



End-of-life care for patients with chronic disease: the need for a paradigm shift

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Death comes to all of us, and if we survive into our late 70s or 80s, progressive organ failure, often with multiple co-morbidities, usually characterises the pathway towards the end of life. The care of patients with end-stage cardiac, renal or respiratory failure feature increasingly in the provision of health services, and the costs are immense particularly in the last year of life.¹

However, it is also increasingly apparent that our current model of care does not provide what is best for patients at end-of-life. No one clinical service is equipped to provide for the patient's needs at all stages of their illness trajectory. Indeed, the philosophy of care and management priorities often differ between service providers. This leads to discontinuity of care. The emergency department and medical teams are geared to dealing with acute deterioration: the model is predominantly curative or "patch up and mend". Palliative care and hospice teams

focus on "end-of-life" much more readily, but tend to operate in another domain, often separated from acute services not just philosophically but often geographically or by cost-centre. Because each of us operates in our separate silos, moving from a "curative" to an "end-of-life" management approach is difficult. Even where the diagnosis of dying has been embraced, our behaviours are more powerfully governed by the context in which we work. Often the default position is to continue as before, however inappropriate that may be.

A new model is required. Appropriate end-of-life care means less intensive, non-curative, symptom-relieving support in which preparing for death is seen as more important than clinging on to life. This means that "a good death" should be regarded as a quality outcome for *all clinical services* irrespective of where and by whom they are provided. It means striving to provide

continuity of care at the end-of-life. It means that chronic disease management, palliative care, end-of-life care and terminal care are regarded as a continuum to which all health care providers contribute. Whether in rest homes, primary care, emergency departments, medical wards or outpatient clinics, the “diagnosis of dying” should be entertained, sensitively communicated, and allowed to shape subsequent management.

In our own unit, a very bad death made us realise that there was a significant gap between our intentions and what we actually delivered. Since that incident, we have been attempting to improve end-of-life care in the Respiratory Medicine service in Dunedin Hospital. But we recognise that the obstacles are considerable, not because of attitudes on the part of individuals, but because “the system” militates against it. We have adopted several practical tools which can be applied to improving end-of-life care, but we realise that these have limited impact unless they are accepted across the wider organisation of a District Health Board. In isolation, progress is almost impossible. As well as specific tools, there is a need for strategic initiatives. The approach has to be “both... and” rather than “either... or”.

The tools

An **Advanced Care Plan** provides the opportunity for patients, their family, and health care providers to enter into the territory of “end-of-life”. Importantly, it opens up conversations. In many cases it is liberating – from denial of the reality that a patient is experiencing and from fear of what might lie ahead. The New Zealand Advanced Care Planning (ACP) Co-operative has been established through the Ministry of Health. Excellent guidelines on the principles and application of ACP have just been published.^{2, 3} Advanced Care Planning is not the prerogative of a single professional group - specialists, General Practitioners or palliative care physicians.

In Dunedin, we have started a **Respiratory Failure Supportive Care Clinic** which includes, among other things, the opportunity to introduce the concept of ACP.

The qualification for referral to the clinic is the so-called “surprise question”, i.e. would we be surprised if the patient were to die within the next year? Areas for discussion include the medical prognosis, the patient’s hopes and fears for the future, palliative treatments that are currently needed, as well as ACP, i.e. treatments that would be acceptable and those that would be excessive or futile in the event of acute deterioration. A generic ACP needs to be modified for specific disease groups such as patients with respiratory failure, and we have recently done so.

 A generic Advanced Care Plan is available from the Advanced Care Co-operative website: <http://acp.hiirc.org.nz>

Try as everyone might, there are still occasions when acute-on-chronic deterioration is too distressing to be managed at home and patients present to hospital. The context of deterioration needs to be urgently considered (is this an end-of-life or terminal event?). The concept of **Ceiling of Care** is relevant in this setting, and derives from the ACP. The aim is to provide guidance to admitting staff who do not know the patient, so that there is continuity with the patients’ previously expressed wishes, and/or limitations to their treatment are clear. We are currently working to have Ceiling of Care information electronically tagged to the patient’s NHI (Figure 1), so that on admission the information is readily available. Of course patients may change their minds about how much intervention is desirable or appropriate – the approach cannot be rigid. But in our experience having the “ceiling of care” defined at the time of admission provides direction and security, particularly to nursing staff, as to how the patient is to be managed. In some centres, the **Liverpool Care Pathway** is also used, again providing a framework for appropriate in-patient management (and not abandonment) of patients who are terminally ill.

 See “Liverpool Care pathway” BPJ 36 (Jun, 2011)

There is also immense scope for improving end-of-life care in the patient’s home and in rest homes, and many in the primary care sector are working to this end. The

CEILING OF CARE / RESUSCITATION PREFERENCES FOR ACUTE ON CHRONIC RESPIRATORY FAILURE

NAME NHI DATE

This patient has been attending the Respiratory Failure Support Clinic and / or has been an in-patient under the care of the Respiratory Service. The following Care Plan has been discussed and agreed with the patient, their family / whānau / carer, and has been confirmed and / or revised by the consultant specialist (electronically signed).

It should be used in the event of an admission to Dunedin Hospital with acute dyspnoea. Assuming that other diagnoses have been considered and excluded (e.g. pneumothorax), the patient's acute respiratory distress should or should not include the following:

SYMPTOM RELIEF: e.g. LOW FLOW OXYGEN / OPIATES / INTRA-NASAL MIDAZOLAM / HALOPERIDOL

Select one or more as appropriate for the patient's needs	ALWAYS
ANTIBIOTICS	YES / NO
PREDNISON	YES / NO
NON-INVASIVE VENTILATION (BIPAP)	YES / NO
ICU / POSSIBLE MECHANICAL VENTILATION	YES / NO
CPR IN THE EVENT OF CARDIO-RESPIRATORY ARREST	YES / NO

Signed (Consultant) (Date)

Figure 1: Ceiling of care document (Southern DHB)

Table 1: Current goals for improving end-of-life care via DHB initiated strategic plans.

Goal #1:	To ensure that provision for end-of-life care and advanced care planning is included in the strategic and business plans for each clinical service operated by DHBs and PHOs
Goal #2:	To ensure that all clinical quality improvement initiatives within the DHB and PHO will address “quality of death” issues as much as they address “quality of life”
Goal #3:	To expedite nurse-led initiatives which will provide consistency in end-of-life care between the community and in hospital: <ul style="list-style-type: none">▪ Provide in-service training in palliative treatments for non-malignant diseases for community and practice nurses▪ Adoption and implementation of the Liverpool Care Pathway across all adult medical and surgical hospital wards
Goal #4:	To explore mechanisms whereby patients in community rest homes have an Advanced Care Plan (where appropriate), and that these plans are central to their management in acute situations

N.B. This list is not exhaustive. These provide a unifying framework in which individual “tools” can be adopted and applied by different teams

introduction of ACP in rest homes is an obvious need. But the tool cannot be applied in isolation. Developing the palliative care skills of community and practice nurses as well as rest home carers is an obvious area where resources need to be allocated. In Otago/Southland criteria for providing “Year of Care” support is going to be extended in 2012 to include end-of-life patients, identified using the “surprise question”. This is an example of how an appropriate philosophy of care and resource allocation can be integrated.

The strategies

Perhaps the most powerful incentive to improve end-of-life care is that this is what patients want,^{4,5} and it is something that we would want for ourselves. Attitudes to death and dying from cancer have been powerfully and positively influenced by the hospice movement. But the philosophy

of care which has been nurtured in that particular setting now needs to be extended and integrated into institutions where “cure and mend” has historically been the over-riding objective. The time has come for “both ... and” rather than “either ... or”. The Southern DHB is currently considering proposals for its “Putting the Patient First” Strategic Plan (Table 1).

Patients at the end of life do not always want – and do not necessarily need – vigorous interventions but quality supportive care.⁶ Quality improvement for such patients will be achieved not by straining indefinitely to extend life via acute medical services, nor by abandoning them when these fail. Adjusting what we do in the light of the diagnosis of dying, and managing the approach to death positively and meaningfully needs to be integrated into all clinical services, not just a few, so that a “good death” is included in what we mean by quality of life.

References

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