



## Example of innovative and best practice in the management of liver disease

<b>Name of project:</b>	End of life care for patients with advanced liver disease	
<b>Project start and end dates:</b>	Start date: February 2016	Project end date: June 2017
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### Aims of the project:

People with Advanced Liver Disease (ALD) have complex end of life needs. Palliative care provision for these patients is often poor, and there is no clear national guidance for the management of end stage liver disease. This case study describes a unique and innovative Shared Care Liver Project (SCLP) between an acute hepatology team and a hospice that was designed to help address the unmet needs of people with ALD.

The aim of this project was to explore the impact of a parallel planning approach on patient outcomes and experience.

### Details of the project:

Patients were recruited by the Hospice Advanced Nurse Practitioner (ANP) in February 2016 using an in-reach approach into hepatology out-patients. The ANP then invited patients and their carers to the hospice to have a holistic needs assessment (HNA). A significant amount of the in-reach work was to offer reassurance due to the misconceptions around hospice care.

The HNA appointment offered patients and their carers the opportunity to discuss their ALD and also any concerns and worries. The ANP signposted patients and carers to the relevant hospice support services. It was emphasized throughout the project that their acute hepatology management would remain with the hospital.

Patients were assessed 4-8 weekly by the ANP depending on need and the following tools were used to measure wellbeing and outcomes.

- I-POS (a brief palliative care outcome scale designed to capture patient's concerns)
- Australian Karnofsky Performance Status (AKPS - a measure of the patient's overall performance status and their ability to perform their activities of daily living).
- Phase of Illness - (a scale used to define the patient's/family's stage of illness, ranging from stable through to bereavement)
- Views on Care - (an assessment of the patient's own ratings of their quality of life, their view of the impact on the services they are receiving and their overall wellbeing)
- Short Form Liver Disease Quality of Life Instrument (SFLD-QoL – a questionnaire that assesses the severity of liver disease symptoms and symptoms relating to the effects of liver disease across a number of discrete domains)

A focus group was held after 8 months to explore patients' perceived impact of the project on their quality of life.

Data collection finished in June 2017 and in addition to analysis of patient data, hospital admission avoidance, GP visits and emergency admissions, the impact on health economics and quality of life will be assessed.

#### **Project outcomes:**

Results to date from the 38 registered patients who have completed at least one assessment show that the study group is predominantly male (63%) with a mean age of 57 years and with a main diagnosis of alcoholic liver disease.

Whilst analysis of the data set is ongoing, the project has observed some encouraging emerging trends. At baseline, our sample (n=36) had a mean i-POS score of 27.4 and a mean AKPS score 68.3. At assessment 5, some 4 months later, the sample (n=23) had a mean i-POS score of 19.7 and a mean AKPS score 77.0.

This preliminary analysis suggests that patients receiving a parallel planning approach have reduced symptom burden and improved performance status at 4 months compared to baseline.

Feedback from the focus group has highlighted continuity of care and open communication as factors contributing to their improved well-being.

To conclude, the initial findings of this study indicate that early and timely introduction to hospice services benefits ALD patients and their carers. Benefits include improved quality of life and access to end of life discussions.

The project demonstrates that joint working between acute hepatology services and palliative care is an effective means of introducing early palliative care interventions to patients with ALD, with the potential to meet many of their unmet needs and positively impact on their symptom burden.