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HOW WE DIE: A VIEW FROM PALLIATIVE CARE

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There is an ongoing global conversation about dying, particularly with regard to treatment abatement decisions, causation and responsibility for death, and relief of physical and existential suffering. There is rising international support for assisted dying. People now tend to die slowly in old age, as a result of multiple chronic illnesses, with more medical decision points and impaired cognitive capacity. This paper describes the dying process from the standpoint of palliative medicine and argues for an improved common recognition of the process of dying, in its contemporary spiritual and social contexts, by the public, medicine, ethics, public policy and the law.

I INTRODUCTION

There is an ongoing global conversation about death and the process of dying. Despite half a century of clinical, academic and public policy activity by specialist palliative care workers, as well as health administrators, academics, lawyers, artists and writers, it is still common to hear the same issues recycled with the oft-repeated comment that we 'do not do this well'. The pathways to death are changing: increasing numbers of people are dying in old age, slowly, over one to two years, with multiple co-morbidities, high incidences of dementia, and more significant medical decision points. On the one hand, the public (fed by a technically optimistic health industry) may have unrealistic expectations of curative capacity; on the other, they exhibit widespread concern about "bad dying". Clinicians still struggle with treatment abatement decisions, and issues related to causation and responsibility for death.

In contemporary discourse and policy, the main issues revolve around causation (euthanasia and assisted dying); causal responsibility by doctors and families (decision-making at the end of life, especially for those who lack capacity); relief of physical and psychological suffering; spiritual, existential and cultural dimensions associated with meaning and coping; and place of death (and dying).

In recent years, three prominent policy 'think-tanks': Demos, the Economist Intelligence Unit, and the Grattan Institute have been commissioned to study dying. In the report compiled by the Economist Intelligence Unit, Australia was recently ranked as the second best country in the world (after the UK) in which to die, albeit using crude global measures of the 'quality' of dying.[1] Clearly much remains to be done everywhere to improve care and decision-making at

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[1] Economist Intelligence Unit, *The 2015 Quality of Death Index. Ranking Palliative Care Across the World* (2015) <http://www.economistinsights.com/healthcare/analysis/quality-death-index-2015>.

the end of life, both within health care systems and in the broader community. The Grattan Institute has pointed out the demographic and economic challenges of dying for an ageing population.[2] Palliative Care Australia has published a guidance document on system reform and care at the end of life,[3] and an updated National Palliative Care Strategy was promulgated in 2010.[4] The Australian Commission on Safety and Quality in Health Care has recently issued a consensus statement on care at the end of life for the acute sector.[5]

In the UK, Demos[6] has strongly criticised care of the dying, despite that country being rated as the global leader in palliative care by the Economist Intelligence Unit ('EIU').[7] The National Health Service ('NHS') End of Life Care Strategy was launched because there had never been a system-wide approach to palliative care, despite excellent care for over 50 years by some of the longest established pioneering specialist palliative care services in the world.[8] Of all NHS complaints in acute hospitals, 54 per cent were found to be related to care at the end of life and bereaved people.[9] A government commission for Healthcare Audit and Inspection found a major mismatch between actual place of death and peoples' preferences, usually for death in their own home.[10] It was estimated that only around one third of the population ever discusses death and dying issues with others. The General Medical Council also published comprehensive updated guidance for doctors on end of life care in 2010.[11]

Palliative care is defined by WHO (2002) as:

> an approach that improves quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention of suffering by early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.[12]

The work of palliative care can be sub-divided into:

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[2] Hal Swerissen and Stephen Duckett, 'Dying Well' (2014) Grattan Institute <http://grattan.edu.au/wp-content/uploads/2014/09/815-dying-well.pdf>.

[3] Palliative Care Australia, *Health System Reform and Guidance at the End of Life: a Guidance Document* (2010) <https://www.pcvlibrary.asn.au/download/attachments/2917053/Care+at+the+end+of+life.pdf?version=1&modificationDate=1327895181539>.

[4] Australian Government, Department of Health, *The National Palliative Care Strategy* (2010) <http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-strategy.htm>.

[5] Australian Commission on Safety and Quality in Health Care, *Safety and Quality of End-of-Life Care in Acute Hospitals: a Background Paper* (2013) < http://www.safetyandquality.gov.au/publications/safety-and-quality-of-end-of-life-care-a-background-paper/>.

[6] Charles Leadbetter and Jake Garber, *Dying For Change* (2010) Demos <http://www.demos.co.uk/publications/dyingforchange>.

[7] Economist Intelligence Unit, above n 1.

[8] Department of Health (UK), *End of Life Care Strategy* (National Health Service, 2008) <http://www.cpa.org.uk/cpa/End_of_Life_Care_Strategy.pdf>.

[9] Commission for Healthcare Audit and Inspection, *State of Healthcare 2007: Improvements and Challenges in Services in England and Wales* (2007) <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/228524/0097.pdf>.

[10] Ibid.

[11] General Medical Council (UK), *Treatment and Care Towards the End of Life: Good Practice in Decision-Making* (2010) <http://www.gmc-uk.org/guidance/ethical_guidance/6858.asp>.

[12] World Health Organisation, *WHO Definition of Palliative Care* (2015) <http://www.who.int/cancer/palliative/definition/en/>.

(i) biological aspects: pain and symptom management;
(ii) psychological and spiritual support: for patients, families, friends, and carers, and after death for the bereaved; and
(iii) communication and decision-making: especially so-called 'death-talk'.

Even from its early days palliative care services espoused multidisciplinary teamwork and whole person-centred care, seeing the patient in their mind-body-spirit and social/kinship context. This care is intrinsically relational in temperament and practice, and its practitioners need to have the necessary expertise, experience, and time to work effectively with their clients. However in order for palliative care to be appropriately accessed and deployed, there needs to be personal, clinical and societal recognition of death and the process of dying. There are barriers in all these domains despite many years of work by specialists in palliative care and many other disciplines, and by concerned politicians and citizens, especially those who have experienced the 'bad' deaths of those close to them.

Across the world, public policy, ethics and the law have all been engaged in trying to unravel the real and perceived difficulties of care and decision-making at the end of life. Personal (patient) autonomy is rightly the main guiding principle in all these deliberations, but it is often not adequately balanced, informed and supported by the realities of death and the dying process. Academic attempts to define, acknowledge, express and work with contemporary 'western' human dying have had limited success in policy and practice. There often seems to be over-investment in the concept of medical 'futility', which now sits in a hotly contested space and cannot be relied upon as a safe conceptual basis in ethics, law or practice for limitation of medical treatment as death approaches.[13]

The first steps in any attempt to clarify these matters is to make some clear observations and statements about the clinical nature of death and dying itself: what the dying process is like, and what can be done both to mitigate its effects on the person who is dying and support those around them. These are obvious questions to ask palliative care workers as their role is primarily to care for dying people.[14] While Part II of this paper describes the experience of dying from a clinical palliative care perspective, Part III will consider the clinical, ethical and legal barriers to good care and decision-making at the end of life. Each of these disciplines makes some contribution to obstructing the concept of a 'natural' dying process. This has consequences for dying people, families, carers, and the wider society.

II THE EXPERIENCE OF DYING

Dying can be broken down into subsidiary experiences: 'when?' (age at death), 'how?' (cause of death, epidemiology), 'where?' (place of care and eventual death), and 'why?' (existential/spiritual considerations). The first three of these will be examined here. The last, the existential and spiritual dimensions, despite their importance, are mostly beyond the scope of this paper.

[13] Michael Ashby, 'The Futility of Futility: Death Causation is the "Elephant in the Room" in Discussions about Limitation of Medical Treatment' (2011) 8 *Journal of Bioethical Inquiry* 151.
[14] See Michael Ashby, 'The Dying Human: a View From Palliative Medicine' in Allan Kellehear (ed), *The Study of Dying: From Autonomy to Transformation* (Cambridge University Press, 2009) 76.

A *When?*

It is now clear that most of the world's population is living longer than ever before in human history. In western countries most people can expect to live into their late 70s or early 80s. The average age of dying in Australia for men is 79.9 years and for women 84.3.[15] By the middle of this century it is predicted that about a quarter of the Australian population will be over 65 years old. It is not just the general proportion of older people that is growing inexorably: projections suggest that the elderly (ie those in their 80s and 90s) will make up more than 5 per cent of the population by 2040.[16] It is also clear that standardised mortality ratios now show that dying is 'saved up': dying for most people is 'compressed' into the years 70-85. It is now less common to die before the age of 65 than ever before.[17]

B *How?*

The cause of death has been shifting inexorably from acute and infective causes to a chronic 'burden of disease' picture for the last century. The ten leading causes of death, which account for just over 51.3 per cent of all deaths, are listed on the Australian Bureau of Statistics ('ABS') website chart, and show trends in 2003, 2007 and 2012.[18] Circulatory disease (heart attacks and strokes) was the main killer in the mid to late 20th century, and still accounts for 29.9 per cent of deaths, down from 36.9 per cent in 2003 (myocardial infarction accounted in 2012 for 13.6 per cent, stroke 6 per cent). Cancer (of all sorts) has been increasing in both incidence and prevalence and is now the leading single cause of death in Australia (with similar trends in most western countries), rising from 29 per cent in 2003 to 29.6 per cent in 2013.[19] While genetic, environmental and lifestyle causes are major causal factors, it is also clear that rising rates of cancer are a feature of an ageing population. The other clear trend is the rise of dementia as the third largest cause of death, having seen a 140.7 per cent increase between 2001-2010, now accounting for about 9000 deaths per annum.[20] The recognition of dementia as a fatal process and a cause of death in its own right is an ongoing task.[21] It is also striking that Australians, on average, now have 3.2 causes listed on their death certificates, as opposed to one sudden single cause such as infection, myocardial infarction or stroke. These causes more

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[15] Australian Bureau of Statistics, *Gender Indicators, Australia, Feb 2014 – Life Expectancy* (2014) <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4125.0main+features3110Feb%202014>.

[16] The proportion of the Australian population aged over 65 years in 1901, 2012 and 2040 (projected) was/is/will be: 4, 14 and 20 per cent respectively; and aged over 85: 0.1, 2 and 4 per cent. See, Australian Bureau of Statistics, *Population Projections, Australia, 2012 (base) to 2101 – Media Release* (2013) <http://www.abs.gov.au/ausstats/abs@.nsf/lookup/3222.0Media%20Release12012%20%28base%29%20to%202101>.

[17] Swerissen and Duckett, above n 2.

[18] Australian Bureau of Statistics, *Causes of Death, Australia, 2012 - Overview* (2014) <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/3303.0~2012~Main%20Features~Leading%20Causes%20of%20Death~10001>.

[19] Australian Bureau of Statistics, *Causes of Death, Australia, 2012* – Circulatory Diseases and Cancers (2014) <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/3303.0~2012~Main%20Features~Circulatory%20Diseases%20and%20Cancers~10037>.

[20] Australian Bureau of Statistics, *Causes of Death, Australia, 2010 - Overview* (2012) <http://www.abs.gov.au/ausstats/abs@.nsf/0/6BAD463E482C6970CA2579C6000F6AF7?opendocument>.

[21] Andrew Robinson et al, 'Who Knows, Who Cares? Dementia Knowledge Among Nurses, Care Workers, and Family Members of People Living With Dementia' (2014) 30 *Journal of Palliative Care* 158.

often occur as part of the increasing chronic disease burden, and the ABS now reports data on multiple causes of death.[22]

Joanne Lynn, a US public health expert, has described three model pathways of dying: (i) a rapid decline (often from incurable cancer), (ii) gradual deterioration with increasing frequent and severe crises (typically chronic obstructive airways disease and heart failure), and (iii) prolonged 'dwindling' (death in frail 'old' old age: 80s and 90s, gradual deterioration with very limited physiological reserve, and often seemingly relatively trivial final cause).[23]

The result is that, in 2015, people are living longer than ever before. This trend is ongoing and almost global. The nature of any limits on human longevity is controversial in gerontology,[24] but it does seem that it will continue to be unusual to exceed the age of 100, although even this great age is being reached by increasing numbers of Australians.[25] The downside to these expanding life spans, however, is that people live with increasing levels of morbidity and disability as they age, with concomitant symptom burdens and dependence levels. These, in turn, result in more frequent encounters with the health system and more clinical decision-making events. If death is not sudden or unexpected (eg, accident, myocardial infarction, suicide), the dying process or 'end of life' is now often one to two years. Murray has posited a 'no surprises' question in which primary care clinicians are asked the question: 'would you be surprised if the patient were to die in the next year?' If the answer is 'no', a shift of care to a palliative approach is implemented.[26] This question is the basis of the Gold Standard Framework ('GSF') in the UK National Health Service.[27]

While it is well accepted that it takes 18 years to grow to adulthood, there is no such socially accepted space to recognise a slow process of dying in old age. Indeed, most 'healthy ageing' emphasises positivistic approaches and attitudes that ignore or downplay the realities of death and dying. It is this that lies behind the seemingly oxymoronic health promotion concept of 'healthy' dying (see below).

There were 147 678 registered deaths in Australia in 2013.[28] It has been estimated that approximately three quarters of these can considered as 'anticipated' as they result from

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[22] Australian Bureau of Statistics, *Causes of Death, Australia, 2012 – Multiple Causes of Death – in Detail* (2014) <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/3303.0~2012~Main%20Features~Multiple%20Causes%20of%20Death%20-%20In%20Detail~10025>.

[23] Joanne Lynn, 'Living Long in Fragile Health: The New Demographics Shape End of Life Care, Improving End of Life Care: Why Has It Been So Difficult?' (2005) 35(6) *Hastings Center Report Special Report* S14.

[24] See Tom Kirkwood's 2001 Reith Lectures: British Broadcasting Corporation, *The End of Age* (2001), <http://www.bbc.co.uk/radio4/reith2001/>.

[25] Australian Government, The Treasury, *2015 Intergenerational Report* (2015) <http://www.treasury.gov.au/PublicationsAndMedia/Publications/2015/2015-Intergenerational-Report> viii.

[26] See Martin Denvir et al,'Future Care Planning for Patients Approaching End-of-Life with Advanced Heart Disease: an Interview Study with Patients, Carers and Healthcare Professionals Exploring the Content, Rationale and Design of a Randomised Clinical Trial' (2014) 4(7) *BMJ Open* e005021; Scott Murray and Kirsty Boyd, 'Using the "Surprise Question" Can Identify People with Advanced Heart Failure and COPD Who Would Benefit From a Palliative Care Approach' (2011) 25 *Palliative Medicine* 382.

[27] See Gold Standards Framework website for details of the approach in the NHS (UK), a comprehensive set of tools and procedures to identify people reaching the end of life who needs a palliative approach to care, with an emphasis on primary care and culture change: NHS, *The Gold Standards Framework* (2015) <http://www.goldstandardsframework.org.uk>.

[28] Australian Bureau of Statistics, *Deaths Registered, Australia, Selected summary details – 2003, 2012 and 2013* (2014) <http://www.abs.gov.au/ausstats/abs@.nsf/mf/3302.0>.

chronic diseases such as cancer, dementia, heart and lung failure.[29] More than 31 500 patients accessed specialist palliative care services in 2013, and this number is rising annually, with, for example, an increase of 3.6 per cent in 2013 compared to 2012.[30] While this population of patients tends to be very debilitated, those patients on community programs are often ambulant and manage to retain significant levels of function, independence and comfort for weeks and often months before death. However as death approaches all of these parameters change, resulting for example in 10 per cent of patients in hospice/inpatient palliative care unit being comatose, and around 20 per cent totally bedridden. Even in community programs where most people are ambulant but require assistance, 11 per cent are in bed for 50 per cent of the time.[31]

Symptom burden is high. Most studies list pain, fatigue, impaired appetite, weight loss, bowel problems, nausea and shortness of breath as the most prevalent, intrusive or distressing.[32] While all diseases, even cancer, have specific symptom patterns but variable incidence and prevalence, comparative studies show that whatever the underlying diagnosis or diagnoses and hence cause of death, the final common pathway for most diseases has a cluster of core common symptoms in the pre-terminal and terminal phase. This has been demonstrated for advanced cancer, AIDS, heart disease, chronic obstructive lung disease and end stage renal failure.[33] The cluster consists of what might be termed generalised 'constitutional' symptoms of tiredness, lack of energy and appetite, coupled with shortness of breath, and pain (often vague, flitting and non-specific), to which one might add cognitive impairment. As death approaches, this constitutional capacity to carry out one's will reduces and eventually disappears altogether in the last hours or days of life. The will can fight against diminishing strength only for so long before it is overwhelmed and has no 'petrol in the tank' left to ignite.

Data provided by the Palliative Care Outcomes Collaboration ('PCOC')[34] for the palliative care service in southern Tasmania show that patients who are judged to be in a stable phase of their illness trajectory have significant levels of moderate fatigue (58.7 per cent) and pain (20.6 per cent), and these levels rise steeply for unstable patients: (moderate fatigue 75 per cent) and (pain 43.1 per cent). Pain is a significant driver (or reflection) of instability: 25.5 per cent of unstable patients have severe pain, as opposed to 1.9 per cent of stable patients. National figures suggest that approximately 50 per cent of patients who have an episode of moderate/severe pain at the beginning of an episode of palliative care will report no pain at the end of the episode of care.[35]

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[29] Palliative Care Australia, *Health System Reform and Care at the End of Life: A Guidance Document* (2010) 24 <https://www.pcvlibrary.asn.au/download/attachments/2917053/Care+at+the+end+of+life.pdf?version=1&modificationDate=1327895181539>.

[30] Australian Institute of Health and Welfare, *Palliative Care Services in Australia 2014* (2014) <http://www.aihw.gov.au/publication-detail/?id=60129548894>.

[31] Palliative Care Outcomes Collaboration (PCOC), *National Report on Patient Outcomes in Palliative Care in Australia* (Report 16, 2013) <http://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow169129.pdf>.

[32] Jean Potter et al, 'Symptoms in 400 Patients Referred to Palliative Care Services: Prevalence and Patterns' (2003) 17 *Palliative Medicine* 310.

[33] Joao Paulo Solano, Barbara Gomes and Irene J Higginson, 'A Comparison of Symptom Prevalence in Far Advanced Cancer, AIDS, Heart Disease, Chronic Obstructive Pulmonary Disease and Renal Disease' (2006) 31 *Journal of Pain and Symptom Management* 58.

[34] See PCOC, above n 31.

[35] Ibid.

Recent trials have shown that referrals to a palliative care service can improve not just quality of life for patients with incurable lung cancer, and of those who survive them, but there could also be a small survival advantage for earlier referral as well.[36] Although length of survival was not the main reason for establishing palliative care services, these studies tend to debunk the idea that good palliative care (which proactively manages the dying process and acknowledges incurability as well as the inevitability of death) actually shortens life by demoralising people.

There are conceptual disagreements about what, if anything, may constitute a 'good' death. Research and experience of those in the field of death and dying reveal that dying people, and those who care for or about them, are able to have a rich conversation in the right settings, including in well designed and executed research studies. A simple landmark qualitative study conducted in Chicago in 2000 showed that patients and families fear bad dying more than death itself. Dying people indicated a strong sense of value in good pain and symptom management, clarity of decision-making, preparation for death, completion, and affirmation of the whole person. They placed a high priority on making contributions of gifts, time and money (meaning/role/usefulness). They also sought to decrease the family burden by planning ahead, arranging affairs, and saying goodbye. Doctors, perhaps understandably, given their core professional responsibilities, tended to emphasise biomedical aspects.[37]

C *Where?*

Place of death figures large in debates around the management of death and dying. This is primarily because those people surveyed when well tend to say that in the event of a foreseen dying process they would prefer to die at home. At first glance it may seem strange to interrogate this rational, emotional and social wish further, given that hospital and residential facilities have capacity limits, and hospital 'avoidance' is a major challenge for all health services. However the reality is not so straightforward. It is undisputed that death and the dying process became 'institutionalised' through the second half of the 20th century. It is equally clear that this process remains stubbornly embedded in western countries with high bed capacities and social structures that tend to 'outsource' care. For instance, in the three influential think-tank reports cited above,[38] it is acknowledged that hospital death rates remain high, and community capacity for care of sick, elderly and dying people is in need of further development and reform, with reorientation of existing services to accommodate the aspiration of dying at home. In the UK, where modern palliative care as it is now understood was first conceived, the home death rate has remained stubbornly low at under 20 per cent despite half a century of innovation and service development, and the UK being ranked by EIU as the world's best provider of such palliative care. Denominator is everything in these comparisons, and whole of jurisdiction data on place of death are hard to obtain. Palliative care service data are of course skewed towards home and hospice death. For instance, in Tasmania approximately 4000 people die each year, and of those who die in an inpatient bed, it is estimated that between 40 and 50 per cent are referred to the palliative care services.[39]

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[36] Ian Haines, 'Managing Patients With Advanced Cancer: the Benefits of Early Referral for Palliative Care' (2011) 194 *Medical Journal of Australia* 107.

[37] Karen E Steinhauser et al, 'In Search of a Good Death: Observations of Patients, Families and Providers' (2000) 132 *Annals of Internal Medicine* 825; Karen E Steinhauser et al, 'Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers' (2000) 284 *Journal of the American Medical Association* 2476.

[38] Economist Intelligence Unit, above n 1; Swerissen and Duckett, above n 2; Leadbetter and Garber, above n 6.

[39] Unpublished Work, Guy Bannink, Email to Michael Ashby, 1 March 2015.

It is clear that different cultures and health systems generate wide variations in place of death statistics, with an overall trend for institutional death rates to remain high in many countries, even where significant community palliative care capacity has been well established for many years. For citizens over 65, 2005 Australian data shows that 54 per cent of deaths occurred in hospitals, 32 per cent in nursing homes and 14 per cent at home or other sites (middle range in international ranking).[40] This can be compared to New Zealand in 2003-2007 with 34 per cent; 38 per cent and 28 per cent respectively (lowest hospital death rate in the world); and to comparable UK 2008 figures of 57 per cent, 21 per cent, and 23 per cent.[41] In Canada, 2006 data from Manitoba shows a middle range of 51 per cent, 32 per cent, and 17 per cent. Among developed countries, Japan and South Korea both have the highest hospital death rates of 69 per cent and 67 per cent respectively.[42]

Specialist palliative care services in Australia tend to operate a triangular care model with regard to location of care, accompanying people as they move around the health system according to needs and wishes, whether it is home (own home, another family home or residential facility), hospital, or inpatient palliative care unit. However, the capacity of specialist services to change location of death and the final terminal phase to home instead of hospital or nursing home is limited. The availability of another able-bodied person in the house around the clock is a real obstacle, as are social factors. Carer research indicates that much can be done to support carers, and there is no room for complacency.[43] Symptoms like incontinence, falls, wandering, delirium and insomnia all make home care difficult and tend to result in admissions. There is also a cultural and social expectation that serious illness and deterioration necessitates professional care, and home care recommendations may be seen as reckless or uncaring. Indeed the intervention of professional domiciliary services may de-skill and marginalise informal networks.[44]

The concept of the 'good enough' death attempts to deal with the idealisation potentially implicit in the 'good' death. It is about recognising that the realistic aim is the best death in the circumstances, as dying is a reflection of the life lived, coupled with the luck of biological fate. Just as birth can be unpredictable, so dying can be turbulent and challenging.[45]

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[40] Joanna Broad et al, 'Where Do People Die? An International Comparison of the Percentage of Deaths Occuring in Hospital and Residential Care Settings in 45 Populations, Using Published and Available Statistics' (2013) 58(2) *International Journal of Public Health* 58, 257-267

[41] Ibid.

[42] Swerissen and Duckett, above n 2.

[43] See various contributions in Peter Hudson and Sheila Payne (eds), *Family Carers in Palliative Care: a Guide for Health and Social Care Professionals* (Oxford University Press, 2008).

[44] Debbie Horsfall, Kerrie Noonan and Rosemary Leonard, *Bringing Our Dying Home: Creating Community at End of Life* (Research Report, University of Western Sydney and Cancer Council of NSW, 2011).

[45] This terminology is taken from the work of the English child psychotherapist DW Winnicott (1896-1971). See Donald W Winnicott, *Home is Where We Start From* (Penguin, 1986). For reflections on the good and good-enough death in hospice and palliative care, see the following: Beverley McNamara, Charles Waddell and Margaret Colvin (1994) 'The Institutionalisation of the Good Death' 39 *Social Science and Medicine* 1501; Beverly McNamara, Charles Waddell and Margaret Colvin, 'Threats to the Good Death: the Cultural Context of Stress and Coping Among Hospice Nurses' (1995) 17 *Sociology of Health and Illness* 222; Bethne Hart, Peter Sainsbury and Stephanie D Short, 'Whose Dying? A Sociological Critique of the "Good Death"' (1998) 3(1) *Mortality* 65.

III ACKNOWLEDGING THE PROCESS OF DYING IN MEDICINE, ETHICS, LAW AND SOCIETY

It is not possible to deploy appropriate and necessary palliative care unless there is assessment and acknowledgement of the dying process. Community expectations of the capacity of modern medicine to prolong life are often at variance with reality. Discussion of death, and preparation for it, do not occur easily in countries like Australia, and there are powerful forces at work that may present barriers to dealing with the realities of death and dying. The demographic trends as seen above not only show large life expectancy increases, but also diminish the reality of death.

Technological advances mean medicine can do so much more. Professionalism dominates medical matters in everyday life so that illness, death and dying, grief and loss are seen as being in the province of specialists. Religious and spiritual life is much more in the province of the individual, with post-modern and existential world-views replacing traditional communitarian denominational church-based structures, which are mostly in decline. Social lives are more individualistic, with increased national and international social mobility, the ever-changing nature of communities, and multiculturalism.[46] Care should be exercised in making these sweeping generalisations lest a misleading revisionist picture of death in history is painted as halcyon days when ordinary people knew how to 'do' dying. It seems doubtful that any modern person would want to return to the unrelieved suffering of the past when people had no alternative to death at home without medical help, particularly given the protracted chronic diseases journeys of most people today described earlier. However, it is important to question and, where necessary, move away from excessive 'medicalisation' of dying, especially where this over-emphasis of medical intervention occurs at the expense of other personal, social and spiritual aspects of life, and has negative and unsustainable consequences for the economy.

A *Barriers to Care and Decision-Making at the End Of Life*

There are a number of major attitudinal barriers to good end of life care for clinicians. Firstly, health professionals and families struggle with death 'talk'.[47] Based on the assumption that you cannot initiate talk of death because patients and families do not want it and you run the risk of precipitating death if you do ('don't talk about death; it will kill him') there is a widespread tendency to avoid it. Secondly, there is a pervasive view that you have to do everything to maintain and prolong life otherwise you are causing death ('you can never give up on a patient'). This is powerfully backed up by a perceived threat of ethical or legal sanction unless all possible treatment is given to patients, no matter how slim the odds of a favourable response or outcome. Thirdly, there is still a lingering doubt that the use of opioids and sedatives in palliative care may contribute to the cause of death, so symptom control is compromised. These barriers are not actually primarily medical in origin: they arise from social, ethical, religious and political considerations of death and dying that are deeply embedded in history, culture

[46] See Pat Jalland, *Australian Ways of Death: a Social and Cultural History 1840-1918* (Oxford University Press, 2002) and *Changing Ways of Death in Twentieth Century Australia: War, Medicine and the Funeral Business* (University of New South Wales Press, 2006) for magisterial accounts and analysis of historical trends in death and dying in Australia, and her other works for similar insights in England, especially with regard to the influence of war.

[47] See Brendan Murphy's 2008 editorial in the *Medical Journal of Australia* exhorting clinicians, especially medical unit heads to take the lead in decision-making at the end of life: Brendan Murphy, 'What Has Happened to Clinical Leadership in Futile Care Discussions?' (2008) 188 *Medical Journal of Australia* 418.

and politics. Nonetheless, preparation for death is an intrinsic spoken or unspoken part of most cultures and religions across time and geographical location.[48]

Catherine Mayer has suggested that it is not so much that we believe ourselves to be immortal, but that we behave as if death does not exist: that is, we are now 'amortal'. She posits the view that we tend not to want to act according to our ages. The narrative of middle life and old age is one of defying any 'natural' limitations that our bodies or society appear to impose upon us.[49] On the other hand, Isaiah Berlin, a Russian-born Jewish intellectual, student of the history of ideas and of the concept of liberalism, who grew up in England and held a chair at Oxford for many years, responded to the deportation of fellow Jews to death camps (usually without knowledge of their fates) by describing it as an affront to their human dignity because this ignorance robbed them of the chance to face death.[50] This is a confronting challenge for present times, suggesting that dealing with death is an existential responsibility for each mature adult.[51] The 'choice' then is not between one treatment and another, or opting in or out of life-prolonging interventions or life support at the margin of life, but whether to face up to and deal with one's own dying.

In the modern western world there is much more emphasis on the individual. In the post-modern existentialist construct each person is responsible for developing their own narrative and meaning. The body is predominant, and for those who have no religious faith, there is often an absence of channels for transcendence of suffering, especially that of the body, but also so-called existential' suffering. Kellehear has pointed out that dying has become part of the trials of 'here and now' of 'this-world' as opposed to 'other world' spirituality.[52] Palliative care, which adopts a holistic multidisciplinary care model and 'total' pain concept, attempts to help patients to deal not only with physical pain and symptoms, but also emotional, spiritual and social/relational issues as death approaches.

B *Preparing for Death: Advance Directives and Care Planning*

While considerable work is being done within health to improve care and decision-making at the end of life, it is clear that death and dying is everybody's business. The community does not speak with one voice on these issues: there is a wide spectrum of opinion and behaviour from 'keep me alive at all costs, no matter what the circumstances' through to 'let me die' and 'help me to die'. While on the one hand there are well-documented obstacles to the changing of goals of care as death approaches, on the other hand there is an on-going debate in most OECD countries about the legalisation of voluntary euthanasia and/or physician-assisted suicide, largely fuelled by public concern about the nature of the dying process.

It seems clear that much more public debate and education about end of life issues is needed, and that it is important to encourage all citizens to ensure that they make their wishes known

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[48] See for instance: Drew Gilpin Faust, *This Republic of Suffering: Death and the American Civil War* (Alfred A Knopf, 2008); Thomas Kselman, 'Death in the Western World: Michel Vovelle's Ambivalent Epic La mort et l'Occident, de 1300 à nos jours' (2004) 9(2) *Mortality* 168; Allan Kellehear, *A Social History of Dying* (Cambridge University Press, 2007).

[49] Catherine Mayer, *Amortality: The Pleasures and Perils of Living Agelessly* (Random House, 2011).

[50] Michael Ignatieff, *Isaiah Berlin: A Life* (Vintage, 2000).

[51] Failure to do so might be seen as 'mauvaise foi' (literally, 'bad faith') in Sartre's 'existentialist' world view: Jean-Paul Sartre, *Essays in Existentialism* (Citadel Press, 1993).

[52] Kellehear, above n 48.

for end of life care so that those around them will have the authority and confidence to stop treatment that is not working, and re-direct care to the goals of comfort, quality and dignity. Substitute decision-making and Advance Care Directives are important tools to ensure that patient wishes are carried out, and that the dying process is not drawn out in a way that benefits nobody, misuses health resources, and fails to address the real needs of patients, their families and carers. Health promotion techniques are needed to ensure that the whole community is engaged in reform and behavioural change.

Advance care planning needs to meet the challenges of limitation of medical treatment and the dying process head-on. Whilst capacity is important, broader action is required. Perhaps the writing of an Advance Care Directive using a format that addresses end of life issues as well as other preferences, beliefs, values and unacceptable treatment outcomes is more pertinent for those diagnosed with life threatening illnesses, or those reaching older ages such as those over 70 (the peak dying time for Australians is now 70-85 years), all adults should be encouraged to talk to those close to them about mortality and their wishes about unacceptable treatment outcomes. They should also be encouraged to appoint an Enduring Guardian (or equivalent substitute decision-maker). Enduring Guardian appointments, including those that specify aspects of personal care, should be actively sought and incorporated into a care plan if the person is admitted into hospital or aged care facility.

C *Communication and 'Death Talk'*

It is important to acknowledge that talking about death and dying, and specifically addressing limitations of medical treatment is both necessary and possible. Training medical practitioners in communication skills has been shown to improve technique, patient satisfaction and confidence.[53] It is always important to start by finding out what the patient and/or family/substitute decision maker understand about the current situation and realistic options available.

Open questions are often the best approach. Questions such as 'how do you see the future?' and 'what are your hopes/fears?' are often revelatory. Doctors often forget how frightened and apprehensive people are in their presence, especially where bad news is anticipated. The 'fight or flight' survival mechanism tends to be operating, and patients' deep listening, logic and learning abilities are shut down or compromised. This means that rational decision-making and information retention may be impaired. Patient and family behaviour may be erratic and tend to mirror the kind of non-linear oscillation that has been well described in the bereaved. In what is known as the Dual Process Model, grieving people move in and out of normal functioning and grief behaviour, often in seemingly random and unpredictable ways. So too, sick people dealing with the threat of impending death often appear to oscillate between reality and hope.[54] Much is also conveyed non-verbally in behaviour, and patients may make us feel things they struggle to tell us in words. There is clearly scope for more psychodynamic understanding in both palliative care and grief work. It is also now clear that dementia is increasing in both incidence and as a recognised principal or contributory cause of death. For most people, regardless of diagnosis, some degree of cognitive impairment is common as death approaches, and eventual terminal restlessness and frank delirium are also often seen prior to eventual coma

[53] See for example, Jonathan Silverman, Suzanne Kurtz and Juliet Draper, *Skills for Communicating With Patients* (Radcliffe Medical Press, 3rd ed, 2013) and University of Washington, *Oncotalk: Improving Oncologists' Communication Skills* <http://depts.washington.edu/oncotalk/>.

[54] Margaret Stroebe and Henk Schut, 'The Dual Process Model of Coping With Bereavement: Rationale and Description' (1999) 23 *Death Studies* 197.

in the final hours or days of life. It is therefore clear that impaired or absent capacity, and legal incompetence, must be anticipated as either a long-term executive issue, or a final terminal state.

D *Health-Promoting Palliative Care*

At first glance the term 'health-promoting' in reference to palliative care and end of life issues might seem almost oxymoronic. However, Allan Kellehear has pioneered the notion of public health promoting palliative care. He identifies major social barriers to dealing with death, and proposes that well-established and effective principles of public health, as laid out in the Ottawa Charter, be used to empower the whole community to deal with death in a more open, direct and 'healthy' way. Kellehear has summarised the goals of health-promoting palliative care as follows:

- provide education and information for health, death and dying
- provide both personal and social supports
- encourage interpersonal reorientation towards a 'natural' death
- encourage reorientation of palliative care services towards public health ideas of prevention, harm reduction and community participation
- combat death-denying health policies and attitudes.[55]

In Tasmania a 'Healthy Dying' initiative has been developed to improve care and decision-making at the end of life.[56] This consists of three components: a 'Goals of Care' framework, an Advance Care Directive for the End of Life, and a number of health-promoting professional and community interventions to raise awareness.

A Goals of Care form has replaced the 'NFR' form at several Australian hospitals and health services. It provides a clinical framework for setting realistic goals during an episode of care into one of three phases: curative/restorative, palliative and terminal. Limitations of medical treatment that are proportional to the assigned phase are transparently established and negotiated, and documented on a dedicated form in the notes. It is based on the 'Physician Orders for Life Sustaining Treatment' ('POLST') approach in the USA.[57] It is a medical order to clarify any limitations of medical treatment for a present condition, and is to be distinguished from advance directives that are usually made by people, in their own 'voice', to inform medical decision-making for future episodes of impaired capacity.[58]

E *Death Causation: Ethical and Legal Basis of Palliative Care*

Two opposing views of death causation, as it applies to care at the end of life, appear to be operating in western societies. On the one hand, modern medical practice, based on the Judaeo-Christian tradition of law and ethics, takes a forensic view of 'natural' death and does not permit human agency to be implicated. Consistent with this, palliative care practitioners hold

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[55] Alan Kellehear, *Health Promoting Palliative Care* (Oxford University Press, 1999); Alan Kellehear, *Compassionate Cities: Public Health and End-of-Life Care* (Routledge, 2005).

[56] Department of Health and Human Services, Tasmanian Government <http://www.dhhs.tas.gov.au/__data/assets/pdf_file/0006/96378/Web_Healthy_Dying_info_combined.pdf>.

[57] POLST – Physician Orders for Life-Sustaining Treatment Paradigm (2015) <http://www.polst.org/>.

[58] Robyn Thomas et al, 'Goals of Care: a Clinical Framework for Limitation of Medical Treatment' (2014) 201 *Medical Journal of Australia* 452.

a position of causal 'neutrality', whereby the process of dying is stated to be neither hastened nor prolonged. On the other hand, there is widespread support for euthanasia, which explicitly allows death to be caused in certain circumstances, at the patient's request.

A study of medical, legislative, legal and parliamentary scrutiny of end of life issues in Australia 1983-1998, and in four comparable OECD countries: the United Kingdom, Canada, USA and New Zealand collated and analysed the arguments about death causation in palliative medicine. All the reports, judgments and parliamentary committee proceedings studied assume that palliative care interventions and treatment abatement decisions may constitute a cause of death. However, these are allowed in law in those jurisdictions due to the public policy imperative to relieve pain and suffering and avoid prolongation of the dying process.[59]

The incorporation of this causal assumption into law and public policy can be traced back to a famous passage of Justice Devlin's instructions to the jury in the case of *R v Adams*[60] in 1957. Devlin J used double effect reasoning to render lawful the use of escalating morphine and heroin doses which contemporary medical evidence had informed the court might have the incidental effect of shortening the life of a dying person.[61] The experience of the hospice and palliative care movement over the past three decades has shown that the safe and effective use of morphine, other opioids, and sedatives in pain and symptom control need not bring cause of death into question. Similarly, treatment abatement is undertaken when futility can clearly be demonstrated for dying persons. It is clear that there is no basis for fear of legal sanction by health professionals if the prevailing standards of palliative care are adhered to. The law takes a common sense and multifactorial view of causation, and will often not even apply a causal analysis, focusing more on legality of actions and presence or absence of duties instead.[62]

Causation can be an important analytical and reflective component of the process of determining whether palliative care is ethical and legal. However, neither the natural death concept, in the strictly forensic sense, nor the palliative care position of causal neutrality can be empirically defended in all cases, and it is not usually helpful or appropriate to do so. Natural death can be more fruitfully understood in a broader existential sense of inevitability, as a composite of causality, autonomy and dignity, and not solely in terms of the presence or absence of human agency. The goals and intentions of drug prescribing and principles of pharmacology in palliative care can and should be made clear.

The Ontario coroner Dr James Young has captured the essence of the basic underlying principles of therapeutic intervention in palliative medicine. He lay down four conditions that need to be satisfied for palliative care interventions to be legal in his jurisdiction:

> (1) The care must be intended solely to relieve suffering; (2) it must be administered in response to suffering or signs of suffering; (3) it must [be] commensurate with that suffering; and (4) it cannot be a deliberate infliction of death. Documentation is required, and the doses must increase progressively.[63]

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[59] Michael Ashby, *Natural Death? Palliative Care and Death Causation in Public Policy and the Law* (Doctor of Medicine Thesis, University of Adelaide, 2001) <http://digital.library.adelaide.edu.au/dspace/handle/2440/38237>.
[60] *R v Adams* [1957] Crim LR 365.
[61] Ibid.
[62] See also Ben White, Lindy Willmott and Michael Ashby,'Palliative Care, Double Effect and the Law in Australia' (2011) 41 *Internal Medicine Journal* 485.
[63] See Parliament of Canada, *Of Life and Death: Report of Special Senate Committee on Euthanasia and Assisted Suicide* (Minister of Supply and Services Canada, 1995) 26; also James Lavery and Peter Singer, 'The "Supremes" Decide on Assisted Suicide: What Should a Doctor Do?' (1997) 157 *Canadian Medical Association Journal* 405.

The intention is to relieve symptoms and suffering, not bring forward the time of death. Whilst this position is sustainable in the palliative phase, it is susceptible to challenge in the terminal phase when death is imminent. It should be acknowledged by practitioners that as death approaches, abatement of life-sustaining treatment and terminal sedation may indeed alter the time of death, although this matter cannot be verified scientifically, one way or the other, in a particular case, or in general. There are serious limitations to the use of clinical studies in this area, and, for obvious reasons, the causal question itself cannot be directly asked in any interventional study. In the absence of palliative interventions or treatment abatement, particularly during the final dying process, we cannot know when a particular patient would have died, and it would be unethical to design controlled trials to find out.

F *Treatment Abatement And Sedation For Incompetent Patients*

Legal scholars have recently argued that there is an uneasy status quo with regard to treatment abatement and terminal sedation - two standard practices in modern palliative care in countries such as Australia, New Zealand, Canada and the UK. Downie, Willmott and White reviewed the legal understanding of unilateral withdrawal of medical treatment for incompetent persons and concluded that the legal basis for such decisions is confused, unreliable and lacks transparency.[64] They argue for this area of law to be tightened up, especially in federal countries, with appropriate consistent legislation that ensures that the issue of consent is dealt with. McLean reviewed terminal sedation practices and concluded that sedation, particularly without medical provision of nutrition and hydration for incompetent persons, may similarly be found to be unlawful.[65] While the major argument is based on autonomy and patient consent, causation is also a concern for many in these two areas.

1 *Sedation*

Sedative drugs are commonly used in terminal care when death is believed to be imminent, in order to maintain comfort and dignity by alleviating agitation, anxiety and so-called terminal restlessness. They are used proportionately to the patient's distress; not to bring about death.[66] It is clear that there is robust disagreement, even within medicine itself, about whether such treatment contributes to the cause of death, and even about what the therapeutic goals are or should be. There are those who contend that within accepted palliative care practice patients are sedated, and the cause of death is either through central nervous system and respiratory depression, or dehydration and starvation. Certainly, palliative care practitioners rarely use morphine for its sedative properties at any stage of an illness, especially when patients are trying to function as normally as possible, and sedation is usually unwelcome. Morphine may even aggravate terminal restlessness in terminal care, probably due to metabolite accumulation. In terminal care sedatives are titrated against agitation and distress, but occasionally also

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[64] Jocelyn Downie, Lindy Willmott and Ben White, 'Cutting the Gordian Knot of Futility: a Case For Law Reform on Unilateral Withholding and Withdrawal of Potentially Life-Sustaining Treatment' (2014) 26 *New Zealand Universities Law Review* 24.

[65] Sheila McLean, 'Terminal Sedation: Good Medicine? Good Ethics? Good Law?' (Keynote address delivered at the International Conference on End of Life: Law, Ethics, Policy and Practice, QUT, Brisbane, 14-15 August 2014) <https://www.youtube.com/watch?v=dYZrHUcvc-c>.

[66] Michael Ashby, 'The Fallacies of Death Causation in Palliative Care' (1997) 166 *Medical Journal of Australia* 176; Danuta Mendelson, 'Quill, Glucksberg and Palliative Care – Does Alleviation of Pain Necessarily Hasten Death?' (1997) 5 *Journal of Law and Medicine* 110.

against another symptom (eg pain or shortness of breath) where other measures have failed and the patient may wish to be less aware of what they are going through. If patients are conscious they are consulted and asked if they wish to be more sedated, but they are often unable to give consent due to incompetence. It should be noted that patients are usually unconscious and/or cognitively impaired, and therefore incompetent, at this stage. Therefore it is clearly not possible to state categorically that such sedation has no effect on time of death. However this is not the really important question, being superseded by the comfort and dignity of the person. The precise timing of death is unpredictable, and verification of the relative causal contributions to that timing of disease, together with physiological and pharmacological factors, is not usually measurable. Outside the setting of terminal care, the use of sedatives to the point of sleep or deep coma for the relief of suffering, sometimes known as 'pharmacological oblivion', is not part of accepted palliative care practice, especially not as a way of ending a patient's life.

2 *Treatment Abatement*

Abatement of burdensome and purposeless treatment during the process of dying does not constitute a cause of death: it is an integral component of palliative care practice. Treatment-related toxicity is diminished or abolished, and the process of dying is not unnecessarily prolonged. Nonetheless, in certain treatment abatement decisions concerning imminently dying persons, for example in the case of *Bland*,[67] death is the intended outcome of treatment abatement. However justified, agreed, appropriate and necessary, this is not part of palliative care practice for dying people.

Downie et al[68] and McLean[69] rightly state that law and clinical practice are inconsistent, at times confused and confusing, and may lack transparency. As a result they warn us that, if tested at law, treatment abatement decisions and terminal sedation episodes may indeed lead to adverse outcomes for practitioners and their employers. This is of course alarming, as defensive clinicians (and substitute decision-makers), fearful of real or inaccurate perceptions of what is required by law, and ethics, will tend not make the decisions necessary to ensure peaceful, unobstructed dying. Seeking a legislative remedy, especially in federal countries where it is difficult to introduce uniform legislation, is a slow and uncertain monumental undertaking which runs the risk of reducing flexibility or creating new unintended legal problems.[70] Where actual medical treatment choices are limited, and pain and distress require immediate action, a more timely remedy would be to alter clinical practice to ensure that a process of contemporaneous 'bedside' consensus is established about treatment abatement and symptom management for people in the terminal phase who lack capacity.[71] This process needs to be based on trust, best interests, and sound clinical assessment delivered by competent clinicians trained to communicate in the necessary conversations.

Using the 'goals of care' approach described earlier, it is suggested that in phase D – the last hours or days of life – a form of 'therapeutic privilege', well established to save life in emergency situations, is permitted for the care of incompetent and imminently dying persons.

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[67] *Airedale NHS Trust v Bland* [1993] 1 All ER 821.
[68] Downie, Willmott and White, above n 64.
[69] McLean, above n 65.
[70] White, Willmott and Ashby, above n 62.
[71] Michael Ashby, Alan Kellehear and Brian Stoffell, 'Resolving Conflict in End-of-Life Care' (2005) 183 *Medical Journal of Australia* 230.

Depending on the jurisdictional requirements, the onus would be on medical practitioners to communicate with, and consult, any substitute decision-makers or persons responsible, and to demonstrate, if need be, to a tribunal or court, that the dying process was underway.[72] It should also be established, in both medical practice and law, that the 'necessaries of life' provisions are suspended in this imminent dying phase, and any legally perceived requirement for medical provision of hydration and nutrition is also dismissed. The basis of the finding in the *Re BWV* case[73] was that medical provision of hydration and nutrition is indeed medical treatment and should be subject to the same evaluative process before deployment as any other. The question is, do hydration and nutrition, on balance, confer benefit on the patient?[74] For an imminently dying person the answer to this is negative: it is a normal part of the dying process for oral intake to slow and stop, and for absorption and digestive processes to cease operation.[75]

It is not the intention of this paper to suggest that need for consent and respect for personhood and autonomy cease before life lapses, nor to restore some kind of medical ascendancy or paternalism, but rather to propose a common sense attempt to remove barriers to dying in the twilight between life and death at the point where decision-making capacity is either minimal or permanently gone. A 'collective gaze' provides transparency and appropriate, timely and necessary terminal care consistent with what is known of the dying person and the realities of the situation, and is framed in ethics rather than avoidance of potential legal sanction.

The last word on this should lie with Justice Thomas, a New Zealand judge, who made the following statement in his judgment in the case of *Auckland Area Health Board v Attorney-General*,[76] where the court was being asked to consider the removal of ventilator support from a patient with very severe Guillain-Barré syndrome:

> Medical science and technology has advanced for a fundamental purpose: the purpose of benefiting the life and health of those who turn to medicine to be healed. It surely was never intended that it be used to prolong biological life in patients bereft of the prospect of returning to an even limited exercise of human life. Nothing in the inherent purpose of these scientific advances can require doctors to treat the dying as if they were curable. Natural death has not lost its meaning or significance. It may be deferred, but it need not be postponed indefinitely.[77]

IV CONCLUSION

The process of dying has probably never been easy unless it is sudden, and despite substantial progress in pain and symptom relief, the chronic disease trajectories of the early 21st century bring new challenges. The (usually) short episodes of unrelieved suffering in the dying of the past have been replaced with longer periods of deterioration and 'area under the curve' of symptom burden, dependence and both global physical and mental deterioration.

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[72] It is not suggested that this exemption be deployed for non-dying persons where life support withdrawal authorisation is being sought. Such decisions do need to be considered, but may require more scrutiny, including legal processes, as death is not imminent.

[73] *Gardner; re BWV* [2003] VSC 173 (29 May 2003).

[74] Michael Ashby and Danuta Mendelson, 'Gardner; Re BWV: Victorian Supreme Court Makes Landmark Australian Ruling on Tube Feeding' (2004) 181 *Medical Journal of Australia* 442.

[75] Pamela Van der Riet, Denise Brooks and Michael Ashby, 'Nutrition and Hydration at the End of Life' (2006) 14 *Journal of Law and Medicine* 182.

[76] *Auckland Area Health Board v Attorney-General* [1993] 1 NZLR 253.

[77] Ibid 253; The court allowed the cessation of ventilatory support.

In care and decision-making at the end of life the deliberative processes and discourse should move away from the almost exclusive focus on human agency and death causation (important though this is) and embrace non-obstruction of the dying process and self-determination so that natural death is seen as having a composite meaning embracing both forensic and existential senses. In the final analysis all would surely agree that there is more to a 'good' or 'good enough' death than causality. If we take Isaiah Berlin's existential challenge and accept that it is an important attribute of humanity and dignity to deal with our own dying, then it is also incumbent upon us to accept that just as we come into the world needing help, as we leave it we will probably need the help of others.[78] We will need to surrender to the inevitable and let the natural forces take us from the world. Even though it may be hard to look at death directly,[79] some preparation is usually required unless the proverbial bus gets us first. There is a time to rage against the dying of the light, and a time to accept the inevitable. Palliative care is a means by which the realities of dying can be dealt with. We need to ensure that individuals, societies and health systems are orientated towards care that meets the real needs and wishes of people as the end of life approaches, and that law and ethics also recognise death and modern patterns of ageing, chronic illness and dying. Causation and choice are important aspects, but ultimately we do not choose whether we die or not; but we can have a substantial say in how we die. Palliative care is a key enabler of this agency, provided it is well backed up by public policy, ethics and law. Lastly, all societies will need to address growing international public support for medical assistance in dying according to their public processes and traditions. There will probably never be universal agreement about this issue due to the deep religious and ethical differences at stake. Palliative care needs to be available for all, regardless of belief about assisted dying, but it also needs to be acknowledged that palliative care, however good and available, does not meet the needs or autonomous wishes of all people.[80]

[78] For a deep political discussion on caring, see Michael Ignatieff, *The Needs of Strangers* (Vintage, 1994).

[79] See *Les Maximes* of Francois de la Rochefoucauld to the effect that 'death, like the sun, cannot be directly looked at' in La Rochefoucauld, *Maxims* (Stuart D Warner and Stephane Douard, English and French Edition, St Augustine Pr Inc, 2009) [trans of *Les Maximes* (first published 1678)], and TS Eliot, 'Humankind cannot stand very much reality' in TS Eliot, *Four Quartets* (Harcourt, 1943).

[80] See *Carter v Canada (Attorney General)* 2015 SSC 5 and *Seales v Attorney-General* [2015] NZHC 1239 (4 June 2015).