looking at healthcare policy documents, only a minority mentioned palliative or end of life care. Specifics on how to tackle variable access to the right care in the context of life-limiting illness were frequently lacking.²³

There are a number of core palliative care guidelines and frameworks advocated for use in the UK across all healthcare settings (NICE, Healthcare Improvement Scotland, Gold Standards Framework)^{24,25,26} which aim to uphold high standards of care for an individual with a life-limiting illness. Although a number of palliative and end of life care quality indicators have been developed, there is no strong evidence that these indicators reliably reflect good quality care.²⁷

Some common components of palliative care quality indicators are:

- comprehensive assessment of physical, psychological, social and spiritual needs
- assessment of caregiver needs
- anticipatory care planning, including discussing illness severity and end of life care preferences
- co-ordinating communication between service providers

The cost of providing palliative care

Funding and commissioning of palliative care services varies throughout the UK. Whilst in England it is overseen by Clinical Commissioning Groups and Local Authorities, in Scotland responsibility for funding sits with Integration Authorities. There is no universally adopted palliative care tariff or unit cost for palliative care. Alongside the difficulties in measuring quality of palliative care provision, it is also difficult to provide accurate information around the cost of such a complex intervention. People with a life-limiting illness frequently require the use of numerous different health and social care services across different settings as their health deteriorates. The existence of multiple information technology systems, that are frequently not connected, hampers straightforward data collection and analysis, and makes it challenging to draw any firm conclusions around expenditure and resource.

Published research has demonstrated changing patterns of healthcare service use by people in the terminal phase of their illness. Expenditure associated with this may start to give some information around the cost of care for patients with palliative care needs. Contacts with healthcare services typically escalate as terminal illness progresses. A recent Scottish study, found that 95% of people utilise unplanned care services in their last year of life, at a cost of £190 million.²⁸ Those with organ failure represented the largest group in this study population, but there was no specific information about expenditure in those with advanced liver disease.

Divergent methods exist to capture information about hospital admissions around the UK. This leads to difficulties in characterising the nature of care delivered, and therefore how to stratify costs. A national study exploring the cost of healthcare use in the last year of life, found that the mean cost of secondary (hospital) care was £10,134 per person.²⁹ However, this study excluded all people who died under the age of 60. Many people with liver disease are of working age, so may not be represented by these data. Much research examining the costs of caring for people who are dying focuses on healthcare expenditure, however it is more difficult to capture information about social care costs.³⁰ The projected cost of providing informal or unpaid care, particularly by family and others close to the individual, is often unaccounted for, however it has been estimated in one study to account for approximately 50% of total care costs, for any given individual.³¹

Without acceptable evidence-based outcome measures which accurately capture the quality of care an individual receives, it is extremely difficult to determine how much an optimum service model would cost.

Inequalities and palliative care

The quality of care delivered to people who are dying varies throughout the UK, although there is a paucity of research quantifying or describing this.

Socioeconomic factors appear to play a part. People from the most deprived areas in the UK are less likely to describe receiving sufficient support from health and social services to care for a loved one at home³² and the role of gender also appears to influence the experience of

carers. An American survey of carers in 2016³³ showed that more than 75% of all caregivers are women, and that they spend 50% more time in this role than men do. People who are LGBTQ+ may avoid or delay sharing their preferences for care at the end of life, due to past discrimination or stigmatisation.³⁴ People of Black, Asian, or Minority Ethnic background were less likely to describe their loved one's care in their last three months of life as "excellent".³⁵

There is a stark discrepancy between the proportion of patients with advanced liver disease who die in hospital (78%) as compared to patients with liver cancer (39%).³⁶ Given that over 90% of patients with liver cancer also have advanced liver disease, these groups are otherwise well matched. These data suggest that early conversations about priorities of care and preferred place of death may occur less frequently in patients with a non-malignant diagnosis.

Hallmarks of Effective Palliative Care in Advanced Liver Disease

Identifying Advanced Disease: Screening Tools

Given the uncertainty associated with the illness trajectory of a person with advanced liver disease, it may be difficult for clinicians to identify the appropriate time to initiate a conversation with a patient about the severity of their illness, and its implications. Mortality risk prediction tools such as the Model for End Stage Liver Disease scoring system (MELD),³⁷ or its UK equivalent (UKELD), are widely used by hepatologists to make decisions about eligibility for transplant assessment, and high scores often confer a poor prognosis. Further screening tools exist to help healthcare professionals identify patients with advanced liver disease who are likely to have a poor prognosis and who may benefit from palliative care, following an initial discussion ideally led by their specialist team.^{38, 39} The Gold Standards Framework is a widely used screening tool which identifies patients with a poor prognosis who may benefit from palliative care.⁴⁰ However, whilst it includes prognostic criteria for cardiac, pulmonary, renal and neurological disorders, criteria for liver disease are omitted.

Communicating Advanced Illness to Patient and Caregiver

Even before a person becomes more unwell due to their liver disease, evidence demonstrates that they and their carer appreciate having information about their illness so they are prepared if or when their health deteriorates.⁴¹ Research has shown that patients and carers consistently want more information about their disease and how to manage it.⁴² In a recent study of patients with advanced liver disease attending an outpatient setting, the most frequently chosen question from a 'question prompt list' was "what is my life expectancy".⁴³

In addition to what information patients and caregivers receive, it matters who delivers it. Patients and carers consistently report that they would rather be given this news by a healthcare professional they know, than an unfamiliar clinician.⁴⁴ This should ideally be a gastroenterologist or hepatologist who has a therapeutic relationship with the patient and those close to them.

Anticipatory Care Planning

Anticipatory care planning (ACP) is the term used to describe having conversations with patients and those close to them, about the future. It has been recommended that this is a core part of providing care for those with liver disease,⁴⁵ and that this happens even early on in their illness trajectory.⁴⁶

For those facing deteriorating health, it really matters to them that these conversations occur. It has been found that when these discussions happen in an open and honest way, it is far more likely that a patient is cared for as they wish to be, which in turn leads to increased satisfaction in their overall care.⁴⁷ In a study of patients with chronic obstructive pulmonary disease, when open conversations about the end of life occurred, patients were twice as likely to evaluate their care as the ‘best imaginable’.⁴⁸

Illness Trajectories

For patients with advanced liver disease, the need to know their prognosis is often accompanied by their wish to know what will happen with their health over a period of time, until they approach their final phase of life. This is sometimes referred to as their ‘illness trajectory’, and it has been suggested that a clinical team’s knowledge and understanding of this concept may improve their ability to meet a patient and carer’s holistic needs as they experience this.⁴⁹

People with advanced liver disease tend to experience repeated acute exacerbations over the course of months or years, typically associated with an admission to hospital. Very often, aggressive medical treatments and interventions follow, aimed at reversing the reason for the sudden deterioration in a person’s health. Recovery and discharge home often occurs, but uncertainty is a core feature of this trajectory, and it is possible that death may occur during (or outwith) any acute dip in health. It is common that, over time, a person becomes more physically weak, requiring increasing help with tasks of daily living.

It is possible that giving information like this to people with advanced liver disease, and their carers, helps people to prioritise what they feel is important, knowing what illness-related challenges may be facing them in their future.

‘Parallel Planning’ Approach

It is imperative to be open with patients and carers about the uncertainty ahead by supporting those with advanced liver disease to ‘hope for the best, but prepare for the worst’. This is sometimes referred to as ‘parallel planning’, and ensures the continued prioritisation of an individual’s quality of life, alongside any active treatments that may be delivered by clinical teams.⁵⁰

Co-ordinating Care

Due to the illness trajectory of advanced liver disease, people often have their care delivered by numerous different teams, spanning hospital and community settings. It is hugely beneficial that crucial information about a patient’s goals, priorities and preferences for their care and treatment, is recorded in an accessible format to allow seamless care to be delivered across different care environments. It is clearly important that this system contains relevant information, and also that it can be updated as a patient’s needs or wishes change throughout their illness trajectory.

A national co-ordinated IT system for recording such information for people with palliative care needs, has been shown to have benefits for patients with life-limiting illness, including a greater chance of being able to die in the place of their choosing when this information is shared with all of those providing care.⁵¹

General Practitioners (GPs) are keen to be closely involved in the care of patients with advanced liver disease, although providing community-based care can be difficult where social circumstances are challenging.⁵² A recent interview study of GPs highlighted lack of

expertise in hepatology, limited confidence with prognostication and a desire for ongoing support from secondary care as concerns that may hamper high quality care provision in the community for people with advanced liver disease.⁵³ A recent study evaluated the utility of a nurse specialist in liver disease, who was given additional training in advanced communication skills and linked in with patients following hospital discharge. This was evaluated positively by patients, carers and healthcare professionals alike and was associated with shortened lengths of hospital stay and a reduced number of GP visits.⁵⁴

Physical Symptom Management

There is a growing volume of evidence that patients with advanced liver disease experience a significant burden of physical symptoms throughout the course of their illness.⁵⁵ Research shows that proactively addressing these symptoms makes a difference to people's quality of life, in particular when hepatic encephalopathy, ascites and malnutrition are managed well.⁵⁶

Concerns are often raised about prescribing pain relief for people with advanced liver disease. The liver plays an important role in metabolising medications, and therefore the risk of certain medication side effects is increased in liver disease. An example is the risk of exacerbating hepatic encephalopathy with morphine-like painkillers (opioids). Though there are some painkillers that are clearly best avoided in end stage liver disease, there is little robust evidence helping clinical teams to manage pain in this group of patients. Patients with end stage liver disease have previously described pain that is inadequately managed, often due to reluctance by doctors to prescribe medications for fear of side effects.^{57, 58}

In order to improve clinicians' confidence in prescribing analgesics and other medications for patients with liver disease, pragmatic guidelines have been synthesised to provide safe, practical guidance to prescribing clinicians throughout the UK.^{59, 60} Although comprehensive assessment and management of pain is one of the cornerstones of good palliative care, to our knowledge, these guidelines are not currently widely utilised, despite their accessibility.

Addressing psychological and spiritual needs

People with advanced liver disease experience higher levels of distress than those with other types of organ failure.⁶¹ There is a strong relationship between high levels of psychological distress and poor quality of life in patients with advanced liver disease.⁶² Depression is also common in this patient group, and is often directly related to the diagnosis of advanced liver disease.⁶³ It is important to note that early hepatitis C treatment, in particular interferon alpha, often precipitated significant psychiatric disturbances, including depression, psychosis and suicidal thoughts. These symptoms sometimes persisted even after treatment was stopped.⁶⁴ There is often a link between psychological ill health and physical symptom burden, highlighting the importance of addressing both needs concurrently.⁶⁵ In cases where lifestyle factors, for example alcohol or drug use, may have contributed towards the diagnosis, patients can experience stigma, guilt, regret and shame which may magnify these burdens.⁶⁶ The social stigma associated with advanced liver disease has also been described in patient groups where alcohol or drug use did not have a causative role, for example those patients whose liver disease was caused by contaminated blood or blood products.

Identifying social and financial needs

In the UK, the presence of chronic liver disease is strongly associated with increasing socioeconomic deprivation. People affected by advanced liver disease are often of working age, and have responsibilities towards dependents. Both patients and carers have acknowledged the financial strain that results from the disease.^{67, 68} It is important to provide patients and

families with information and guidance around how to access the financial support that is available to people living with life limiting illness in the UK, from local services or charitable organisations.

Providing caregiver support

The majority of carers of patients with advanced liver disease are partners or spouses and a significant number report having to give up work altogether, or cut down the number of hours worked as a result of the demands of caring.^{69, 70}

A report published by Carers UK in 2015 found the economic contribution made by unpaid carers is £132 billion per year, almost double its value in 2001.⁷¹ Although carers do describe positive aspects of this role, it is an extremely challenging one, with multiple competing demands placed on people who, in most cases, do not have formal training.⁷² There are several factors that have been shown to increase caregiver burden in advanced liver disease: multiple hospitalisations, a history of hepatic encephalopathy, additional dependents in the household, low household income and active alcohol use.⁷³ Ensuring carers are aware of local support services, as well as the financial assistance they may be eligible for, acknowledges the importance and difficulty of their role. Patients often want carers to be involved in Anticipatory Care Planning (ACP) discussions, recognising that if they lose the ability to make important decisions for themselves, it is reassuring to know their carer is aware of their prior wishes and can be an effective advocate for them. Evidence suggests carers cope better with bereavement if their loved one received prolonged palliative care input prior to their death.⁷⁴

Examples of Excellence

A recent review paper described 4 models of palliative care provision for those with advanced liver disease, demonstrating the potential to work collaboratively between specialties to achieve excellent palliative care.⁷⁵

Worthing collaboration between Western Sussex Hospitals NHS Foundation Trust and St Barnabas House Hospice – Advanced Liver Disease Multidisciplinary Team (MDT) Meeting and Community Liver Disease Nurse

- patients identified as having advanced liver disease are discussed at a monthly MDT
- attendees: hepatology and palliative medicine consultants, community liver disease nurse (CLDN), alcohol liaison services and social worker
- meeting purpose: identification of those patients who would benefit from referral to CLDN and other services, as well as agreement on appropriate medical interventions for next decompensation and co-ordination of care
- patients receive a palliative care holistic assessment, including assessment of carer's/ family needs
- opportunity for patient participation in Anticipatory Care Planning discussions
- Anticipatory Care Plans are created and held with the patient, on electronic end of life register for paramedics, and in hospital notes
- after 2 years (2017–2018), 77% (58/75) of patients dying from CLD had contact with specialist palliative care services, and 52% were referred to the CLDN
- hospital deaths comprised 61% overall, but for patients known to CLDN and hospice services, only 28% died in hospital—the remainder died at home or in the hospice

Palliative care clinical nurse specialist (CNS) for liver services at Royal Free Hospital

- hospital palliative care CNS based within the palliative care team employed to work alongside the hepatology team
- clinical Nurse Specialist attends regular board rounds to aid identification of patients with palliative care needs, including complex symptom control, psychological support, carer support, anticipatory care planning and referral to community services
- weekly MDT meeting established to identify and discuss the supportive and holistic care needs of those inpatients identified as having advanced disease
- active participation in research focusing on improving the care of patients with advanced liver disease in order to improve the quality of evidence available in this patient group
- strong educational component, with the aim to empower other staff to recognise palliative care needs, improve knowledge, facilitate core palliative care delivery and recognise when specialist palliative care input is needed
- role has helped sustain cultural change
- referrals for specialist palliative care input for non-cancer liver disease increased by 227% in 1 year

Exeter advanced liver disease MDT

- all patients with new episode of decompensated liver disease discussed at monthly MDT attended by hepatologists, palliative care physicians, a dietitian, physiotherapist, occupational therapist, alcohol support worker and a member of the community hospice team
- cases are discussed, and patients are triaged to the most appropriate services
- individual care plans agreed for each patient, discussed with the patient and their carer
- in patients with very advanced disease, an emergency treatment plan is ratified, including preferred place of death and plan for managing decompensating events (e.g. use of endoscopy in gastrointestinal bleeding)
- this appears at the top of the patient's online medical records - immediately available to acute medical and emergency staff who may review the patient out of hours

Basildon Shared Care Liver Project

- established between St. Luke's Hospice and Basildon & Thurrock University Hospital
- crosses traditional boundaries and gives patients and their carers access to the supportive care services of the hospice
- this approach now fully embedded into standard care for patients with advanced liver disease who meet referral criteria

Question 11: To what extent does palliative care for advanced liver disease (as presently offered by the NHS in the UK) demonstrate these hallmarks? In particular:

(a) how (if at all) does palliative care differ from area to area?

Core palliative care for patients with liver disease is currently provided in hospitals throughout the UK, by general physicians, gastroenterologists and hepatologists, and the wider multidisciplinary team (MDT) associated with these teams. In the community, it is provided by General Practitioners and community nursing colleagues.

Specialist palliative care for inpatients is provided by hospital palliative care teams, consisting primarily of senior medical and nursing staff specialising in palliative care. These teams usually provide an advisory and liaison service, working alongside the index caregiving team, relying on the team caring for the patient making a referral to the hospital palliative care service when they feel specialist input is required. Specialist palliative care in the community is delivered by hospice teams. This care may be given to patients within a hospice inpatient unit, or within their own home.

There are currently no repositories of data providing objective information or any detail about what palliative care is provided for people with advanced liver disease receiving care in different parts of the UK.

As there is no national consensus on what constitutes a standard model of care for people with advanced liver disease and palliative care needs, palliative care provision both at core and specialist level is dependent upon individual clinicians in all settings being interested in providing this care themselves, or requesting collaborative support from specialist palliative care teams.

As outlined elsewhere in the report, there are pockets of excellent practice throughout the UK.⁷⁶ However, there is no data available which describes how many people with advanced liver disease have access to these services, or the geographical availability of them.

(b) how, if at all, does it differ depending upon the nature of the hospital concerned (teaching/non-teaching; rural/urban; etc)

The Public Health England Atlases of Variation help to assess the value that healthcare provides to both populations and individuals, and may demonstrate differences in healthcare provision that may not be conducive to the highest quality care.⁷⁷ The 2nd Atlas of Variation for liver disease in England⁷⁸ was produced in 2017. This document did not give any information about healthcare services in Wales, Scotland or Northern Ireland.

This report identified significant variations in service provision and outcomes for patients with advanced liver diseases. Examples of areas in which significant variation was identified included:

- per patient expenditure
- number of bed days occupied by people with liver disease in their last year of life
- level of specialist hepatology staff between smaller district hospitals and large transplant centres
- the proportion of patients requiring emergency admission for drainage of ascites (abdominal fluid) as opposed to having access to a medical day unit where this procedure could be performed in a planned way

It is difficult to interpret these data conclusively due to the differing needs and demographics of geographically distinct populations, and movement of patients between different centres. Measures of process do not necessarily provide evidence of the quality of care provided. Robust mechanisms obliging institutions to cost and record delivery of palliative care interventions would afford better quality data, through which care inequalities could be directly addressed.

(c) in what particular respects is it lacking?

(d) by what reasonable means can any shortfall in standard be remedied – and how easy would this be?

Responses to questions 11c and 11d are addressed in questions 13 and 15, and are not repeated here.

Question 12: Do barriers currently exist to patients accessing advanced palliative care for liver disease, and if so what are they?

Barriers to anticipatory care planning discussions and palliative care utilisation for patients with advanced liver disease have been identified, but the degree to which they impact on individual patient care will vary between institutions, depending on the experience and beliefs of healthcare workers, availability of resources and patient factors.

Perceptions of palliative care

The perception that palliative care is mutually exclusive to disease modifying treatments, in particular liver transplantation has been recognised as a key barrier in the timely initiation of core palliative care measures.^{79, 80, 81} Palliative care is often mistakenly thought to be synonymous with end-of-life care by healthcare workers, patients and carers. Clinicians report concerns that use of the term “palliative” would cause unnecessary distress to patients and families, that it might compromise patients’ hope, or result in the idea that the clinician has ‘given up’ on them. This belief can lead to a reluctance to initiate conversations about anticipatory care planning or referral to specialist palliative care unless patients are clearly reaching the end of life. Palliative care is therefore often considered late, when the patient is obviously dying rather than earlier in the disease process, potentially alongside active treatment, when there may be more benefit to the patient and their family. Historically, patients with liver disease (due to any cause) have been stigmatised by society and also by some members of the medical profession. In an attempt to address this stigma, other clinicians may deliver inappropriately aggressive interventions when a patient is likely to be approaching the end of their life, under the impression that they are advocating for that individual. In this context, palliative care may be viewed by some as ‘giving up’, leading to a reluctance to consider this approach.

The unpredictable disease trajectory of advanced liver disease

Chronic liver disease often follows an unpredictable clinical trajectory which makes predicting prognosis difficult. Other non-malignant diseases such as heart failure or chronic obstructive pulmonary disease (COPD) often follow a similar trajectory, and it is well recognised that predicting prognosis accurately in these patients is more challenging than for patients with, for example, cancer.⁸² Patients with advanced liver disease often present to hospital extremely unwell, but many recover completely from the acute admission. Similarly, improvement can

be seen if the cause of the cirrhosis is removed, for example in some patients with hepatitis C when the infection is successfully eradicated, or in patients with alcohol-related liver disease who successfully maintain abstinence. This uncertainty can make it difficult for physicians to know when to initiate anticipatory care planning conversations, or when to involve specialist palliative care teams.⁸³ Patients and their carers may have a poor understanding of illness trajectory and the role of palliative care, which can lead to unrealistic expectations and an unwillingness to embrace early palliative care.⁸⁴

Although liver transplantation only remains an option for a minority of patients with advanced liver disease, the possibility of a curative approach can lead to false optimism among healthcare workers, patients and relatives. Overly-optimistic attitudes from hepatologists may hinder discussions about dying, despite evidence suggesting that even patients who are active on the transplant waiting list benefit from early specialist palliative care input. Some clinicians view non-aggressive care options, such as a referral to specialist palliative care or a do-not-resuscitate status, as contradictory to the pursuit of transplantation which can act as a significant barrier to early discussions about palliative care.⁸⁵

Routinely identifying patients with palliative care needs

There are no existing national or international guidelines outlining specific criteria which should prompt clinicians to initiate palliative care, leading to significant variations in clinical practice. Clinical scores have been developed which outline specific criteria for specialist palliative care referral in patients with advanced liver disease, such as the SPICT (Supportive and Palliative Care Indicators Tool) score⁸⁶ and the Bristol Screening Tool,⁸⁷ however use of these is not widespread and they are not well validated in this population. Some UK centres use clinical triggers, such as the development of symptoms specific to advanced liver disease, to prompt discussion about patients in advanced liver disease multidisciplinary team (MDT) meetings, whereas other centres may only consider palliative care for patients who are not eligible for transplant. This lack of clear guidance for clinicians means individuals' beliefs about the role of palliative care in advanced liver disease will lead to variation in utilisation; some clinicians lack confidence in referring patients without clear criteria in place.

Core palliative care skills within the hepatology community

There is also uncertainty regarding who should initiate conversations about palliative care. Although the majority of gastroenterologists and hepatologists feel initial discussions regarding anticipatory care planning should be initiated by themselves, many have expressed concerns that they lack formal training in palliative care, or advanced communication skills and do not always feel well prepared to deal with the reactions of patients and relatives.⁸⁸ Conversations about anticipatory care planning and palliative care often take a significant amount of time due to their complex nature, yet traditional models of care have not acknowledged or planned for this and competing demands for clinicians' time act as another barrier to core palliative care provision. However, hepatologists and gastroenterologists have also described a sense of responsibility towards their patients and expressed concerns that specialist palliative care professionals may lack experience in managing specific complications of advanced liver disease, such as variceal bleeding or hepatic encephalopathy. There can be discomfort regarding the role of specialist palliative care physicians in joint care which can manifest as reluctance to refer patients for specialist palliative care review.⁸⁹

Access to healthcare for patients with advanced liver disease

On a national level, chronic liver disease disproportionately affects people from more deprived backgrounds and many of those affected come from marginalised groups within society. There is stigma attached to the diagnosis of chronic liver disease, regardless of the cause, and this can impact negatively on the relationship between patients and healthcare workers. Many of the patients affected have limited social support available to them and struggle to attend appointments which can make provision of good quality care logistically difficult. For those patients who do not have a stable home environment, for example those who are homeless or living in hostels, or for those who do not have close family or friends who can assist with their care needs, effective and realistic anticipatory care planning is extremely challenging. There are also concerns that traditional models of end-of-life care, such as community palliative care support in the home or hospice care may not always be the best option for these patients. Even when patients do have high levels of support available from family and friends, the level of care required, and the challenges of managing particular complications outside of the hospital environment, may make caring for them at home extremely challenging.

Hepatic encephalopathy can be especially difficult and distressing for carers to manage as it can result in patients becoming uncharacteristically aggressive, extremely agitated and confused or very sleepy and unable to mobilise or eat and drink. The onset of hepatic encephalopathy can also leave patients lacking capacity and unable to participate in anticipatory care planning discussions if they are left too late.⁹⁰ Finally, there is limited evidence for the safety and efficacy of many medications in patients who have advanced liver disease, which can make achieving adequate symptom control extremely challenging. Concerns that opiate analgesia, in particular, may precipitate or worsen hepatic encephalopathy may act as a barrier to adequate pain control. Clinicians may also be reluctant to refer patients to specialist palliative care services, due to concerns they will recommend the use of medications that hepatologists are not comfortable with.⁹¹

Question 13: If there are such barriers, how best can they be overcome?

Support within national specialty organisations and clinical practice guidelines

In order to give clinicians the confidence to initiate anticipatory care planning discussions and to consider referral to specialist palliative care services, support from sub-specialty societies is important and hepatology-specific clinical guidelines, which outline the role of palliative care in advanced liver disease, are needed. In the UK, support for utilising the principles of palliative care in managing patients with advanced liver disease is already growing.⁹² The British Association for the Study of the Liver and the British Society of Gastroenterology are powerful voices for the gastroenterology and hepatology community in the UK. Their ongoing advocacy for patients with advanced liver disease, through clinician education, promotion of guidelines based on the best available evidence, and improving service delivery, will help overcome some of the barriers that affect patients' access to palliative care. Inclusion of palliative care into specialty-specific treatment guidelines will improve the standard and consistency of care and should help mitigate concerns clinicians have voiced about palliative care discussions being misinterpreted by patients and carers.

Improved communication of disease trajectory and prognosis

Improved communication with patients and carers about disease trajectory, prognosis and management options, including the potential role of palliative care, is essential. However, alternative methods for providing information are needed, alongside acknowledgment of the time required and the value in spending this time on patient and carer education. Communication aids, such as question prompt lists, help to focus conversations onto patients' specific needs.⁹³ Multimedia resources may also help - health literacy levels among patients are variable and written resources are not always helpful.⁹⁴ A recent study in the US has shown how an anticipatory care planning video decision tool can be an effective and feasible way to help patients gain a clearer understanding of complex issues such as do not attempt resuscitation decisions.⁹⁵

Education of healthcare professionals

Continuing education of healthcare workers is needed in order to dispel the myth that palliative care is synonymous with end of life care and emphasise the benefits of early palliative care for patients with advanced liver disease and their carers. Targeted educational interventions are needed to address misperceptions of the role of palliative care and, in addition, provide non-specialists with the knowledge and skills needed to provide high quality core palliative care. A recent study in the US found that providing a virtual programme of palliative care training for hepatologists was feasible, acceptable, and improved learner knowledge and confidence in palliative care skills.⁹⁶ Availability of specialist palliative care services, like all healthcare services, is limited and referral should be limited to those patients with complex needs who will benefit most from specialist input. This is only possible if healthcare professionals managing these patients develop the skills required to ensure effective delivery of core palliative care. Developing core competencies in palliative care, that can be integrated into hepatology training in the UK, may improve confidence and ensure clinicians feel better prepared to integrate principles of palliative care into the management of their patients.

Improving models of care delivery

At a local level, many departments have acknowledged the complex needs of this group and designed novel models of care to address them. A key element of these approaches is recognition that conversations about prognosis and anticipatory care planning take time, and adequate resources need to be allocated for these services to be effective. Several organisations have developed roles for specialist nurses which bridge the gap between hepatology and palliative care and between primary and secondary care.⁹⁷ Unfortunately, without more evidence showing financial benefit, departments may struggle to secure funding for similar models. Trusts providing these services will need to monitor impact, audit actively and share findings widely to provide data to help other departments compile business cases. The Improving Quality in Liver Services (IQILS) scheme offers an opportunity to encourage widespread practice improvement.⁹⁸ Inclusion of metrics which recognise the importance of high-quality coordinated care, early anticipatory care planning discussions and palliative care input will enable impact to be evaluated and provide a standard of excellence for services to aim for.

Improving multi-disciplinary working

For departments with constrained resources, an advanced liver disease MDT meeting is an achievable goal.⁹⁹ Liver disease is 'multi-dimensional', affecting people socially, psychologically and financially, as well as physically. Such MDTs encourage discussion of patients with unstable disease, and should ideally comprise a hepatology consultant, liver

specialist nurse, palliative medicine specialist, pharmacist, dietitian, physiotherapist, social worker and alcohol liaison nurse (where appropriate). The MDT aims to clarify optimal chronic medical management for patients, discuss emergency treatment plans, establish reasonable ceilings of care and consider holistically other factors that might improve quality of life. MDT outcomes can guide future conversations with patients. A key part of effective working is ensuring good, consistent communication; plans can be shared with community teams (GP, district nurses, paramedics and hospice) as well as patients and their families to improve continuity of care. If clear criteria are used to identify patients who may benefit from discussion, regardless of their transplant status, a more consistent approach to care based on patient need will result.

There remain a number of barriers to accessing advanced palliative care for patients with chronic liver disease, however, there have been significant improvements made over recent years in the UK and increased recognition of the need to consider the palliative care needs of this group of patients. The main task moving forwards is to provide consistent care across institutions, taking into account the different levels of resources available.

Question 14: What (if any) improvements have there been since 2000 in:

a) understanding of the role and nature of palliative care in advanced liver disease

Clinical models which integrate the principles of palliative care into the wider management of advanced liver disease represent a relatively recent development within hepatology. A recent, comprehensive literature review did not identify any academic articles on the subject prior to 2013.¹⁰⁰ However, interest has risen exponentially over the last few years as the role of palliative care in optimising quality of life for both patients and carers is increasingly recognised. This increasing interest is reflected in the number of published articles on the topic in peer-reviewed medical journals and in the content of national and international hepatology conferences, which now frequently include sections on palliative care.

In 2018 the British Association for the Study of the Liver (BASL) established an 'end of life' specialist interest group, which now has over 150 members made up of healthcare professionals across the fields of palliative medicine and hepatology. The group collaborates to provide clinical resources and guidance for healthcare professionals, publish articles surrounding best-practice, and actively progress clinical research in the field. Palliative care for patients with liver disease has been identified as a priority in the recent British Society of Gastroenterology research strategy.¹⁰¹ A similar American specialist interest group on the subject was established in 2021.

(b) providing it, compared to what happened before then?

Increasing research on the subject of palliative care in advanced liver disease has afforded a better understanding of the unique issues faced by patients and carers, and this is starting to be reflected in the way clinical care is delivered.

Over the past 5 years various instruments have been developed with the aim of supporting liver healthcare professionals to deliver high quality palliative care. Clinical scoring systems have been designed which routinely identify patients with poor prognosis, such that clinicians are signposted to palliative care interventions in a timely fashion – in parallel to ongoing curative/disease modifying care where appropriate.¹⁰² Communication aids have been

developed to assist clinicians with difficult conversations with patients and carers (e.g. in the delivery of news of poor or uncertain prognosis).¹⁰³ In 2019, the BASL specialist interest group (see question 6a) produced prescribing guidelines to assist with managing difficult physical symptoms in advanced liver disease.¹⁰⁴

Multi-disciplinary team (MDT) meetings are being increasingly utilised as a means to afford a wider breadth of expertise to patients with advanced liver disease, to improve co-ordination of care between the hospital and community, and to inform anticipatory care planning. Typically, MDTs include hepatologists, specialists in palliative care, community nursing, alcohol support, dietetics and physiotherapy/occupational therapy. They allow patients' individual needs to be addressed, for example in the use of physiotherapy for patients with frailty, expert dietetic input for patients with malnutrition, or specialist palliative care for patients requiring complex anticipatory care planning or who have physical symptoms that are difficult to control.

There is increasing recognition that the standard models of care delivery for patients with advanced liver disease, which typically revolve around inpatient care in acute hospitals, are frequently incompatible with the end of life needs of patients and carers.¹⁰⁵ Models of care delivery are being adapted to reflect this. For example, day case units are being increasingly used to undertake procedures to drain ascites (abdominal fluid). Through performing this procedure in a planned fashion, unplanned and prolonged hospital admissions can often be averted. A 2018 study of all patients who died from liver disease with ascites in England between 2013-2015 demonstrated that use of a day case unit was associated with significantly lower healthcare costs, reduced levels of emergency hospital admission/readmission/inpatient bed days within the last year of life, and an increased chance of death occurring outside of the hospital environment (e.g. at home or in a hospice).¹⁰⁶ Further to this, research surrounding the use of long-term abdominal drains, which can be primarily managed in community settings, is ongoing (REDUCe).¹⁰⁷ A National Institute for Health Research (NIHR) grant application for a UK-wide randomised controlled trial of this intervention has been submitted and is currently under consideration.

The importance of palliative care provision in advanced liver disease has been recognised by the Royal College of Physicians, through its inclusion in their criteria for accreditation of UK liver units (IQILS – Improving Quality in Liver Services).¹⁰⁸ To achieve accreditation, centres now need to demonstrate their capacity to provide a day case service for patients who require drainage of ascites, and their ability to offer anticipatory care planning. In 2021 the importance of palliative care in advanced liver disease was recognised in the British Society of Gastroenterology guidelines on the management of ascites.¹⁰⁹ This represents the first time that palliative care has been explicitly recommended in the care of non-malignant liver disease by a national or international body.

Despite the above developments, the provision of palliative care for patients with advanced liver disease remains patchy across the UK, and is contingent upon local interest, expertise and resource. The patient and carer experience of healthcare for advanced liver disease remains frequently poor – reflecting an illness trajectory typically characterised by recurrent and prolonged unplanned hospital admissions, a high burden of untreated physical and psychological symptoms, considerable social stigma and suboptimal end of life care.

Question 15: What would best secure continuing improvement?

Increased awareness and support from sub-specialty societies

Increased public awareness of the burden of liver disease in the UK is vital. Despite being the leading cause of death for persons of working age,¹¹⁰ it is rarely talked about in the national media. Improving the provision of palliative care for patients with advanced liver disease will require increased allocation of resources. With the many demands on the healthcare system, raising the profile of liver disease, and improving public understanding of the needs of patients and carers is vital. Such publicity would also raise the profile of charitable organisations such as the British Liver Trust, and other local and national agencies, who are committed to addressing the needs of patients and carers.

Support from sub-specialty societies is also key. In the UK the British Association for the Study of the Liver (BASL) and the British Society of Gastroenterology (BSG) have a key role to play in raising the profile of the role of palliative care in the management of patients with advanced liver disease. This will give clinicians the support needed to secure funding for services, as well as the confidence to initiate anticipatory care planning discussions and to consider referral of their patients to specialist palliative care services. Sharing resources (and widening clinicians' awareness of these) on sub-specialty websites such as the British Association for the Study of the Liver End of Life Special Interest Group, should promote the benefits of palliative care for patients with advanced liver disease and their carers, and give pragmatic guidance to support busy clinical teams to provide high standards of holistic care. Hepatology-specific clinical guidelines, outlining the role of palliative care in liver disease, are also needed. The American Association for the Study of Liver Diseases (AASLD) is due to publish guidelines on this topic later this year, which is a very positive step forward. Acknowledging the integral role of palliative care in the management of patients with advanced liver disease at a national and international level should result in more consistent care across institutions.

Response to training needs

In order to improve palliative care provision for patients with advanced liver disease it is important to recognise training needs. Limited specialist palliative care resources mean hepatologists and gastroenterologists need to take responsibility for core palliative care provision as they are best placed to identify and support patients who may benefit from anticipatory care planning discussions. Gastroenterology trainees and specialist nurses need to receive robust practical training in the principles of palliative care and advanced communication skills to help achieve this. Inclusion in the training curriculum for gastroenterology trainees would help to highlight the importance of these skills by mandating appropriate training and experience. Many palliative care physicians and specialist nurses will need to increase their experience of managing patients with advanced liver disease to ensure they are confident in managing disease-specific complications, such as hepatic encephalopathy, and understand the particular care needs of this group. Historically their training and experience has focused on patients with hepatocellular cancer rather than chronic liver disease. This need has already been acknowledged, and from 2022 palliative medicine doctors will train both in General Internal Medicine and Palliative Medicine. They will need to gain the skills and experience required to care for patients with long term conditions, including advanced liver disease.

Robust National Accreditation Process

The Improving Quality in Liver Services (IQILS) scheme¹¹¹ is a national accreditation process for hepatology services, supported by the Royal College of Physicians, which aims to improve the quality of medical liver services throughout the UK. It offers an opportunity to encourage widespread practice improvement and includes metrics which recognise the importance of high-quality coordinated care, early anticipatory care planning discussions and palliative care input. As more hospitals sign up to the scheme and seek accreditation, the overall quality and consistency of all aspects of care, including palliative care provision, will improve for patients. It is hoped that IQILS will provide a standard of excellence for all hepatology services to aim for.

Identification of patients

Deciding which patients will benefit from palliative care input and when to initiate conversations is challenging. Patients being assessed for liver transplant, by definition, have advanced disease and a high symptom burden. Many will be assessed as not being suitable for liver transplant, others will die on the transplant waiting list or be removed from the list because their condition deteriorates. Research has already shown these patients benefit from early palliative care input,¹¹² and inclusion of a specialist palliative care assessment in the multidisciplinary transplant assessment process will demonstrate that patients who are still eligible for active treatment can benefit from palliative care input. This will help alter perceptions of patients, carers and healthcare workers that palliative care is synonymous with end of life care. Acknowledgement of the benefits of early palliative care input by transplant centres will likely encourage more widespread integration of palliative care principles into the management of patients with advanced liver disease.

At a local level, advanced liver disease multidisciplinary team meetings are already becoming more common and usually include a representative from palliative medicine. These meetings aim to clarify optimal chronic medical management for patients, discuss emergency treatment plans, establish reasonable ceilings of care and consider holistically other factors that might improve patients' quality of life, including the need for anticipatory care planning. Robust use of MDTs should ensure that patients receive optimal and consistent care. By establishing these meetings in more centres, patients who may benefit from palliative care involvement and anticipatory care planning discussions will likely be identified earlier.

The reciprocal education that occurs as a result of collaborative MDT working between specialties has the potential to increase the knowledge, skills and awareness of both hepatology and palliative care teams. In increasing referrals to palliative care in hospital teams by hepatologists, this should in turn increase the likelihood that an individual with advanced liver disease gains access to hospice and community specialist palliative care teams, where they and their family may receive the additional support required to meet their needs, on their discharge home.

Resource allocation

Improved communication with patients and carers about disease trajectory, prognosis and management options, including the potential role of palliative care, is an essential component of improving care for patients with advanced liver disease. However, departments and organisations need to recognise that these conversations take time and adequate resources will need to be allocated if these services are to be effective. Several NHS departments have already developed roles for specialist nurses which bridge the gap between hepatology and palliative care and between primary and secondary care. Support for these roles in

more organisations will likely improve patient and carer experience and also improve the efficiency of services by reducing the number of unnecessary admissions to hospitals. The recently published European Lancet report recommends community provision of palliative care for patients with advanced disease.¹¹³ However, patients with advanced liver disease have complex care needs and, historically, the majority of their care has been provided by secondary care services. If primary care practitioners are to feel confident taking on this role, ongoing support and oversight from secondary care is likely to be required.¹¹⁴ Advanced nurse practitioners, working between primary and secondary care, offer an effective solution for bridging this gap.¹¹⁵

Incentivising units to provide high quality care

Models of ambulatory/day case care for patients with advanced liver disease are strongly associated with improved end of life care outcomes.¹¹⁶ Similarly, a multidisciplinary team approach to care is likely to enhance quality of life for patients and carers. Financially incentivising units to adopt systems such as these, which integrate palliative care into the management of advanced liver disease, may encourage healthcare organisations to develop such services. The Commissioning for Quality and Innovation (CQUIN) payment framework¹¹⁷ enables commissioners to link income to the achievement of a quality improvement goal. An approach such as this would be feasible for the provision of palliative care in advanced liver disease, and may widen areas of good practice, although the CQUIN framework is currently only available in England and Wales.

Equity of Specialist Palliative Care services

Whilst good palliative care can, and is often, provided by non-specialists there will always be areas of complexity – for example in the management of difficult to control physical symptoms. As described in response to question 2, access to specialist palliative care is not universal and is influenced by factors such as disease type (malignant vs non malignant), deprivation, geography and ethnicity. Ubiquity of access to specialist palliative care could potentially be legislated for, and indeed the new Health and Care Bill represents a possible opportunity for this.¹¹⁸ We would support the expansion of specialist palliative care provision, such that all organisations providing care for patients with advanced liver disease have access to specialist services when required.

Research

In order to improve clinician confidence and encourage widespread change in practice, high quality research is needed. Unfortunately, while interest in the role of palliative care in advanced liver disease is growing, research has been limited to small non-randomised studies. Large-scale, high-quality studies are needed to evaluate the impact of early palliative care on patient-reported outcomes, as well as resource utilisation and care coordination. A recent review of research gaps has been published in the United States which should help to direct resources.¹¹⁹ A higher profile at conferences may also help to stimulate research interest in this field.

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Verifying statements

Each contributing group member confirms that he or she understands his or her duty to provide independent evidence and has complied with that duty.

All contributing group members confirm that in respect of those parts of the report to which they have contributed:

- (i) They have made clear which facts and matters referred to in this report are within their knowledge and which are not.
- (ii) Those that are within their knowledge they confirm to be true.
- (iii) The opinions they have expressed represent their true and complete professional opinions on the matters to which they refer.

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Dr Hazel Woodland will shortly be taking up a consultant post in Hepatology and Gastroenterology at Salisbury District Hospital. Hazel has researched improving the end of life care for patients with chronic liver disease and collaborated with Public Health England to identify inequities in end-of-life care provision for patients with chronic liver disease and hepatocellular carcinoma. She is a member of the British Association for the Study of the Liver end-of-life special interest group and the British Liver Trust clinical advisory group.

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Dr Fiona Finlay is a Consultant in Palliative Medicine at the Queen Elizabeth University Hospital in Glasgow. For her Master of Public Health (Palliative Care Research) degree with the University of Dundee, Fiona completed a dissertation on symptom prevalence in outpatients with cirrhosis. She led a study looking at the integration of palliative care with gastroenterology in people with end stage liver disease.

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He is a member of the British Association for the Study of the Liver, and the British Society of Gastroenterology research development group. He was involved in the analysis and publication of data from the English early access programme for new hepatitis C therapies and has also published on the epidemiology of hepatitis C.

