Using Care Profiles to Augment the End of Life Care Pathway

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Background of Care Profiles

- Care Profiles first developed in 1990s in selected Community Trusts across country
- Targeted care delivered in community settings
- Make explicit the expected service offered to a patient group to meet their needs
- Describe patterns of care or treatment at each stage of Care Pathway
- Clarify relationship between clinical practice and resource use
- Incorporate quality standards and outcomes
- Common framework facilitates comparisons

Care Profiles complement Care Pathways

Liverpool PCT piloted Care Profiles approach to commissioning of End of Life care in early 2010

The Process

Workshops

4 half-day action learning- workshops over 2 month period.

Each workshop targeted different stage of End of Life Care Pathway

Consensus developed iteratively amongst a large number of participants covering full range of commissioning, provider, professional and service user interests

Outputs evaluated by an external reference group.

- **Innovations included setting "Percentage in Group" and Vignettes to describe clinical examples**
- **Fully inclusive process with maximum dissemination**

Design, Structure and Content:

The Generic Template Contains Information on:

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

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

It enables description of what service "an average patient" would be expected to receive at a particular stage of a given disease 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)

% 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		
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		

****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.**

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 of projected death),**
  - **Stage D: Final Days (plus post-death bereavement support up to time of funeral)**
  - **"Uncertainty" Profile: What happens when a patient/ carer is uncertain of what to do, when they are on their own and a problem or crisis arises?**
- **Comprehensive requirements identified for people living at home or in a care home.**
- **Skill mix, delivery, quality and outcomes set for each stage of End of Life pathway**
- **Consistent with local End of Life Supportive Care Register and Read codes**
- **Basic End of Life service requirements are same irrespective of the related disease.**
- **Integration into Liverpool PCT's End of Life Care commissioning process**

Conclusions:

- ⇒ **Care Profiles enable Commissioners to break down Care Pathways into constituent parts.**
- ⇒ **Commissioners can match expected service with required resources**

Care Profiles:

- **Are simple and flexible, and Complement and augment integrated Care Pathways**
- **Record outcomes throughout the patient journey**
- **Support audit and quality systems**
- **Enable the commissioning of End of Life and other services**
- **Enable consensus across sectors and interests through transparency**
- **Will evolve over time**

⇒ **End of Life services will vary between PCTs, benchmarking is important.**

⇒ **Care profiles can support GP commissioning by providing clinically relevant and detailed information to specify and cost servic**

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