

## We need to talk about Palliative Care

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### **1. Personal and professional background (D R Taylor)**

I am an academic respiratory physician, currently working for NHS Lanarkshire (NHSL) as a consultant. Since 2010, I have had a specific interest in improving quality of care for patients admitted as emergencies to acute hospitals and who are at the end of life. This is the focus of this submission.

Following a substantial pilot project in 2014, I have been commissioned by NHSL to implement a locally developed Hospital Anticipatory Care Plan in Hairmyres, Monklands and Wishaw General Hospitals. This is currently under way, and will be completed by mid 2016.

### **2. Personal and professional background (C J Lightbody)**

I am a consultant in emergency medicine currently working for NHSL in Hairmyres Hospital A&E department. I have a specific interest in improving standards for end-of-life care provided for appropriate patients at the point of admission to hospital.

I am leading the implementation of NHSL's Hospital Anticipatory Care Planning as standard practice within Hairmyres A&E. The provision of pragmatic and compassionate end-of-life care in the acute hospital setting is a key professional priority.

### **Providing good end-of-life care: the PROBLEMS**

- For historic reasons dating back to the 1960s, the curative “fix-it” model has been universally applied to severe illness irrespective of prognosis. This has been the *raison d’être* for acute services in our major hospitals. However, changes in the pattern of disease mean that a significant proportion of patients being admitted with severe illness are at the end of life (up to 30%). *A one size-fits-all approach at the front door of our hospitals is no longer valid and service provision needs to be modified accordingly.*
- Expertise in Palliative Care (PC) is highly advanced in the UK. Unfortunately current resources and established practice mean that only a minority of patients who are nearing the end of life benefit from this expertise. Typically PC specialists only become involved at the last stages of a patient’s illness, often once it is apparent that conventional treatment is not working. This is too late. Also, patients with a cancer diagnosis make up a disproportionate number of cases receiving PC, despite the fact that many patients with long term conditions would benefit from improved end-of-life care. The Scottish Government’s guidance on “*Caring for people in the last days and hours of life*” (December 2014) acknowledges this need, and it is also a central theme in the “Living and Dying Well” Action Plan. *The delivery of quality end-of-life care needs to be within the remit of all acute specialties and not just the job of PC specialists. This will only be*

*possible with a change in mindset of the medical profession, accompanied by a shift in resource allocation in favour of end-of-life care.*

- The move to have end-of-life care delivered more substantially at home (which is the preferred place to die for more than 50% of patients who eventually die in hospital) is to be welcomed. However, many of the acute medical crises that occur towards the end of life cannot be adequately managed at home. We must avoid perpetuating the current separation of responsibilities by falsely believing that the future role of hospitals should not include end-of-life care. However much medical care is shifted into the community, *acute hospital services need to be reconfigured so that patients with long term conditions and who are approaching the end of life are treated more appropriately. This means taking the prognosis as well as the principal diagnosis (often with co-morbidities) into account.*
- A multiplicity of factors contributes to a “bad death” in hospital.
  - a. The prognosis in relation to end-of-life has been deferred or neglected. This can be because of reluctance on the part of the patient / family or the health care professional. This is a major cultural issue in society and in medicine. Prognostic conversations are the gateway to appropriate patient-centred care.
  - b. Even if prognosis has been discussed, it has often not been recorded or it is not communicated. The use of Anticipatory Care Plans is important in this regard (though they have significant limitations; they are not a panacea).
  - c. Where they exist, Anticipatory Care Plans are often ignored by ambulance staff, A and E and other hospital staff. The “fix it” approach is enshrined in health and safety protocols which do not allow ACPs to be consistently applied.
  - d. The management of acute crises in hospital is also driven by protocols that demand intervention (e.g. Early Warning Scores, Structured Response to the Deteriorating Patient) irrespective of whether death is inevitable or avoidable. In the absence of this distinction over-treatment (striving for recovery) and under-treatment (neglect of end-of-life needs) are common consequences.
  - e. Similarly, the management of acute crises in hospital is seriously affected by discontinuity of care. In the absence of a written Plan, the default response on the part of staff, especially at night and at weekends, is driven by unfamiliarity with the patient, as well as fear of censure or litigation. Too often this results in over-treatment. These situations are also a major source of stress and anxiety for well-meaning staff notably junior doctors and staff nurses.

### ***Providing good end-of-life care: the SOLUTIONS***

I (DRT) am a very keen advocate of Anticipatory Care Plans. I have myself developed one for patients with COPD (currently being introduced in NHSL), and one for use in rapidly emergent situations (Hospital ACP, currently being rolled out across NHSL hospitals). ACPs improve the quality of the end-of-life experience for patients and families, and are also an effective means of reducing harm from futile medical interventions.

A workable ACP is based on prognostic “end-of-life” conversations (EOLC). This is the key starting point. In the absence of this interaction between a patient and their medical / nursing provider, access to appropriate palliative care (and on the flip side, perpetuation of inappropriate care and illusions of recovery) is likely to occur.

Importantly, there are three different types of ACP:

*Type 1.* This ACP is essentially an Advance Directive, often drawn up when the individual is well and has capacity. It specifies what ought not to be done (e.g. CPR or artificial ventilation) in the event of an *unknown* illness (e.g. stroke). It is rarely employed.

*Type 2.* This ACP takes account of a patient’s current health status when stable, in the light of a longer term prognosis (weeks or months). It includes positive goals and choices as well as provisions for other end-of-life needs. It requires to be regularly updated.

*Type 3.* This type of ACP, which is informed by and overlaps with (2), deals with the choices / priorities of treatment at times of acute deterioration and instability in the patient’s status. This is usually the case at times of hospital admission. This type of ACP needs to be reviewed and revised frequently. It is designed to avoid inappropriate over-treatment (NB when what is being done is likely to be **futile, burdensome and contrary to the patient’s wishes**) and under-treatment (NB where palliative interventions are being neglected or deferred). Hospital ACP includes the concept of DNACPR, but is easier to introduce discuss. The NHSL Hospital ACP is an example that Taylor and Lightbody are currently implementing.

Some people advocate “ACP for all”. In some nursing homes, drawing up an ACP is part of the admission process (where they have become a “tick box” exercise, they are often of poor quality). In the Netherlands, it is an expectation that all patients with long term conditions will have an ACP when they call an ambulance or when they are admitted to hospital. That is a long-term ideal, but in the UK it is currently more realistic to be selective as to who should have an ACP (type 2) e.g. patients admitted to nursing homes, the over 85’s, individuals who have had 2 or more hospital admissions in the last year, patients with a recognised life threatening condition.

### ***Practical recommendations***

1. Engaging in prognostic conversations is a professional ethical responsibility. Like the recently recognised duty of candour with regard to medical errors, discussing prognosis and providing the opportunity to draw up

an anticipatory care plan should be a duty of care in the management of patients with long term conditions and who are known to be on an end-of-life trajectory. EOLCs can be declined by the patient but ought not to be neglected by the clinician.

**EOLC and ACP training should be mandatory in all under-graduate and post-graduate medical and nursing training, irrespective of specialty or role. This is the responsibility of Faculties of Medicine in the Universities and the Royal Colleges of Physicians and of Surgeons.**

2. Anticipatory Care Plans need to be communicated between professionals, and when they are available and communicated, they should be acted upon.

**Resources provided to improve access to the Key Information Summary for GPs and hospital doctors, and the template should be user friendly and highlight information that is based on / conforms to an Anticipatory Care Plan.**

**Referring to a patient's ACP should be mandated for all staff dealing with medical emergencies i.e. NHS-24, out of hours doctors, ambulance officers, and triage nurses in A and E. Model legislation which reinforces this provision has been enacted in British Columbia and should be adopted in Scotland with appropriate local modifications.**

3. Given:

- the frequency of hospital admissions for patients at the end of life (up to 30% of acute admissions are in the last year of life)
- the frequency with which these admissions are characterised by further crises (up to 10% are terminally ill and die during that admission)
- the frequency with which harm is caused by discontinuity of care and inappropriate or futile interventions leading to adverse effects, poor quality of life and "bad death", and subsequent family complaints ...

**Hospital ACPs (type 3) should be introduced across all hospitals in Scotland as a Health Improvement Strategy. The training, education and implementation strategies should be similar to current activities in relation to DNACPR and Death Certification.**

***D. Robin Taylor - Calvin J. Lightbody***