

<b>Name</b>	<b>Early integration of palliative care into the management of patients with advanced liver disease</b>
<b>Type of project</b>	Multi-centre pilot study of joint palliative care/hepatology consultations across 3 sites: Bristol Royal Infirmary, Queen Elizabeth University Hospital (Glasgow) and Royal Free Hospital (London)
<b>Aims/objectives</b>	<ul style="list-style-type: none"> <li>• Recruit 20-30 patients to trial if model can be set up within current service framework</li> <li>• Assess the impact of early involvement of palliative care specialists on patients' symptoms, mood and quality of life</li> <li>• Assess acceptability of joint consultation to patients and their carers</li> <li>• Create an opportunity for knowledge and skill sharing between specialists in hepatology and palliative care</li> </ul>
<b>Inclusion/exclusion criteria</b>	<p>Inclusion criteria:</p> <ul style="list-style-type: none"> <li>• Diagnosis of cirrhosis (any aetiology) with refractory ascites or</li> <li>• &gt;1 admission with decompensated liver disease (variceal bleed, jaundice, ascites, reversible encephalopathy) in preceding year</li> </ul> <p>Exclusion criteria:</p> <ul style="list-style-type: none"> <li>• Lack of capacity, inability or refusal to provide informed written consent to participate in research</li> <li>• Diagnosis of hepatocellular carcinoma or any other malignancy</li> </ul>
<b>Description of intervention</b>	<ul style="list-style-type: none"> <li>• 1-hour joint consultation with a hepatologist/gastroenterologist and a palliative medicine consultant.</li> <li>• Consultation takes place in a private room, either on the ward during an inpatient admission, before/during/after paracentesis or during a specifically booked outpatient clinic (maximum 3 patients on list).</li> <li>• Consultation follows basic template across all three sites, though adapted to individual patient needs using IPOS questionnaire as guide.</li> <li>• Ongoing palliative care input arranged if required.</li> <li>• QOL and anxiety/depression screening questionnaires administered prior to consultation and again after 2-4 months.</li> </ul>
<b>Measures used to assess progress</b>	<ul style="list-style-type: none"> <li>• Hospital Anxiety and Depression Scale (HADS)</li> <li>• Integrated Palliative care Outcome Score (IPOS): <a href="https://pos-pal.org/maix/ipos_in_english.php">https://pos-pal.org/maix/ipos_in_english.php</a></li> <li>• Carer Experience Questionnaire (CES): <a href="http://www.birmingham.ac.uk/research/activity/mds/projects/HaPS/HE/ICECAP/CES/index.aspx">http://www.birmingham.ac.uk/research/activity/mds/projects/HaPS/HE/ICECAP/CES/index.aspx</a></li> <li>• Feedback from both consultants immediately after the consultation</li> <li>• Feedback from patient +/- carer 2-4 months post consultation</li> </ul>
<b>Resources required</b>	<p>Funding: No specific extra funding</p> <p>Staff: recruitment performed by patient's usual clinical team. Consultation with consultant hepatologist and a consultant in palliative medicine (1hr per consultation)</p> <p>Facilities: private room either on ward or in clinic</p> <p>Paperwork: measures freely available but CES and IPOS need to inform of plan to use</p>

<b>Progress</b>	Trial ongoing – plan to complete recruitment of 20-30 patients by May 2019
<b>Lessons learnt</b>	<ul style="list-style-type: none"> <li>• Literacy levels for patients often lower than previously realised</li> <li>• Patients often have practical concerns regarding benefits etc therefore written resource produced with contact details for local services/charities that can assist with benefits advice + carer support)</li> <li>• High carer burden but also many patients (especially with ARLD) do not have a regular carer - may impact on advance care planning</li> </ul>
<b>Future plans</b>	n/a
<b>Resources produced</b>	<p>Patient leaflet (local) – practical advice for patients including advice about benefits assistance and carer support available locally</p> <p>British Liver Trust leaflet on supportive and palliative care in ESLD</p>
<b>Contact details</b>	<p>Dr Hazel Woodland <a href="mailto:hazel.woodland@uhbristol.nhs.uk">hazel.woodland@uhbristol.nhs.uk</a> (Bristol)</p> <p>Dr Fiona Finlay <a href="mailto:fionafinlay@nhs.net">fionafinlay@nhs.net</a> (Glasgow)</p> <p>Ms Lynda Greenslade <a href="mailto:Lynda.greenslade@nhs.net">Lynda.greenslade@nhs.net</a> (London)</p>