

Editorial: When is it our time to die?

We write this editorial during Palliative Care Week and at a juncture in health care when a 'perfect storm' brews involving escalating healthcare costs, worldwide economic 'austerity measures', calls for discussion and action on 'rationing' health care and profound ethical disquiet among health professionals about 'futile' and almost inhumane treatments and interventions visited on seriously ill older people. As one doctor commented:

'It feels like we are just playing with these peoples' lives, giving them these ridiculously complex, painful and expensive medical procedures just because we can, not because they have value' (Boughton 2012).

The sensitivities around these issues are significant. Somehow, even gently alluding to the possibility that there may be a time to say 'No' to life-saving treatment for some older, chronically sick people raises spectres of ageism, compulsory euthanasia, callous indifference, eugenics or worse. But talk about this we must, difficult as it may be, for these issues are confronting both clinicians and families daily.

To allay such concerns at the outset, we do not advocate compulsory euthanasia or any arbitrary 'cut-off' age beyond which older people will be 'denied treatment' by death panels or 'left to die' in the absence of loved ones and comfort (Goodman 2012). What we do question is a seemingly unstoppable 'technological imperative' towards increasingly aggressive investigations and treatments of the oldest and sickest of the population. When we have elderly people with multiple comorbidities in intensive care units, or living with minimal cognitive functioning in nursing homes while receiving dialysis and nutrition via a feeding tube, only to be rushed by ambulance to the nearest emergency

department for treatment or routinely being given cardiopulmonary resuscitation (CPR) as a 'default position' (Blinderman *et al.* 2012), we must ask, 'How did it come to this?'

Defensive medicine and the heightened fear of litigation are widely recognised, to the point where 'do everything possible' is seen as the safest option or 'path of least resistance' (O'Connor *et al.* 2011). This mindset is, however, notoriously difficult to roll back on an individual case basis and is a genuine minefield for clinicians who wonder if they could ever keep abreast of the burgeoning plethora of legislation, guidelines, policies, compliance requirements and recommendations that seek to govern their every decision. When even the best medico-legal experts find it hard to agree on confronting cases, the average nurse or doctor must wonder whether they can confidently make the best decision (Lawrence *et al.* 2012).

Paternalism in health care is now so ideologically unfashionable that any semblance of a doctor or nurse actually making a decision or suggesting a 'best course of action' smacks of 'dominance'. We have no wish to return to an era of non-negotiable medical omnipotence and authoritarianism, but we recognise that there may be times in people's lives when they want and appreciate that a health professional and indeed yes, even an 'expert', is prepared to 'tell it straight' and to honestly advise what may be the best thing to do, difficult though this may be. Some, such as Williams-Murphy (2012), argue more pointedly that even involving (or should that be implicating?) families and relatives in end of life decisions by telling them that this decision is theirs, is an abdication of professional responsibility, possibly

'cruel' and no more than 'burden(ing) families with CPR decisions in the face of futility'.

Advances in health care, technology and therapeutics have been a double-edged sword and the law of unintended consequences (where a policy or law aimed at a positive benefit in one area inadvertently produces a negative effect in another area) applies with a vengeance. Thanks to better health and general living standards in developed countries, people and especially the baby boomers, are living much longer, albeit with the same chronic, debilitating, expensive illnesses that billions of dollars in research and health funding have not eliminated (Callahan 2011). Worse, people may simultaneously believe that advances in medicine's ability to save their lives and fix their every ailment will happen just as it does on television (Diem *et al.* 1996, Godlee 2006). The proliferation of prescribed medicines for chronic illnesses in developed countries attests to this (Busfield 2010).

Herein perhaps lies the existential crisis at the heart of the financial one: Have we moved from a view of dying and death as sad but integral elements of life's natural closure, to a view of death as a cultural and professional embarrassment or failure that is to be postponed and fought against, almost regardless of circumstances? The questions we pose 'When is the right time to die?' and 'What is it OK to die from?' will always be difficult for health professionals, and even more so for individuals and their families to answer, but we cannot refrain from asking them. Given a contemporary reluctance to acknowledge that 'old age' may become a cause of death and that 'dying' may make sense as a diagnosis, Heath (2010) is refreshingly direct in her discussion of

treating elderly people: 'When one cause of death is curtailed, others must inevitably come forward to fill the gap. Everyone is obliged to die of something.' 'Yes, but not my mother or father' or 'Yes, but not my patient' are the often unarticulated responses that have helped fuel the current malaise that risks trapping families in prolonged modes of grief.

If the international concerns about soaring healthcare costs do not focus professional and societal attention onto this issue, it is hard to know what will. For example, as Callahan (2012) explains from a US perspective:

'As of 2008, there were 44,831,390 Medicare beneficiaries. Between 2010 and 2030, the number will grow from 46 million to 79 million, a 17.7% increase in just 20 years. During that same period, the ratio of workers (who pay the taxes for Medicare) to retirees will decline from the present ratio of 3.7 to 2.9. The costs of the programme will increase from \$503 billion to \$937 billion, a 93% rise.' (p. 11).

In a familiar scenario in most developed countries, he also notes that: 'Some 65% of our healthcare costs are incurred by 20% of our population, mainly the elderly, dying slowly of chronic illnesses' (p. 13). Difficult decisions will have to be made about where healthcare funds are spent as the current healthcare system is clearly unsustainable. There is no evidence at all to suggest that society/ies as a whole and especially the younger, tax-paying component are prepared to make the massive financial contribution necessary to sustain such an open-ended commitment to prolong life with scant consideration of its quality.

Currently, many elderly people who are admitted to acute care hospitals are debilitated, immobile and infirm, possibly with dementia, perhaps suffering the adverse effects of polypharmacy (Williams 2011) and experiencing a questionable quality of life (Taylor & Cameron 2002). Despite this, their treatment can comprise burdensome life-sustaining interventions, including permanent feeding tubes and urinary catheters, internal defibrillation devices and inappropriate resuscitation attempts. While deci-

sions around acceptable quality of life should reflect primarily the individual's understanding and wishes, rather than those of relatives or health professionals, people are often unable to articulate their wishes about further treatment or to have these wishes heeded and respected. A new survey has found for example, that three quarters of doctors would ignore a patient's chest tattoo saying 'Do Not Resuscitate' (Cousins 2012).

Advanced directives were introduced to provide a plan of an individual's preferences for future health care (Silveria & Schneider 2004). However, there have been multiple problems with their implementation which include the directives not being read, being too vague, incomplete or confusing (Smith *et al.* 2009), or being unavailable when needed (Cwinn *et al.* 2009). In addition, physicians are rarely involved in counselling patients about completing these directives (Teno *et al.* 1997) nor may they have had any significant discussion with the patient about their preferences at the end of life, when it is they, the doctor, who ultimately directs the treatment plan (Griffiths 2008). There are ongoing efforts to finesse advance care planning into more than a checklist or yes/no tick boxes but those having the conversations need the time and skills to initiate and continue conversations (Hammes & Briggs 2005) and importantly they must have the desire to do this. The law espouses the autonomy of the individual to decide matters of their own health care, and yet in clinical practice, it seems that this may be the exception rather than the rule.

Calling a halt to expensive, invasive, unnecessary medications, tests, treatments and hospitalisations should not be synonymous with a callous washing our hands of seriously ill older people nearing the end of life. Rather than a defeatist, 'There is nothing more we can do' apologia, we propose that there is a great deal that can and should be done: a great deal more that helps families and patients talk about and accept death as a natural part of living; a great deal more that supports people and helps them to die peacefully in their home or place of choice; a great deal more that enables people to be comfortable and pain free

as death approaches; a great deal more that helps surround the patient with love, things they love and those they love; and a great deal more that creates memories of a loved one's death that families will cherish and hold dear, rather than recollections of a traumatic, medicalised death that families forever try to forget.

When considering our own deaths, all of us will readily talk of a desire for our uniquely own 'good death'. Few express a desire to depart this life intubated, insufflated, ventilated, dialysed, medicated, afraid, suffering or distressed, and yet for many older people, this is how they will approach their last days. It would be good to end on a positive note, but the diverse literature in this area from economics, ethics, law and clinical practice gives little cause for optimism and the current, horrible reality is that this situation is certainly not confined to the elderly.

A sustainable healthcare system and indeed a better society demands that, as Goodman (2012) argues, we need to stop 'doing death so badly'. We need more open and explicit discussion about death and dying and to have our expressed wishes understood and respected by those treating and caring for us. We need to keep a clear focus on the big picture 'outcome' of how we want to spend our last days rather than be sidelined into acceptance or refusal of any specific treatment or procedure. Without significant and possibly uncomfortable change in how we personally envision death, how we plan and prepare for our own deaths and those of our loved ones, and how we provide end of life care within our health services, we will need to heed Kompanje's (2010, p. 733) warning that, 'we must prepare ourselves for the worst is yet to come'.

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