Anticipatory care planning for patients with advanced cirrhosis: helping patients avoid unwanted admissions and procedures towards the end of life

Background
Liver disease is the fifth most common cause of death in the UK and the only major cause of death still increasing year on year. Patients with advanced liver disease are more likely than other chronic conditions to die in hospital, even though most patients with terminal illness prefer to die out of hospital. As part of a larger project to improve end of life care for patients with liver disease, we have started discussing and creating anticipatory care plans with appropriate patients, to plan care in advance for predictable liver decompensation.

Conclusions
Despite the complex medical needs of this group of patients, detailed anticipatory care plans can enable patients with Advanced Liver Disease to have predictable future decompensations managed at home or in the hospice, avoiding unwanted hospital admissions. In addition, these care plans can avoid unwanted procedures such as endoscopy. A coordinated multidisciplinary approach is required, with close collaboration between palliative care and hepatology.

Results
Of the 22 patients referred to the Advanced Liver Disease Nurse in the first year of the project, 16 (73%) died at home or in the hospice, only 27% dying in hospital (vs national figure of 73% dying in hospital). 68% of patients died in their preferred place. Anticipatory care plans covering management of seizures, haematemesis and ascites prevented at least five hospital admissions, and allowed one patient to avoid further emergency endoscopies when admitted with haematemesis, as per his wishes documented on the care plan.

Aim
To increase the numbers of patients with advanced liver disease having an anticipatory care plan, as one method in a project to help patients avoid unwanted admissions and procedures towards the end of life, and help more die in their preferred place of care.

Method
Patients referred to the hospice Advanced Liver Disease Nurse were offered discussions on anticipatory care planning, and in conjunction with the palliative care and hepatology consultants, care plans were written. Copies are held in the patient’s house and within EPaCCS (Electronic Palliative Care Co-ordination System), for paramedics and primary care teams to access.

Example of anticipatory care plan for patient at risk of variceal bleed

**AGREED INTERVENTION/CONTINGENCY PLAN**
INCLUDE REFERENCE TO MCA

John has decided he does not want further endoscopies and would prefer to avoid hospital admission if possible and remain at home for end of life care.

In the event of GI bleed, wife will call 999 for support only (not for conveyance to hospital).

Paramedics to administer midazolam 5–10mg subcutaneously if John is distressed, repeat after 10 minutes if needed.

Contact St Barnabas House for further advice.

**POSSIBLE DEVELOPMENTS SPECIFIC TO THE PATIENT**

Variceal haemorrhage

**SIGNS TO RECOGNISE**

Haematemesis, hypotension, tachycardia, melaena

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