

# End-of-life care for patients with chronic disease: have we made a difference?

In late 2011 we published an article on end-of-life care for patients with respiratory failure, contributed by **Professor D. Robin Taylor**, who at the time was a Professor of Respiratory Medicine, at the Dunedin School of Medicine, University of Otago. Professor Taylor has since moved on from this role, but continues his research on end-of-life care at the University of Edinburgh. In his article, Professor Taylor called for a paradigm shift in the way that health care organisations and their staff provided care for patients with chronic illnesses, who are dying. Professor Taylor described what measures the service that he worked for were implementing to address these concerns. However, he noted that progress would not be made unless healthcare organisations adopted these tools at a strategic level. Organisations must work cohesively to attain the best outcome possible for the patient who is dying. Where death is

an inevitable end-point, the ultimate aim is to achieve “a good death”.

Now, over three years on, we revisit Professor Taylor’s article and question whether this paradigm shift has occurred. The philosophies that Professor Taylor expresses are still highly relevant, however, some aspects have changed, such as the rise and fall from favour of the Liverpool Care Pathway. Things have moved in a positive direction since 2011, and there is much greater interest in advance care planning across health care organisations, but there is still room for improvement. We invited **Dr Syed Hussain**, Respiratory Physician and Advance Care Planning “clinical champion” at Auckland City Hospital, to comment on how far we have come in the provision of end-of-life care, and how much further we need to go.

## Part 1: The need for a paradigm shift

Contributed by: **Professor D. Robin Taylor**

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.<sup>1</sup>

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”.

### The tools

An **Advance 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 Advance 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.<sup>2,3</sup> Advance 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.

 Resources, including generic templates, are available from the Advance Care Planning Co-operative website: [www.advancecareplanning.org.nz/resources/](http://www.advancecareplanning.org.nz/resources/)

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 patient’s 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, so that on admission, along with adverse drug reactions, 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.

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 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.



## The strategies

Perhaps the most powerful incentive to improve end-of-life care is that this is what patients want,<sup>4,5</sup> 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”.

Patients at the end of life do not always want, and do not necessarily need, vigorous interventions, but quality supportive care.<sup>6</sup> 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 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.

## Part 2: The distance we have travelled

Contributed by: Dr Syed Hussain

Most of us find it difficult to talk about death and subsequently delay making decisions primarily due to fear of the unknown. Discussion and planning improves the care and assistance that the patient and their whānau/families receive at the end of life. There have been positive changes in the past few years in the way the Auckland Region delivers care to our chronic condition patients during their final years of life, by implementation of Advance Care Planning (ACP).

In the last few years there has been training of healthcare staff in our region through the ACP Collaborative, and since mid-2012 there has been ongoing integration of ACP into the routine clinical work of each service within DHBs. There are now “champions” in many institutions and departments who lead the ACP for their own chronic disease patients, which is helping patients make informed choices for their future healthcare.

It is quite important that a discussion of ACP does not start at the time of the patient’s diagnosis or by someone who has never been involved in the patient’s care. We need to remind ourselves that it is all about the patient, not about us. The patient has to make their own informed, competent decision and has to **write down their own** Advance Care Plan.

## References


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5. Curtis J, Wenrich J, Carline S, et al. Patients’ perspectives on physician skill in end-of-life care: differences between patients with COPD, cancer, and AIDS. *Chest* 2002;122(1):356-62.
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The first steps in identifying patients suitable for starting a conversation about ACP are to consider the following questions:

- Is the person seriously ill?
- Is their condition deteriorating or unlikely to improve
- Will their condition worsen or cause death?
- What is your response to the “surprise question”, i.e. “Would I be surprised if this patient died in the next 12 months?”

For patients with chronic respiratory conditions, the main identifying points that they are ready for a conversation about ACP are as follows:

- Severe airflow obstruction (FEV<sub>1</sub> < 30%)
- Meets criteria for long-term oxygen therapy
- Breathless at rest or on minimal exertion, or housebound
- Falling BMI
- More than three hospital admissions in one calendar year or any admission with respiratory failure requiring non-invasive ventilation

 More details are available at:  
[www.advancecareplanning.org.nz](http://www.advancecareplanning.org.nz)

More structured ACP will in most cases take away the burden of trying to set the ceiling of care by unfamiliar staff in consultation with family members during an acute admission, and allow implementation of a patient's expressed choice of health care when they are no longer capable of that expression. At present the ACP is filed as a clinical alert in the Concerto electronic record and therefore visible to all secondary care staff. There is continuing work to make the ACP a living electronic document visible on the system for primary care.

The Liverpool Care Pathway, which was introduced to improve care in the terminal phase of illness, has been under a considerable amount of criticism in the United Kingdom after the Government commissioned review headed by Lady Neuberger. However, the fault was not with the pathway itself but was due to "wrong interpretation by inadequately trained staff members" which led to the "misuse and misunderstanding" of the pathway. In Auckland DHB we now use the Last Days of Life Care Plan Pathway (LDL CP). As with any pathway this supports, but does not replace, clinical judgment and good communication between all involved, which is the key to successful planning for end of life care.

## Have your say

What aspects of these commentaries most resonated with you?

In terms of the provision of end-of-life care in your organisation/ DHB/geographical region, what aspects are being done well and what could be improved?

Do you find it difficult to know when or how to raise the subject of end-of-life planning, e.g. with a patient with COPD?


How do patients usually respond to initial conversations about end-of-life planning?

Do you use an advance care plan or ceiling of care document with your patients? What aspects of these plans work the best? Are there any aspects which do not work so well?

Visit [www.bpac.org.nz/BPJ/2015/February/end-of-life.aspx](http://www.bpac.org.nz/BPJ/2015/February/end-of-life.aspx) to answer any of these questions or make your own comment. We encourage you to interact with your peers and share experiences and opinions.

## A conversation that counts

Conversations that Count Day on the 16th April, 2015, is an event to raise awareness about advance care planning, so that people start thinking, talking and planning for their future and end-of-life care.

 For further information, see:  
[www.conversationscount.nz](http://www.conversationscount.nz)

