

Name	<b>Management of advanced chronic liver disease in a hospice setting – a shared care strategy.</b>
Type of project	Collaborative Quality Improvement Project between St Luke’s Hospice and Basildon & Thurrock NHS Foundation Trust
Aims/objectives	The Shared Care Liver Project (SCLP) was established following a successful pilot in 2013 between St. Luke’s Hospice and Basildon & Thurrock University Hospital (BTUH) to explore the impact of a collaborative approach to the care of patients with advanced liver disease (ALD) and their carers. 36 patients were recruited using jointly agreed inclusion criteria and their progress was measured using a comprehensive set of qualitative and validated quantitative outcome measures. This approach crossed traditional boundaries, giving patients and their carers access to the supportive care services of the hospice.
Inclusion/exclusion criteria	<p>Inclusion Criteria</p> <ul style="list-style-type: none"> <li>• Diagnosis of Grade 4 fibrosis/cirrhosis</li> <li>• Pre-cirrhosis with an episode of decompensation</li> <li>• Presence of encephalopathy, ascites, jaundice, coagulopathy</li> <li>• Presence of a functional risk, eg psycho-social, economic, addictions</li> <li>• A life-threatening episode (alcoholic, steatotic, hepatitis) with evidence of fibrosis</li> </ul>
Description of intervention	<p>The following diagram illustrates the original pathway for patients with Advanced Liver Disease (dark green) in Basildon and Thurrock, Essex.</p> <p>The Blue shows the additional services offered to ALD patients and their carers by St Luke’s Hospice and the light green illustrates the interface between the 2 teams working collaboratively.</p> <pre> graph TD     A[Patient referred into BTUH liver clinic by GP] --&gt; B[Patient seen for initial hospital appointment within 18 weeks]     B --&gt; C{Patient meets project inclusion criteria}     C --&gt; D[Patient referred into shared care pathway]     C --&gt; E[Patient remains under active care at BTUH]     D --&gt; F{Referral appropriate and patient consents}     F -- No --&gt; E     F -- Yes --&gt; G[Patient's carer invited for needs assessment]     G --&gt; H{Carer declines}     H --&gt; I[Carer informed of carer support group]     G --&gt; J[Carer consents]     J --&gt; K[Appointment arranged at St. Luke's for holistic needs assessment]     K --&gt; L[SNP refers and signposts patients to appropriate services eg day hospice programme, social work, counselling etc]     L --&gt; M[Patient has monthly follow up assessments at St. Luke's]     J --&gt; N[Carer's coordinator refers and signposts carers to appropriate services]     N --&gt; O[Carer has follow up appointments as needed]     M --&gt; P[Follow up appointment within six months]     P --&gt; B     O --&gt; M     E --&gt; B     </pre> <p><b>Referral criteria into shared care pathway:</b></p> <ul style="list-style-type: none"> <li>• Diagnosis of Grade 4 fibrosis/cirrhosis</li> <li>• Pre-Cirrhosis with an episode of de-compensation</li> <li>• Presence of encephalopathy; ascites; jaundice; coagulopathy</li> <li>• Presence of a functional risk, eg, psycho-social; economic; addictions</li> <li>• A life-threatening episode (alcoholic; steatotic; hepatitis) with evidence of fibrosis (F1-4)</li> </ul> <p><b>Key</b></p> <ul style="list-style-type: none"> <li>■ existing acute care pathway</li> <li>■ shared care pathway</li> <li>■ pathway interface</li> </ul> <p>For more information see:  <a href="https://www.health.org.uk/sites/default/files/IFI%20R3%20final%20report%20St.%20Luk%20e's%20Hospice%20(7546)%20v2.pdf">https://www.health.org.uk/sites/default/files/IFI%20R3%20final%20report %20St.%20Luk e's%20Hospice%20(7546) %20v2.pdf</a></p>

<b>Measures used to assess progress</b>	<p>Short Form Liver Disease Quality of Life (SFLDQOL) questionnaire</p> <p>From the Outcome Assessment and Complexity Collaborative (OACC suite):</p> <ul style="list-style-type: none"> <li>• Phase of Illness</li> <li>• Australian Karnofsky Performance Status (AKPS)</li> <li>• Integrated Palliative care Outcome Score (IPOS)</li> <li>• Views on Care</li> </ul> <p>Carers completed the validated Carers Support Needs Assessment Tool (CSNAT)</p>
<b>Resources required</b>	1 Project Lead, 1 Advanced Nurse Practitioner, 1 project support officer
<b>Progress</b>	<ul style="list-style-type: none"> <li>• Overall patients were <b>stabilised</b></li> <li>• QoL seemed to be maintained in those <b>expected</b> to deteriorate over the year <ul style="list-style-type: none"> <li>- 3 patients went on to be recommended for <b>transplant</b></li> <li>- One died pre-transplant</li> <li>- One temporarily taken off list due to improved compliance</li> </ul> </li> <li>• One successfully transplanted</li> <li>• <b>All patients</b> (n=36) had opportunity to discuss end of life care planning (PPC/D) &amp; DNACPR</li> </ul> <p>Please note a full project evaluation was completed in collaboration with the Marie Curie Palliative Care Research Unit. The above simply gives a flavour of the significant findings</p>
<b>Lessons learnt</b>	<p>The project evaluation showed that there is significant unmet need in patients with advanced liver disease and their carers.</p> <p>The collaborative approach to this group of patients showed that quality of life (even in the immediate period prior to death) improved significantly with the additional support of St Luke's Hospice.</p>
<b>Future plans</b>	<p>St Luke's and BTUH continues to work both regionally and nationally to disseminate the findings of this important study.</p> <p>Currently an article is being written collaboratively to publicise the findings of the study</p> <p>Please note that the work was also done in collaboration with Marie Curie Palliative Care Research Unit.</p>
<b>Resources produced</b>	Final article currently being written but further in-depth information can be given from contact (Virginia Campbell)
<b>Contact details</b>	<p>Virginia Campbell, Assistant Director of Care &amp; Quality, St Luke's Hospice</p> <p><a href="mailto:viriniacampbell@stlukeshospice.co.uk">viriniacampbell@stlukeshospice.co.uk</a></p>