Using End of Life Care Profiles to Support Advance Care Planning

Dr Rob Gandy[1], Professor Brenda Roe[2] & Jean Rogers[3]

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. Neoplasm); 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.

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.

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)

% in group	Plan/Protocol	Skill Mix	Frequency	Duration	Location	Outcomes/ Outputs
Assessment: Home setting						
100%	Undertake Assessment	1 x Band 6 DN 1 x Band 5 DN	Once	Range 1 – 2hrs Mean 1 hr 20min	Home	Goals assessed & Care plan identified Related medicines received Initial care delivered & Symptoms managed Variances recorded with outcomes Information provided Equipment/sundries identified & received
		GP**	Once	30min		
**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.						
Ongoing Assessment and Treatment: Home Setting						
100%	Morning	1 x Band 6 DN plus 1 x Band 3	Once daily	Range 1hr 30min–2hr Mean 1hr 45min	Home	LCP completed at each visit Goals reassessed Care plan delivered Symptoms managed Variances recorded with outcomes Carer/ families reassured / information supplied Patient supported Care provided in place of choice
	Afternoon	1 x Band 5 DN plus 1 x Band 3	Once daily	Range 30-45 min Mean 35 min		
	Evening	1 x Band 5 DN plus 1 x Band 3	Once daily	Range 30-45 min Mean 35 min		
35%day; 55% night; & 10% 24/7	Support worker depending upon need	Support worker 1x Band 3	As required	Range 1-24hr		
40%	CPSN(Specialist or Matron): Accompany DN when DN on (above) scheduled visit	1x Band 7 DN	Once over pathway	Range 30–45min Mean 35 min		

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"**

For More Information Contact: **Dr Rob Gandy, Senior Honorary Associate Lecturer, Care Profiles Development Programme, Email:** rob.gandy@ntlworld.com,
Telephone/ Fax: 0151 334 6160; Mobile: 07774 937449 See: http://www.edgehill.ac.uk/health/businessenterprise/cpdprogramme

[1]**Dr Rob Gandy** *NHS Healthcare Consultant and Honorary Senior Lecturer, Edge Hill University.* [2]**Professor Brenda Roe** *Professor of Health Research, Evidence-based Practice Research Centre, Edge Hill University; Honorary Fellow, Personal Social Services research unit, University of Manchester.* [3]**Jean Rogers** *Commissioning Manager - End of Life Care, Strategic Commissioning, Liverpool Primary Care Trust*

Edge Hill University