Using End of Life Care Profiles to Support Advance Care Planning

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Liverpool PCT pioneered Care Profiles approach to Commissioning End of Life (EoL) Care services (2010):

- Series of four half-day facilitated action learning-related workshops over two months
- Each workshop targeted different stage of EoL Care Pathway
- Consensus developed iteratively amongst a large number of participants covering the full range of commissioning, provider, professional and service user interests
- Outputs evaluated by an external reference group
- Innovations: setting “Percentage in Group” and Vignettes for clinical examples
- Fully inclusive process with maximum dissemination

Outline of Care Profiles:

Generic Commissioning template:

Health Needs Group (e.g. Neoplasms); Care Aim; Expected Outcome; Plan/ Protocol: Skill Mix/Frequency/ Duration/Location/ Outcome; Consumables; Costing; Limiting Factors; Quality Standards.

Enables description of what service “an average patient” would be expected to receive at a particular stage of a given disease process

Enables Commissioners to specify what service(s) a patient should expect to receive; at what stage in the disease process; with what resources; with what expected outcomes.

Results:

- Care Profiles developed for:
  - Stage A: Supportive Care (6-12 months ahead of projected death),
  - Stage B: Palliative Care (1-6 months ahead of projected death),
  - Stage C: Anticipatory Palliative Care (Final Days – one month ahead),
  - Stage D: Final Days (plus post-death bereavement support to funeral)
- “Uncertainty” Profile: What happens when a patient/carer is uncertain of what to do, or a problem or crisis arises?
- Comprehensive requirements for people at home or in care home.
- Skill mix, delivery, quality and outcomes set for each stage of EoL pathway.
- Consistent with local EoL Supportive Care Register and Read codes.
- Basic EoL service requirements are same irrespective of disease.
- Integration into Liverpool PCT’s EoL Care commissioning process.

Example Extract from Section 4: Plan/ Protocol of End of Life – Stage D: Final Days Pathway (plus post-death bereavement support up to time of funeral)

<table>
<thead>
<tr>
<th>% in group</th>
<th>Plan/Protocol</th>
<th>Skill Mix</th>
<th>Frequency</th>
<th>Duration</th>
<th>Location</th>
<th>Outcomes/ Outputs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessment: Home setting</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>100%</td>
<td>Undertake Assessment</td>
<td>1 x Band 6 DN 1 x Band 5 DN</td>
<td>Once</td>
<td>Range 1 – 2hrs Mean 1hr 20min</td>
<td>Home</td>
<td>Goals assessed &amp; Care plan identified Related medicines received Initial care delivered &amp; Symptoms managed Variance recorded with outcomes Information provided Equipment/sundries identified &amp; received</td>
</tr>
<tr>
<td><strong>GP</strong></td>
<td></td>
<td></td>
<td></td>
<td>30min</td>
<td></td>
<td><strong>GP face-to-face visit required at some point, as GP normally certifies death, which requires GP seeing patient within the 2 weeks prior to death:</strong></td>
</tr>
<tr>
<td>Ongoing Assessment and Treatment: Home Setting</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>100%</td>
<td>Morning</td>
<td>1 x Band 6 DN plus 1 x Band 3</td>
<td>Once daily</td>
<td>Range 1hr 30min–2hr Mean 1hr 45min</td>
<td>Home</td>
<td>LCP completed at each visit Goals reassessed Care plan delivered Symptoms managed Variance recorded with outcomes Career/ families reassured / information supplied Patient supported Care provided in place of choice</td>
</tr>
<tr>
<td></td>
<td>Afternoon</td>
<td>1 x Band 5 DN plus 1 x Band 3</td>
<td>Once daily</td>
<td>Range 30-45 min Mean 35 min</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Evening</td>
<td>1 x Band 5 DN plus 1 x Band 3</td>
<td>Once daily</td>
<td>Range 30-45 min Mean 35 min</td>
<td></td>
<td></td>
</tr>
<tr>
<td>35% day; 55% night; &amp; 10% 24/7</td>
<td>Support worker depending upon need</td>
<td>Support worker 1x Band 3</td>
<td>As required</td>
<td>Range 1-24hr</td>
<td></td>
<td></td>
</tr>
<tr>
<td>40%</td>
<td>CPSN(Specialist or Matron): Accompany DN when DN on (above) scheduled visit</td>
<td>1x Band 7 DN</td>
<td>Once over pathway</td>
<td>Range 30–45min Mean 35 min</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Conclusions:

Care Profiles are: Simple and flexible; Complement Care Pathways; and can support GP commissioning by providing clinically relevant and detailed information to specify and cost services.

It follows that agreed EoL Care Profiles can:
- Inform and support Advance Care Planning
- Assure the range, quality and consistency of information given to patients and carers, irrespective of discipline of lead professional.
- Serve to highlight choices, where appropriate.

EoL Care Profiles Support Advance Care Planning (Results from 2011 Workshop):

- Provide key reference about available services in primary and community care
- Provide “local” information relating to “Information Prescriptions”
- “Local” “Information Prescriptions” arrangements should provide personalised information to patients and carers to support Advance Care Plans:
  - # Should be electronic with “pick list” for professionals # Leaflets should also be available # Avoid inappropriately raising expectations

Local “Information Prescriptions” database should include information not covered by Care Profiles, e.g. Specialist palliative care in hospitals

“Plan/ Protocol” Care Profiles is that most relevant to Advance Care Plans—but is too detailed and technical as it stands:

Summarised details to be kept simple—types of staff quoted but not grade; Percentage figures replaced by “All”, “Some” & “Most”

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