

**Getting it Right:**  
Improving End of Life Care for  
People Living with Liver Disease

February 2013

# Reader page

<b>Title</b>	<b>Getting it Right: Improving End of Life Care for People Living with Liver Disease</b>
Authors	Dr Elizabeth Kendrick, GPwSI Older people and Chair End of Life Clinical Innovation Team, NHS North East
Publication date	February 2013
Target Audience	Commissioners, providers, hepatologists, nurses, patients, carers, patient groups
Circulation list	<ul style="list-style-type: none"><li>• CCG leads</li><li>• PCT medical directors</li><li>• Health and Wellbeing Boards</li><li>• Acute trust MDs / Directors of Nursing</li><li>• Hepatology / Gastroenterology leads</li><li>• Patient groups and professional bodies</li><li>• National End of Life Care Programme</li><li>• National Council for Palliative Care</li></ul>
Description/purpose	This document takes the end of life care pathway as described in the End of Life Care Strategy and considers how it can be applied for patients with advanced liver disease.
Cross Ref	Department of Health (2008). End of Life Care Strategy.
Superseded docs	N/A
Action required	Best practice / for reference
Timing	Ongoing
Contact details	<a href="mailto:admin@liver.nhs.uk">admin@liver.nhs.uk</a>

# Contents

Foreword.....	4
Executive summary.....	5
How this document might be used.....	6
Introduction.....	7
Why is end of life care for people with liver disease particularly challenging?.....	11
Adopting the End of Life Care Pathway for liver disease.....	15
1. Discussions as the end of life approaches.....	15
2. Assessment, care planning and review.....	16
3. Coordination of care.....	18
4. High-quality care in different settings.....	19
5. Care in the last days.....	20
6. Care after death.....	20
Appendix A: The role of hepatologists and gastroenterologists in improving end of life care.....	21
Appendix B: Examples of good practice.....	22
Appendix C: People who helped to develop this document.....	23
References.....	25

# Foreword

Death is never an easy topic for clinicians to discuss with their patients, even when it can be foreseen in the course of illness or during the progression of a disease. For liver disease, where the patient population is typically younger and the trajectory of the disease more uncertain than other potentially terminal diseases, care at the end of life poses additional and particular challenges.

The End of Life Care Strategy was published by the Department of Health in 2008 and there have been general improvements in delivery of care since then. For many clinicians involved in the treatment of people with liver disease, however, who are immersed in detail of acute care and 'rescuing' patients from complications, considering end of life care issues, care planning and having difficult conversations about death can become obscured.

Liver doctors have developed several predictive models of death and seem to recognise very well the signs leading up to the end phase of life yet surprisingly few have developed programmes to help those patients or their families either to appreciate this or to navigate the realities and hurdles of their final months of life.

For these reasons we have sought to bring together evidence and opinion on the issue here in one place, which we hope will help to improve the way we address this issue in the NHS. We hope that this document, focusing on end of life care for patients with liver disease, will help clinicians, educators, commissioners and patients to discuss this important issue, and to work towards improvements in service provision and outcomes.

I would like to offer my sincere thanks to the many people, including patient groups, hepatologists, gastroenterologists and palliative care physicians and nurses, who have contributed to this document (who we have listed in Appendix C). If their enthusiasm and creativity can be replicated at a local level, using this document as a useful resource to drive conversations and action to improve services, we will have achieved our aims.



Professor Martin Lombard  
National Clinical Director for Liver Disease  
Department of Health



# Executive Summary

Liver disease is a significant public health issue, and in 2010 it represented the fifth biggest cause of death after cancer, circulatory disease, respiratory disease and dementia<sup>1</sup>. Of particular concern is that whilst the mortality for cancer, circulatory and respiratory disease is falling, deaths due to liver disease are relentlessly rising. It is therefore a significant issue for health care providers across all settings and also for commissioners of health care.

The fluctuating course of liver disease makes identification and management of the end of life period challenging. Patients may benefit from both active medical management and palliative and supportive care. Integration of these processes allows active treatment of medical crises whilst preparing the patients, those close to them and the clinical team for the possibility of death. This will require a change in culture amongst some healthcare professionals and the ability to share acknowledgement that recovery is uncertain.

The Department of Health's End of Life Care Strategy described an end of life care pathway in six steps, to help provide excellent end of life care. This includes:

1. Discussions as end of life approaches – some prognostic indicators or clinical triggers for liver disease have been identified.
2. Assessment, care planning and review – there is a need to identify healthcare professionals who, with appropriate training, could discuss prognosis and future care preferences with patients who have advanced liver disease.
3. Co-ordination of care – an identified healthcare professional needs to coordinate care to minimise duplication and ensure information is shared promptly between healthcare providers.
4. High quality care in different settings – each patient will need identified contacts for palliative care advice and liver advice both in and out of hours.
5. Care in the last days of life – patients with advanced liver disease can have complex medical needs and may require frequent medical attention as death approaches, highlighting the need for care planning and review of preferred place of death as illness progresses.
6. Care after death – bereaved relatives of liver disease patients can have complex psycho-social needs both before and after the patient's death needing support.

The pathway also includes carer support, social care, spiritual care and access to end of life information as overarching considerations.

This document takes the end of life care pathway as described in the End of Life Care Strategy and considers how it can be applied for patients with advanced liver disease.

# How this document might be used

This document aims to set out a strategic approach to improve end of life care for those living with advanced liver disease.

## **Patient Groups**

- This document should help patient groups to have a role in discussion about the provision of end of life care for people with advanced liver disease. There are particular issues and problems in liver disease which they will be familiar with and can help at a local level to develop improvements in care for those with advanced liver disease.

## **Providers of Healthcare**

- The increase in deaths from liver disease may encourage providers to explore this area of healthcare for patients with liver disease as part of ongoing development in this area.
- Providers may wish to assess if their workforce has the skills needed to deliver excellent end of life care in terms of communication skills and knowledge.
- Providers may also need to identify who in their organisation is best placed to take responsibility for each step in the end of life care pathway.
- Providers may also like to think about who can provide clinical leadership to bring about the changes in culture required.

## **Commissioners**

- Commissioners may find it useful to benchmark their current situation against this document and use the output of that to inform commissioning intentions.
- Commissioners may like to think about how to commission access to liver advice and palliative care advice 24/7.

## What is end of life care?

A working definition of end of life care is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support<sup>2</sup>.

End of life care and active treatment can carry on simultaneously. End of life care should not be restricted to a patient's last few weeks and days when death is felt to be imminent and inevitable. When a patient has a condition or symptoms that may persist up to the point of death then active treatment and palliative strategies can be integrated, allowing the patient, carers and professionals to proceed with active therapy while anticipating and preparing for the possibility of death. This 'plan B' approach avoids the nihilistic or defeatist connotations of introducing palliative strategies and leaves the door open for patients to anticipate, enquire about and plan for future deteriorations in their health. An acknowledgement that in a given condition or situation 'recovery is uncertain' can allow patients and professionals to engage in shared decision making about how treatment should proceed now and in the event of potential or anticipated future deterioration.

## What do we know about end of life care for people with liver disease?

The National End of Life Care Intelligence Network published a report this year into deaths from liver disease and the implications for end of life care in England<sup>3</sup>. This report shows there has been a 25% increase in liver disease deaths between 2001 (9,231 people) and 2009 (11,575 people). This is in contrast to other major causes of death, which have been declining.

Whilst only 2% of the population as a whole die from liver disease, 90% of these people are under 70. Indeed, more than 1 in 10 of deaths of people in their 40s is from liver disease. When measured as 'years of life lost', liver disease is therefore much more prominent.

The report highlights that 60% of deaths from liver disease occurred amongst men and 40% amongst women. The most common diagnosis is alcohol-related liver disease, accounting for well over a third (37%) of all liver disease deaths. Furthermore, 22% of liver deaths are from primary liver cancer, the majority of which will have alcohol-related liver disease as their underlying cause. However the prevalence of deaths from alcohol-related liver disease varies greatly between males (41% of liver disease deaths) and females (30% of liver disease deaths). Alcohol-related liver disease is also more common in the most deprived areas (44% of liver disease deaths) than the least deprived areas (28% of liver disease deaths).

The complex needs of many patients who die from liver disease mean that over 70% die in hospital, compared to 55% of total deaths in 2009.

The number of people affected also varies in different parts of the country making it a greater issue and challenge in some areas. The age standardised mortality rate (2001-09) was highest in:

- North West (24.0 per 100,000, of which 11.4 were from alcohol-related liver disease)
- North East (21.9 per 100,000, of which 10.1 were from alcohol-related liver disease)
- London (20.2 per 100,000, of which 6.5 were from alcohol-related liver disease)

Data from Nottinghamshire suggest that people who die from alcohol related liver disease have on average seven hospital contacts in the preceding five years, suggesting that there is often opportunity to identify advanced liver disease and offer opportunities for care planning<sup>4</sup>.

The results of the Department of Health's first survey of bereaved people (the 'VOICES survey')<sup>5</sup>, which asks people who register a death about their relative's experience of end of life care, were published earlier this year. It is expected that this survey will be repeated regularly and will be a key data source for measuring the end of life care indicator in the NHS Outcomes Framework. The first sample included 367 responses from carers of someone with liver disease, and this number is expected to increase as the survey is repeated. Results from this first report included:

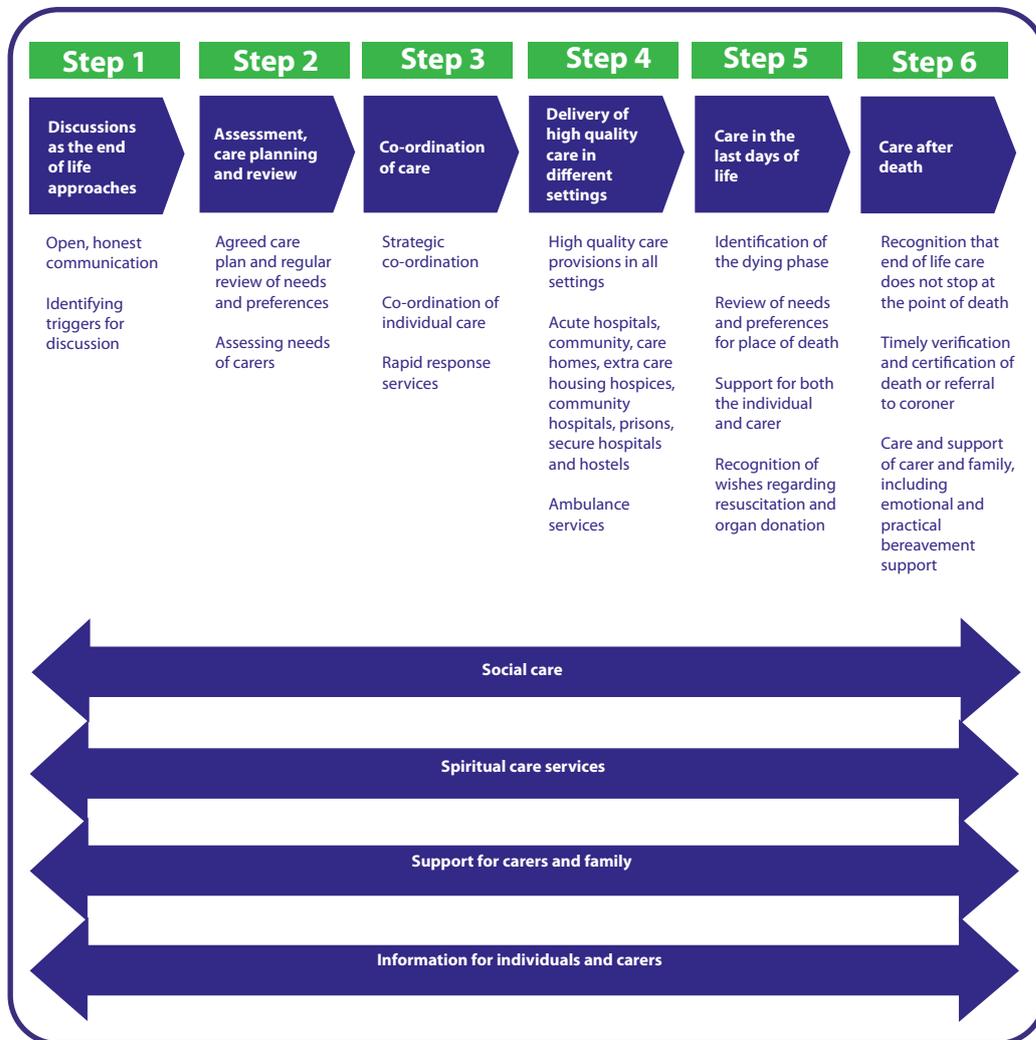
- Where liver disease was mentioned, carers were less likely to rate the overall quality of care as outstanding compared with others, and were more likely to rate the overall quality of care as poor.
- Where liver disease was mentioned, carers were less likely to rate the quality of care by GPs as excellent compared with others, and were more likely to rate their care as poor. There were no significant differences in ratings for care of hospital staff.
- Where liver disease was mentioned, carers were more likely to rate the co-ordination of care as not working well together compared with others. For hospital services with community services, where liver disease was mentioned carers were less likely to rate the co-ordination as working together 'to some extent'.

### **What national policy or guidance is there on end of life care?**

#### End of Life Care Strategy

The End of Life Care Strategy was published in 2008 and sets out six key steps for an end of life care pathway, to provide guidance to anyone providing health and social care to people nearing the end of life. The care pathway aims to ensure that high quality, person-centred care is provided which is well planned, co-ordinated and monitored while being responsive to the individual's needs and wishes<sup>6</sup>. Such principles are obviously also applicable to those dying from end stage liver disease.

Figure: The End of Life Care Pathway



The cross-cutting themes of carer support, patient and carer information, social care and spiritual, cultural and psychological care are particularly relevant in liver disease where the need for such services is often considerable but the provision is limited compared to other fields such as cancer care.

NHS Outcomes Framework

In the new NHS architecture, the NHS Outcomes Framework<sup>7</sup> will be used to provide a national-level overview of how well the NHS is performing, to act as an accountability mechanism between the Secretary of State and the NHS Commissioning Board, and as a catalyst for quality improvement through the NHS. It is structured around five domains, which set out the high-level national outcomes that the NHS should be aiming to improve.

The NHS Outcomes Framework will measure improvements in end of life care in Domain Four. This will be measured through a survey of bereaved relatives (the 'VOICES survey').

#### NICE Quality Standard

In November 2011, the National Institute for Health and Clinical Excellence published a Quality Standard on end of life care for adults<sup>8</sup>. The Quality Standard contains 16 quality statements which cover all settings and services in which care is provided by health and social care staff to all adults approaching the end of life. These standards are broken down into structural, process and outcome measures, which could be measured and adapted for liver disease.

The Secretary of State for Health and the NHS Commissioning Board will be under a duty to have regard to Quality Standards in carrying out their functions, particularly their new statutory duty to improve service quality. The Board will also use Quality Standards in developing the commissioning guidance that clinical commissioning groups will have to follow.

#### Equalities

The Department of Health has published evidence that some groups in society have reduced access to, or engagement with, end of life care services; some of these groups have a higher than average prevalence of liver disease, so particular consideration should be given to equity of access to services and consideration of different beliefs, values and behaviours. Guidance is available at:

[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_086272.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_086272.pdf)



# Why is end of life care for people with liver disease particularly challenging?

## For individuals...

- Deaths occur on average at a younger age than most other long term conditions
- Younger patients may not have pre-existing relationship with primary healthcare
- Indolent early phases of disease may result in patients presenting later in disease process
- Lifestyle and cultural barriers to accessing healthcare
- Perceived stigma resulting in decreased access to care
- Some patients may have on-going issues with addiction and mental health
- In contrast to cancer, lack of public awareness that liver disease is commonly fatal

## For healthcare professionals...

- Complex and uncertain prognosis represents challenges to transition to end of life care
- Adoption of end of life care planning in parallel to active intervention in periods of uncertainty will require culture change in many hepatologists, gastroenterologists, intensivists and healthcare professionals
- Gastroenterology and hepatology training programmes do not currently teach end of life care

## For healthcare organisations...

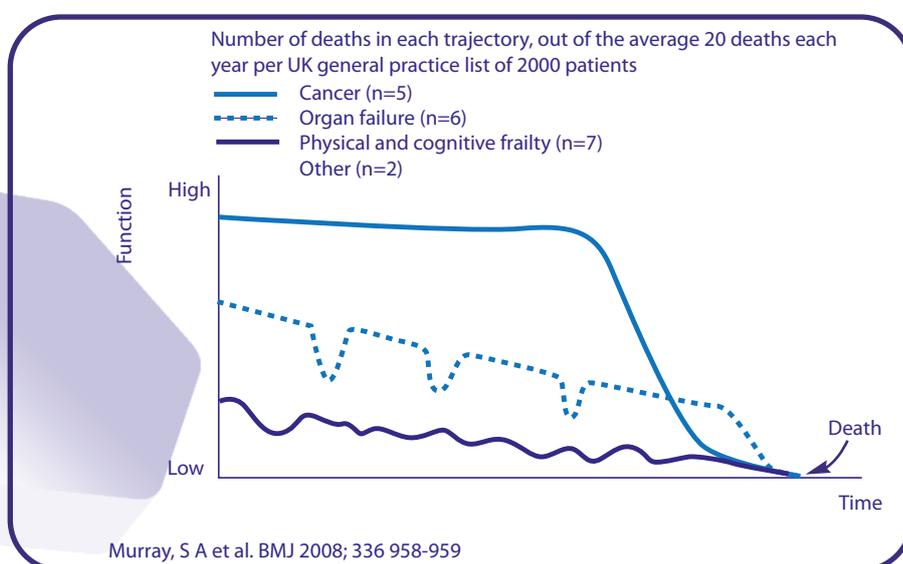
- Many hospitals may lack a specialist with an interest in liver disease
- Inconsistent access to out of hours specialist experience, both for liver and palliative care advice
- Number of people dying from liver disease is increasing which may put a strain on existing resources

When a person is dying of alcohol-related liver disease there are often additional needs for the family which might require to be considered in the provision of end of life care. Living with a family member with alcohol related issues affects family functioning and can contribute to problems with mental health or social functioning. As a consequence there may be a need for specific counselling and additional input after the patient's death in order to support the family in overcoming some of the long term affects of alcohol addiction and minimising their impact on future family functioning.

Specialist clinicians who regularly encounter patients with advanced liver disease are often familiar with providing high-quality management of symptoms (ascites, encephalopathy, itch, fatigue) when they become severe, and have seen many patients present with such symptoms and respond temporarily to treatment several times before death. Conversely we know from patient reports, that accessing expertise and high quality care for liver disease is often a challenge for them. This document aspires to set out an agenda for providing seamless integrated high-quality care for patients with advanced liver disease, to manage symptoms and support early identification and communication about advance care planning across healthcare settings from periods of active intervention to care in the last days of life.

### Trajectories of decline in liver disease

The concept of illness trajectory, the pattern in which a person's general health and ability to function varies during the course of an illness, can be useful in anticipating the final phase of life and the opportunity to benefit from anticipatory care planning. It can also help explain why identifying the terminal phase of an illness can be difficult, particularly in chronic organ failure conditions such as heart failure, COPD and advanced liver disease. In these conditions, deteriorating health is not always a 'one-way street' and an episode of decline may reverse, either spontaneously or with medical treatment, and a patient's ability to function may return to a level at or near the level it was at before the episode. Thus a rapid decline does not necessarily signal imminent, unavoidable death and, unless the patient disagrees, it can be helpful to reassess progress after a period of (intensive or conservative) management<sup>9</sup>. This fluctuating trajectory can be a challenge to manage across healthcare settings and for those healthcare professionals with limited knowledge of liver disease.



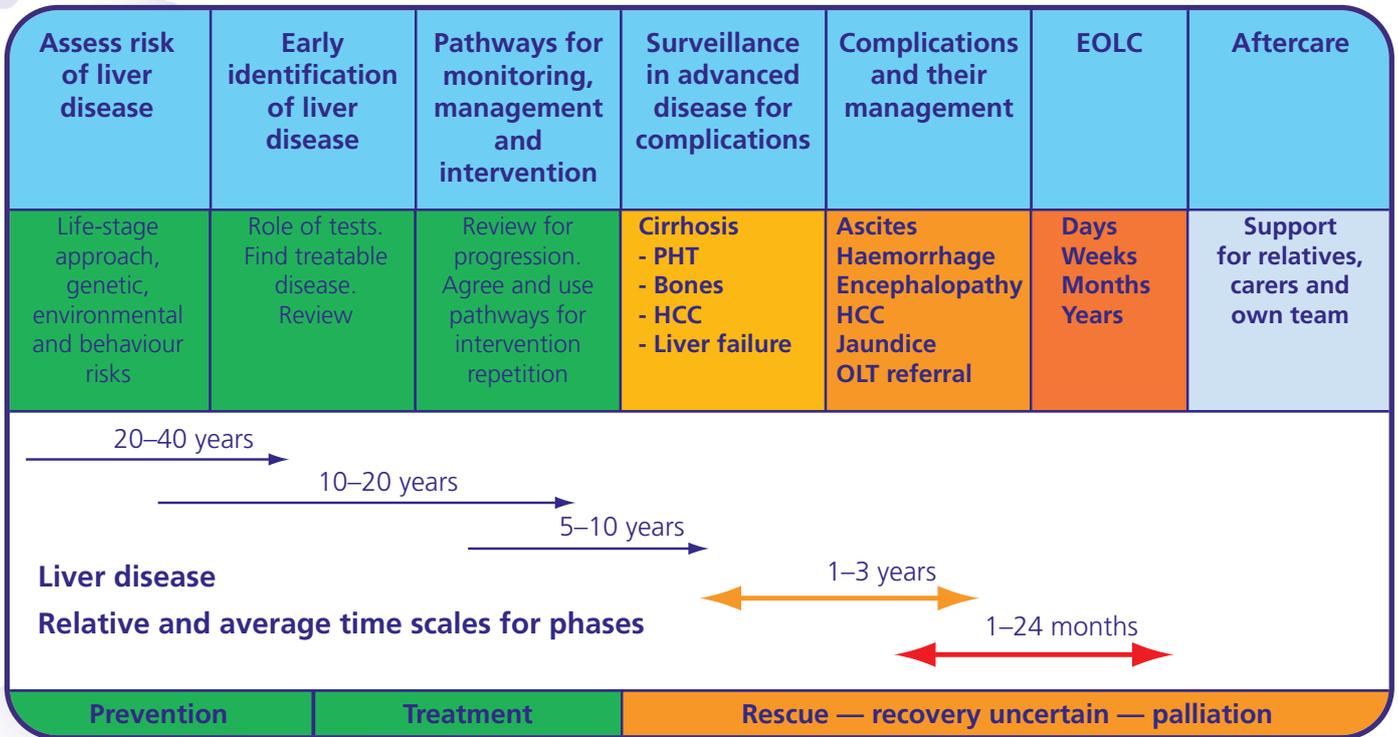
Patients with advanced liver disease can follow widely differing trajectories, and decisions about an individual patient should be based on that patient's individual progress, preferences and needs rather than a generalised model of illness trajectory. Many patients with advanced liver disease experience repeated episodes of deterioration (termed 'decompensation') when one or more symptoms (such as ascites, oedema, encephalopathy, jaundice, bleeding) become more limiting and the patient's ability to function declines. Symptoms may fully or partially resolve either spontaneously or as a result of medical intervention with an improvement in the patient's ability to function. Some patients experience an episode of decompensation from which they do not recover and death follows. Several factors may influence whether a particular episode becomes a terminal decompensation, including: the patient's physiological reserve ('fitness'); the presence of multiple symptoms; superadded complications such as infection or kidney failure; the timing, appropriateness and vigour of medical intervention; and the patient's views on and engagement with active treatment. It can therefore be difficult for patients and professionals to judge the appropriate balance of palliative and active interventions at the onset of an episode of decompensation. In these situations the shared acknowledgement that 'recovery is uncertain' can facilitate integration of active and palliative management. Examples might include:

- 1) Instituting vigorous organ support on the shared understanding that if health deteriorates despite the intervention it can be withdrawn, but alongside this active management, comfort and dignity are also maintained as a key focus of care.
- 2) Setting 'ceilings of active treatment' to avoid interventions which patients and professionals agree would be futile or undesirable may be useful. Such decisions should be subject to repeated review and dialogue.

### Transitions to supportive, palliative and end of life care

The integration of supportive and palliative care with active treatment is a new concept for many professionals and yet so much of the care and treatment provided in managing liver disease is 'palliative' rather than restorative. Sometimes identification and management of the transition can be challenging. Research has shown that there are no clear means of identifying the point at which end of life care will become necessary, so to wait until the need is certain may result in missed opportunities for symptom control and advance care planning<sup>10</sup>. The hepatology community, however, has for years been able to produce and use models that predict poor outcomes but these still tend to be used to consider escalation of treatment (e.g. liver transplant) rather than be used as a prompt for discussion of future care preferences.

Recognising when it is appropriate to introduce elements of end of life care will vary with patient, clinician and disease factors. A simple tool that can sometimes help to inform the process is the 'surprise question'. This prompts clinicians to ask themselves 'Would I be surprised if this patient were to die within the next 12 months?' or '...the next week?' A pragmatic starting point is 'Would I be surprised if this patient were to die in the current circumstances?' which can then lead on to the more time-dependent questions. This intuitive approach to a complex question allows integration of specific diagnostic and prognostic indicators with co-morbidity, functional, nutritional and social factors<sup>11</sup>.



# Adopting the End of Life Care Pathway for liver disease

## Introduction

As detailed above, the end of life care pathway was described in the End of Life Care Strategy published by the Department of Health in 2008. In this chapter, each step of the care pathway is looked at individually and its relevance to and application in the care of people with liver disease considered.

## Step 1 Discussions as the end of life approaches

The 'surprise question' can help prompt discussions about end of life issues with patients whose liver disease is becoming life-limiting. Experienced clinicians will often answer the question based on global impression ('gut feeling') but specific triggers may help the process in advanced liver disease: <http://www.spict.org.uk/>

- Patients who have had one or more unplanned admissions with decompensation in the previous 12 months have an increased probability of further and more frequent decompensation episodes and may benefit from increased supportive and palliative care.
- Patients who have been assessed for liver transplantation will have had an evaluation of their symptoms and risk of death in the following 12 months. This information can be used to guide supportive and palliative interventions independently of the decision to proceed to transplantation or not. Similarly patients who have been seen by hepatologists may have had a prognostic score calculated (eg Child Pugh, MELD, UKELD) which gives a cohort based probability of death and can prompt discussion of care preferences with patients.
- Decreasing performance status or ability to function.
- The presence of ascites, hydrothorax or encephalopathy that is unresponsive to treatment.
- Deteriorating renal function.
- Episodes of spontaneous bacterial peritonitis or severe infections.
- Recurrent variceal bleeding.
- Hepatocellular cancer that is metastatic or progressive despite locoregional therapy.
- Ongoing alcohol consumption in survivors of acute alcoholic hepatitis.

Once it has been identified that the patient may be reaching the end of their life it is essential that the primary health care team are informed of this. It is important to clarify that the patient may receive active management alongside palliative and supportive care. GPs have a palliative care register and reports suggest that patients on these registers tend to have better co-ordinated palliative care in the community.

## End of life care and liver transplantation

The majority of patients listed for liver transplantation have unresolved symptoms and 20% of patients on the waiting list die before an organ becomes available. The wait for transplantation can generate additional social and psychological difficulties for patients and those close to them. Being placed on the transplant waiting list should prompt rather than preclude consideration of the need for supportive and palliative care. Transplant co-ordinators and transplant social workers are well placed to co-ordinate this care<sup>12</sup>. Those patients who have been assessed and deemed unsuitable for transplant are a group with urgent need for palliative care review; study has demonstrated their expected survival may be 2-3 months<sup>13</sup>. Proactive engagement with those declined a transplant who have advanced progressive disease should also be considered as by definition this group of patients will be symptomatic and have a poor prognosis.

The content of end of life care discussions will vary with patients' personalities, preferences, past experiences, social circumstances and clinical condition. Some may not wish to engage in these discussions, others may find sufficient an open acknowledgement that they are likely to die of liver disease and a reassurance that care will continue to be guided by their needs and wishes, while others may accept the opportunity to ask about the future and engage in advance care planning. Clinicians need to consolidate the skills needed to identify these needs in their patients and to respond appropriately. Help in these difficult discussions can be found at:

<http://www.endoflifecare.nhs.uk/search-resources/resources-search/publications/imported-publications/finding-the-words.aspx>  
<http://www.endoflifecare.nhs.uk/education-and-training/communication-skills>

### Step 2 Assessment, care planning and review

Care planning for patients with advanced liver disease can be informed by the generic national guidance found at <http://www.endoflifecare.nhs.uk/care-pathway/step-2-assessment,-care-planning-and-review.aspx>

Care planning embraces the care of people with and without capacity to make their own decisions. It involves a process of assessment and person centred dialogue to establish the person's needs, preferences and goals of care, and making decisions about how to meet these in the context of available resources. It can be oriented towards meeting immediate needs, as well as predicting future needs and making appropriate arrangements or contingency plans to address these.

Should an individual with capacity wish to record choices about their care and treatment, in advance of losing capacity they have several options. They could produce:

- An advance statement
- An advance decision to refuse treatment
- A Lasting Power of Attorney (for property and affairs, and/or health and welfare)

Where a person lacks capacity to decide, care planning must focus on determining their best interests (through consultation with the person's companions and key professional carers) and making decisions to protect these. Any information about what the person's views might have been about the issue at hand, and any relevant advance statement (see below) that they made prior to their loss of capacity, should be taken into account when trying to work out what is in their best interests. If a person who has lost capacity has a valid and applicable advance decision to refuse treatment (ADRT) and / or has registered Lasting Powers of Attorney (LPA), these must be respected. Anything done under the authority of the LPA must be in the person's best interests.

Any choices or advance decisions to refuse treatment recorded in advance of loss of capacity only become relevant when a person loses the capacity to decide about those issues.

Where an individual has capacity to decide, then they must check and agree the content of any care planning record.

The person concerned should be encouraged to regularly review any care planning documentation, to update this as appropriate, and to ensure that revisions are shared with those they wish to involve in their care.

Important points relating to liver specific conditions include:

- Patients who are liable to become encephalopathic may have a fluctuating capacity so may wish to take part in advance care planning whilst they still have capacity. They may also have had previous experience of hospital treatment including intensive care management that they may be able to reflect on. They may wish to set out an advance statement, and advance decision to refuse treatment or appoint a lasting power of attorney for health and wellbeing who can make decisions for them when they lose capacity. Depending on their degree of encephalopathy some patients may retain capacity to make decisions about their care even when encephalopathic. Capacity is also specific to each individual decision to be made.
- Alcohol or drugs can temporarily affect a person's capacity.
- Patients with established Wernicke-Korsakoff syndrome may lack capacity and so may need to have their capacity assessed and if found to be lost a decision regarding treatment must be made under the best interests section of the mental capacity act.

If a person who lacks capacity has no close family or friends and has not recorded any choices about their care and treatment or made an advance decision to refuse treatment in advance of losing capacity, then an Independent Mental Capacity Advocate (IMCA) should be instructed and consulted regarding decision making about serious medical treatment or about placement in hospital for longer than 28 days or a care home for longer than eight weeks.

The checklist in NHS North East guidelines ([www.theclinicalnetwork.org](http://www.theclinicalnetwork.org)) can be used as a framework for professionals who are assisting patients with advanced liver disease in writing an emergency health care plan (EHCP) or an advance decision to refuse treatment. An emergency health care plan allows people to set out the treatment that they wish in an emergency. They are extensively used in paediatrics and in adults with progressive life limiting disease to clarify goals of care and set ceilings of treatment. The list is not exhaustive but highlights common liver-related problems which patients and care givers may wish to anticipate and discuss with the most appropriate healthcare professional.

These discussions take time and need to be carried out at a pace which is comfortable for the patient. Whilst some initial discussion regarding prognosis may need to take place during an inpatient admission, patients may feel more able to make an informed decision about their future care once they have recovered from an acute deterioration.

### Step 3 Co-ordination of Care

While many professionals may be involved in delivering medical, palliative, psychological and social care to a patient with liver disease, it will help to identify a single professional to co-ordinate care. This will improve communication with patients and between professionals, and minimise duplication or unintended interaction of investigations or interventions. The professional best placed to co-ordinate care may change during the course of a person's illness, for instance it may be a hospital professional when hospital attendances are frequent with investigations, interventions and treatment adjustments, then a GP when hospital attendances are fewer and community-based interventions predominate, and a palliative care physician or nurse when there are challenging issues of symptom management or hospice attendances. Frequent contact and information-sharing between professionals (for instance, by prompt copies of clinical letters) will facilitate effective co-ordination and help maintain quality of care. 76% of the time is outside normal working hours so seamless information-sharing with out-of-hours providers is essential. Patient-held information may help patients and carers to participate actively in the coordination of their own care. Electronic palliative care co-ordination system (EPACCS) solutions being developed may help end of life information to be shared electronically. National guidelines have been produced to help with sharing of information electronically and can be accessed at:

<http://www.endoflifecareforadults.nhs.uk/strategy/strategy/coordination-of-care/end-of-life-care-information-standard>

The co-ordinating professional will not necessarily be the best person to assist a patient with emergency health care planning, advance decisions to refuse treatment and decisions about cardiopulmonary resuscitation (CPR). To make these decisions, a patient may require information and assistance from more than one source. Gastroenterologists and hepatologists may be best able to help a patient anticipate the healthcare emergencies that may arise in the course of liver disease. Inclusion in the GP palliative care register means that care is likely to be better co-ordinated in the community. However it must be made clear if the patient is for active management as well. Specialist palliative care may also have a role to play in assisting with the most complex patients.

The co-ordinating professional should ensure that the documentation from any care planning is circulated to the other professionals involved in care and lodged in relevant clinical records. See End of Life Care Co-ordination: Record Keeping Guidance for more information –

[http://www.endoflifecare.nhs.uk/assets/downloads/EoLC\\_\\_Record\\_Keeping\\_Guidance\\_FINAL.pdf](http://www.endoflifecare.nhs.uk/assets/downloads/EoLC__Record_Keeping_Guidance_FINAL.pdf)

#### Step 4 High quality care in different settings

Providing high quality liver care includes providing high quality symptom management and supportive care for patients whose symptoms are likely to persist or exacerbate up to the point of death. Patients with advanced liver disease are often treated in a variety of settings (home, primary care, local hospital, regional liver centre) and access to specialist palliative care and specialist liver medicine advice may be inconsistent. For each patient there should be an identified contact for palliative care advice and an identified contact for liver advice so that other professionals can maintain high quality care even when the clinical problem is not one with which they are familiar. In an emergency, local arrangements should be in place for out-of-hours specialist palliative care advice and out-of-hours emergency liver advice through regional liver centres, including the regional liver centres providing advice on the relief of liver specific symptoms where necessary. Specialist palliative care services include both hospital and community based services along with in-patient beds and day services in hospices. Specialist palliative care services should be available to those patients with more complex physical and psychosocial needs. The timing of a referral to specialist palliative care is dictated according to patient and family 'need', not at a specific time point in their illness. Access may be appropriate much earlier on in the disease trajectory and should not be reserved just for the last few weeks or days of life. Collaborative working is essential in order to ensure high quality care is delivered.

Specific advice relating to achieving good end of life advice for people living in hostels or who are homeless which may apply to some liver patients can be accessed at:

<http://www.endoflifecare.nhs.uk/search-resources/resources-search/publications/ihtm-eolc-rts-evaluation.aspx>

#### Step 5 Care in the last days

Terminal care in advanced liver disease can require frequent medical attention if there are complex care needs such as encephalopathy or haemorrhage. These needs may limit the number of patients whose death can be supported at home or in nursing homes. Some patients and their families may feel more secure with the level of medical attention available in hospital or hospice care. Ideally, patients who want to discuss their preferred place of dying should have the opportunity to discuss their wishes and what this may mean in terms of symptoms and treatment. These wishes can be recorded in an Emergency Health Care Plan (EHCP). Decisions to decline specific treatments by a patient who wishes their decision to be followed in the event of their losing capacity can be recorded in an Advance Decision to Refuse Treatment (ADRT).

Care in the last days of life can be guided by an end of life integrated care pathway<sup>14</sup> such as the Liverpool Care Pathway (LCP), to ensure high quality care is provided. The LCP has the advantage of being generic and familiar to professionals in a range of clinical settings. The overall principles guiding practice apply but caution is needed with some drug doses in end stage liver disease<sup>15</sup>. However, good symptom management is crucial so regular clinical review is essential. Patients who have rapidly deteriorating kidney function may have more effective palliation of symptoms if the renal prescribing guidelines for the LCP are used instead. More difficult clinical situations may benefit from specialist palliative care input.

## Step 6 Care after death

Care after death includes timely certification of cause of death. Accurate inclusion of causes of liver disease, particularly those due to alcohol, viral hepatitis and drug use, improves the accuracy of national mortality statistics and informs the allocation of future health resources to fill unmet need. Families often read death certificates and in some cases may have been unaware of elements of diagnosis. Such instances will require sensitive discussion.

Deaths due to alcohol can cause particular problems for those close to the patient with feelings of guilt and anger. Opportunities for ongoing psychological and social support should be made available, for instance bereavement counsellors may need additional training. Community alcohol services may want to think about their role in care after death. Further information on care after death can be accessed at:

[http://www.endoflifecare.nhs.uk/assets/downloads/Care\\_After\\_Death\\_\\_\\_guidance.pdf](http://www.endoflifecare.nhs.uk/assets/downloads/Care_After_Death___guidance.pdf)



# Appendix A: The role for hepatologists and gastroenterologists in improving end of life care

## Education, training and continuous professional development

A recent report by the Royal College of Physicians (RCP) highlighted that delivery of good care at the end of life cannot be left to specialists in palliative care but is an important part of the role of most physicians.

[http://www.rcplondon.ac.uk/sites/default/files/eolc\\_clinicians\\_leaflet\\_web.pdf](http://www.rcplondon.ac.uk/sites/default/files/eolc_clinicians_leaflet_web.pdf)

The report contains the following important recommendations:

- Medical consultants should provide leadership in establishing opportunities for professional development in end of life care in their own settings, including agreeing how best to implement this as a department/directorate and across the trust. This will clearly apply to medical admitting teams, local hospital gastroenterology teams and regional liver centres.
- In order to influence their practice and ensure that patients have time to adjust, physicians must recognise that end of life care is not just care in the last few hours and days but that it marks the last phase of life, which may be many months or sometimes years.
- It also includes an important prompt tool for use on ward rounds and in out patients as well as a prompt tool to use at MDT meetings.
- It stresses the importance of all physicians including end of life care in their PDP and developing strong links with specialist palliative care teams.
- Secondary and tertiary care physicians must be informed of the fact that general practitioners have palliative care registers to help co-ordinate care for people in the community.
- It would seem sensible for all units looking after people with liver disease to have a lead clinician for end of life care to champion the change in practice required.
- Local liver networks will be important for setting standards, developing regional procedures and guidance and linking specialist advice and training.
- During admissions with decompensation the balance between 'rescue' and pragmatism can be difficult, particularly given the negative attitude that people with liver disease sometimes encounter from some healthcare professionals. It is essential that liver specialists seize control of this space in order to best serve their patients' needs.

The National End of Life Care Programme website also hosts a range of education and training tools, including core competencies and principles for end of life care and an e-learning package. These can be found at:

<http://www.endoflifecare.nhs.uk/education-training.aspx>

# Appendix B: Examples of good practice

NHS North East liver network have developed a framework for supportive care in advanced liver disease collaboratively between palliative care specialists and hepatologists. This aims to provide guidance for professionals and can be accessed at: [www.theclinicalnetwork.org](http://www.theclinicalnetwork.org). The framework will help in the management of specific liver symptoms.

Many areas around the country are developing electronic palliative care coordination systems (EPACCs) which should help with the transfer of key information relating to end of life patients and more information can be found at [http://www.endoflifecareforadults.nhs.uk/assets/downloads/EPaCCS\\_Overview\\_Road\\_Shows.pdf](http://www.endoflifecareforadults.nhs.uk/assets/downloads/EPaCCS_Overview_Road_Shows.pdf)

Nottinghamshire Healthcare NHS Trust has a community matron who has developed a case management approach to high volume service users with addiction issues. This has included care planning for people with advanced liver disease. [www.nottinghamshirehealthcare.nhs.uk](http://www.nottinghamshirehealthcare.nhs.uk)

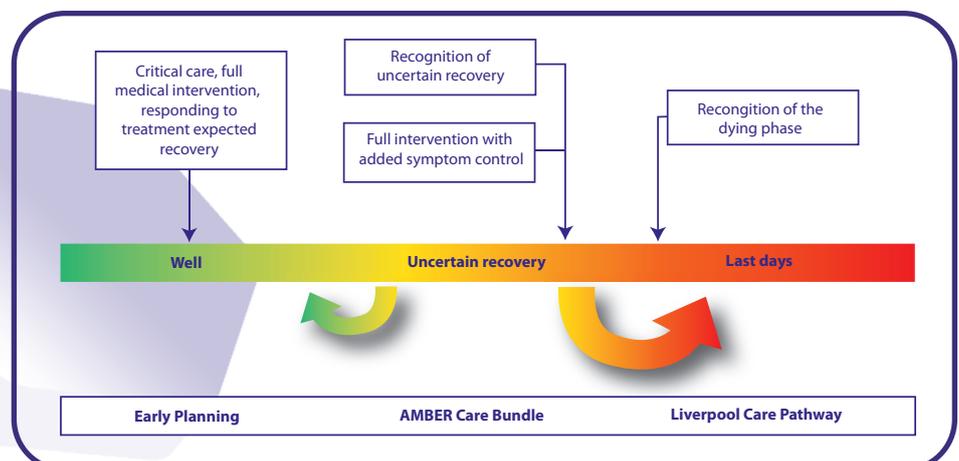
The BASL nurse forum has developed an e-learning resource which includes end of life care and is free to use by all healthcare professionals and can be accessed at: <http://www.basl.org.uk/education-and-training/>

King's College Hospital NHS Foundation Trust has a dedicated palliative care clinical nurse specialist and palliative care consultant who work as integrated members of the liver team. This has fostered an increased awareness of palliative and end of life care issues.

County Durham and Darlington Foundation Trust is appointing a palliative care nurse specialist in liver disease to work in community services.

NHS North East also provide detailed generic guidance on decision triggers, care planning and shared decision making including the Mental Capacity Act in Deciding Right.

The AMBER care bundle <http://www.ambercarebundle.org/homepage.aspx> is a tool developed by Guys and St Thomas' NHS Trust which provides a systematic approach to manage the care of hospital patients who are facing an uncertain recovery and who are at risk of dying in the next one to two months. The bundle aims to identify that recovery is uncertain and therefore aim to make clear decisions regarding a medical plan and discuss preferences for care with both the patient and carers. It is an intervention that can fit within any care pathway or diagnostic group for patients whose recovery is uncertain. The AMBER care bundle may be particularly useful for liver patients in an episode of decompensation when there is potential to benefit from active intervention but recovery remains uncertain.



# Appendix C: People who helped to develop this document

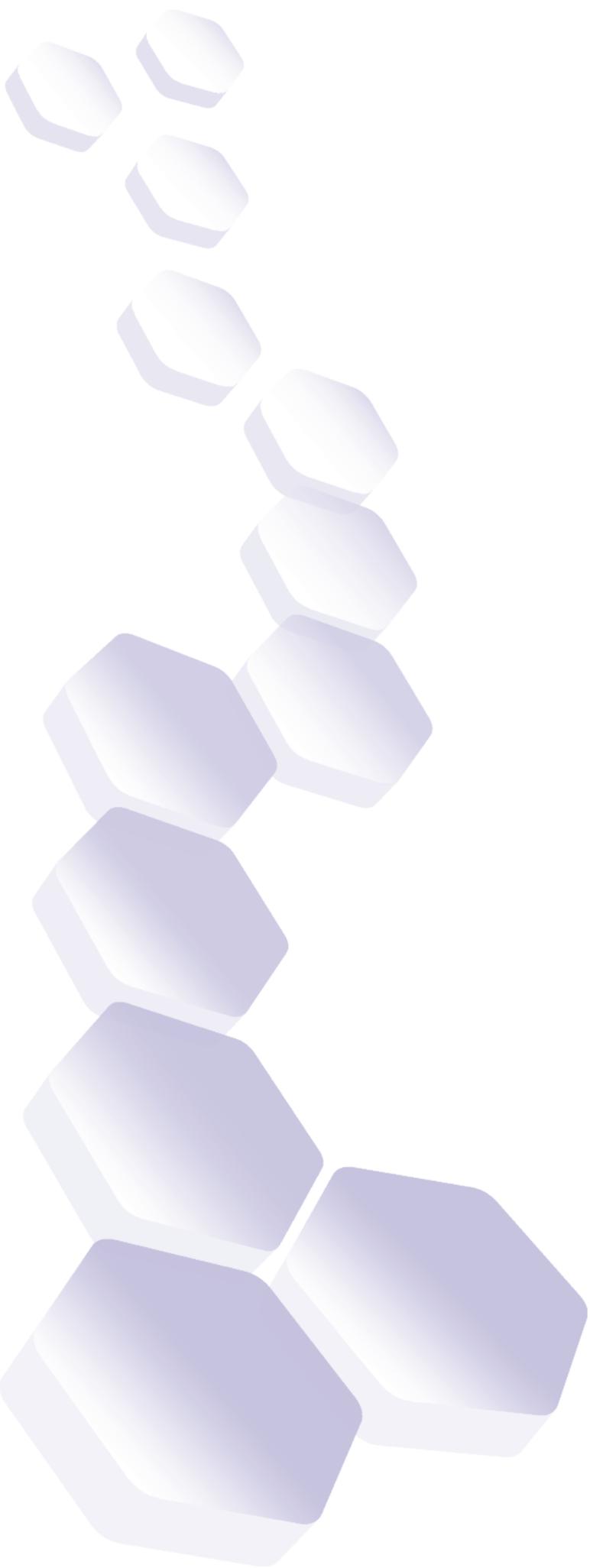
Dr Elizabeth Kendrick	GPwSI Older people and Chair End of Life Clinical Innovation Team, NHS North East
Dr Stuart Kendrick	Consultant Hepatologist, Newcastle University and Newcastle Hospitals Foundation Trust
Andrew Langford	CEO, British Liver Trust
Amanda Clements	Hepatology Nurse Consultant, Derriford Hospital, Plymouth
Anita Hayes	Deputy Director, National End of Life Care Programme
Beverley Matthews	Director, NHS Liver Care
Catherine Arkley	Chief Executive, Children's Liver Disease Foundation
Charles Gore	CEO, Hepatitis C Trust
Dr Claud Regnard	Consultant in Palliative Medicine at Newcastle Hospitals Trust
Joanna Clarke	Deputy Head, Respiratory, Liver, Diabetes and Kidney Programmes, Department of Health
Professor John Ellershaw	National Deputy Clinical Director for End of Life Care
Dr Laura Chapman	Consultant in Palliative Medicine, Royal Liverpool University Hospital
Mark Holmes	Clinical Nurse Specialist, John Storer Clinic, Nottingham
Dr Mark Hudson	Chair of Liver Network, NHS North East
Professor Martin Lombard	National Clinical Director for Liver Disease
Sian Gordon-Brown	Department of Health
Dr Stephen Kriese	NIHR Doctoral Research Fellow, Cicely Saunders Institute, King's College London
Dr Wendy Prentice	Consultant / Honorary Senior Lecturer in Palliative Medicine, King's College Hospital NHS Foundation Trust

The following people also attended a consultative event in January 2012 on end of life care for people with liver disease that helped to inform the development of the document.

Kosh Agarwal	Doctor	Kings College Hospital
Allister Grant	Consultant Hepatologist	University Hospitals Leicester
Amanda Clements	Nurse Consultant Hepatology	Plymouth Hospitals NHS Trust
Andrew Langford	Chief Executive	British Liver Trust
Andy Pring	Senior Analyst	South West Public Health Observatory
Balasubramaniam Vijayan	Consultant Gastroenterologist	NHS Grampian
Barbara Kimbell	Doctoral Researcher	University of Edinburgh
Beverley Matthews	Director	NHS Liver Care
Cherry Bartlett	Programme Lead	NHS Kidney Care
Douglas Thorburn	Consultant Hepatologist	Royal Free Hospital
Elizabeth Kendrick	Chair End of Life Clinical Innovation Team	NHS North East
Fiona Finlay	St4 Palliative Medicine	NHS Tayside
Fiona Hicks	Senior Clinical Lead for End of Life Care	Yorks & Humber SHA
Fiona Lisney	Consultant in Palliative Medicine	Heatherwood & Wexham Park Hospitals NHS Foundaton Trust
Gary Pulman	Volunteer	British Liver Trust
Guruprasad Aithal	Consultant Hepatologist	Nottingham University Hospitals NHS Trust
Hattie Roebuck	Consultant Palliative Medicine	St Josephs Hospice
Ian Harrison	Homelessness Medical Manager	Brownlow Group Practice
Jane Thompson-Hill	Macmillan Nurse Consultant Palliative Care	University Hospital of North Staffordshire NHS Trust
Jeremy Shearman	Consultant Gastroenterologist	South Warwickshire NHS Foundation Trust
Julia Verne	Deputy Regional Director of Public Health	South West Public Health Observatory
Karen Fisher	Alcohol Team Manger	Notts Health Care Trust
Karen Frame	Consultant Palliative Medicine	Imperial College Healthcare NHS Trust
Kathryn Collins	Associate Director	Merseyside & Cheshire Cancer Network
Lesley Oates	End of Life Care Facilitator	Sussex Community Trust
Louise Mason	Consultant in Palliative Medicine	Brighton & Sussex University Hospitals NHS trust
Lynda Greenslade	Clinical Nurse Specialist in Hepatology	NHS
Margaret Bassendine	Professor of Hepatology	Newcastle University
Mark Holmes	HVSU Community Matron	Nottinghamshire Healthcare
Martin Vaux	Chairman	Liver Transplant Support Group, King's College Hospital
Mercy Nzuruba	Hepatology Clinical Nurse Specialist	Chelsea & Westminster Hospital Foundation NHS Trust
Michael Heneghan	Consultant Hepatologist	King's College Hospital
Michelle Clayton	Lecturer in Liver Care	University of Leeds
Naglaa Youssef	Phd Research Student	University of Stirling
Paul Desmond	Executive Director	Hepatitis B Foundation UK
Roberta Lovick	User	EoLC Programme
Sarah Spencer-Adams	Clinical Nurse Specialist - Palliative Care	King's College Hospital
Sheilah Blackwell	Consultant Nurse Palliative Care	Staffordshire & Stoke On Trent Partnership Trust
Siobhan Fahey	Project Manager	Department of Health
Stephen Oxberry	Consultant in Palliative Medicine	Kirkwood Hospice / Calderdale Huddersfield NHS Trust
Stephen Ryder	Consultant Hepatologist	Nottingham University Hospitals NHS Trust
Stuart Kendrick	Liver Fellow	Newcastle Upon Tyne Hospitals Trust
Sushma Saksena	Consultant Physician and Hepatologist	University Hospital North Durham
Wendy Prentice	Consultant in Palliative Medicine	King's College Hospital
William Bernal	Consultant Intensivist	Institute of Liver Studies

# References

1. Deaths registered in England and Wales in 2010, by cause. London: Office of National Statistics, 2011.
2. National Council for Palliative Care (2006) End of Life Care Strategy: The National Council for Palliative Care Submission. London: NCPC.
3. National End of Life Care Intelligence Network (2012) Deaths from liver Disease: Implications for End of Life Care in England.
4. OP01 Who dies from alcoholic liver disease and where are possible therapeutic interventions missed? An analysis of 755 deaths in a health community 2007-2010. S Ryder, T Coles, K Bash, T Allen. Gut2011;60:Suppl2 A50
5. Department of Health (2012) First National VOICES survey of bereaved people – key findings report. London: Department of Health
6. Department of Health (2008) End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life. London: Department of Health.
7. Department of Health (2012) The NHS Outcomes Framework 2013 - 14
8. NICE (2011). Quality standard for end of life care for adults.
9. Murray, SA et al. (2005) Illness Trajectories and Palliative Care. BMJ 2005; 330: 1007.
10. Gardiner, C et al. (2011) Exploring the Transition from Curative Care to Palliative Care: A Systematic Review of the Literature. BMJ Support Palliat Care 2011; 1: 56-63.
11. Regnard, C (2012) Deciding Right: An Integrated Approach to Making Care Decisions in Advance with Children, Young People and Adults. Newcastle upon Tyne: NHS NorthEast.
12. Lawson, AM and Curtis, JR (2006) Integrating Palliative Care for Liver Transplant Candidates. JAMA 2006; 295: 2168-2176.
13. Kriese S et al. Outcome of patients declined for liver transplantation: should prognostic score guide proactive palliative care review? Abstract AASLD 2012
14. Marie Curie Palliative Care Institute (2009) Liverpool Care Pathway for the Dying Patient. Liverpool: Marie Curie Palliative Care Institute.
15. Rhee C, Broadbent AM. Palliation and Liver Failure. Palliative Medications Dosage Guidelines. JPM 2007, vol 10, no. 3;677-655
16. National LCP Renal Steering Group (2008) Guidelines for LCP Drug Prescribing in Advanced Chronic Kidney Disease. Liverpool: Marie Curie Palliative Care Institute.



# Notes

NOTES

[www.liver.nhs.uk](http://www.liver.nhs.uk)