Improving end of life care for patients with advanced liver disease

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Introduction

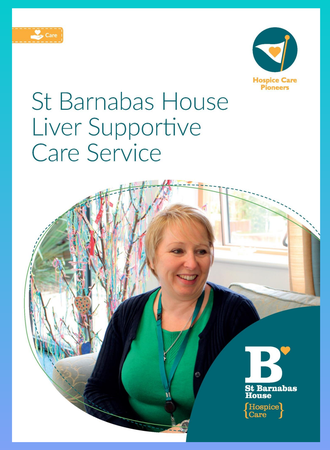
- Liver disease is the fifth commonest cause of death in the UK and is the only major cause of death still increasing year on year[1].
- National data shows that 73% of deaths due to liver disease occur in hospital and few patients are referred to palliative care services [2] despite having similar, or indeed more complex symptom burden and psychosocial needs as patients with other life limiting conditions.
- Although preferred place of death for patients with liver disease specifically is unknown, studies of patients with all diagnoses show the majority of patients would prefer to die at home, rather than in hospital[3].

Aims & Method

- To increase access to palliative care services for patients with End Stage Liver Disease (ESLD) and to ascertain the preferred place of death for patients with ESLD.
- To provide holistic care and help patients with liver disease die in their preferred place of care (PPD), through multidisciplinary team meetings (MDT), appointment of a hospice ESLD Clinical Nurse Specialist (CNS), Advance Care Planning (ACP) and contingency planning.
- We commenced a monthly ESLD MDT, comprising Hepatology and Palliative Care Consultants, community ESLD CNS, Alcohol Liaison Nurse, Social Worker and hospital Palliative Care Nurse. Patients were identified in both the outpatient and inpatient setting and referred to the meeting for discussion. The MDT reviewed patient needs, coordinated care and initiated referrals to additional community services and the ESLD CNS. Patients referred to the ESLD CNS have a holistic assessment with ACP, including PPD and contingency planning for future acute events (e.g. encephalopathy, variceal bleed).

References:

(1) Public Health England Liver Profiles 2015; (2) National End of Life Intelligence Network. Deaths from Liver Disease 2012; (3) Office of National Statistics. National Survey of Bereaved People (VOICES) survey 2015



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Results

- In the first 12 months of the new service there were 43 deaths with ESLD in our locality – 60% in hospital, 37% in the community (home/hospice). This contrasts to 73% and 26% nationally. 79% of all patients were known to palliative care services at the time of death.
- Of the 22 patients that expressed a preference for their place of death, 11 chose home, 10 chose hospice – ***none preferred to die in hospital.***
- Of the 22 patients under the ESLD nurse in the community, 16 (73%) died out of hospital (7 at home and 9 in the hospice). 68% of patients under the ESLD nurse died in their preferred place of care.

Conclusion

- Most patients with ESLD prefer to die out of hospital, consistent with other terminal illness.
- Although this patient cohort remains a heterogenous and complex one with challenging symptom burden it appears that a coordinated and multidisciplinary approach including a dedicated ESLD CNS can help increase referrals to palliative care services, and help more patients die in their preferred place of care.
- We would encourage a continued focus on improving end of life support and care planning for patients with ESLD.