

SUBMISSION TO INQUIRY INTO PALLIATIVE CARE IN TASMANIA (House of Assembly Standing Committee on Community Development, 2016)

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This submission presents an individual professional and academic opinion for the consideration of the select committee and does not speak on behalf of either the Tasmanian Health Service or the University of Tasmania.

Personal profile

I am a consultant in palliative and pain medicine practising in Tasmania, and professor of palliative care at the University of Tasmania, Australia. I graduated from St Bartholomew's Hospital, London University, in 1978 and trained in medicine and radiation oncology in the United Kingdom, France and Australia.

I have over 25 years' experience of leadership in palliative care medicine. I held clinical, academic, leadership and managerial positions from 1989 in Adelaide and Melbourne, prior to moving to Hobart in 2007.

I am a fellow or member of the following professional Royal Colleges:

- Royal College of Physicians, London since 1981
- Royal College of Radiologists, London since 1986
- Royal Australian College of Physicians since 1992
- Australian Chapter of Palliative Medicine, Royal Australasian College of Physicians since 2001 (foundation fellow)
- Faculty of Pain Medicine, Australian and New Zealand College of Anaesthetists since 2003

My doctoral thesis was entitled *Palliative care and death causation in public policy and the law*. (MD, Doctor of Medicine Thesis, University of Adelaide, 2001).

From 1989 until 1994, I was inaugural director of palliative care at the Royal Adelaide Hospital and the Mary Potter Hospice, Calvary Hospital, North Adelaide. I provided advice to a parliamentary committee on death and dying and advised two state health ministers, Jennifer Cashmore and Michael Armitage, on matters related to the drafting of the *Consent to Medical Treatment and Palliative Care Act SA (1995)*.

In 1995 I was appointed to Victoria's first chair level appointment in palliative care at Monash University. I directed the Centre for Palliative Care at Melbourne University for two years before coming to Tasmania.

I currently hold the following positions:

- Clinical director of complex, chronic and community care, and director of palliative care, Royal Hobart Hospital, Tasmanian Health Service;
- Professor of palliative care, Faculty of Health Sciences, University of Tasmania; and
- Adjunct professor, Menzies Research Institute.

I have held the following other positions in Tasmania:

- Member, Tasmanian Lead Clinicians Group (2012- 15)
- Member, Tasmanian Clinical Advisory Council (2009-12)
- Clinical leader, Palliative Care Network, DHHS, Tasmania (2009-2011)
- Clinical leader, Respecting Patient Choice Program, RHH (2007)
- Chair, Clinical Ethics Committee, RHH (2007-present)
- Member (representing Tasmania), AHMAC. CTEP Sub-committee National Advance Care Directive Working Party, (NACDWG) (2012)

I have held the following national leadership positions:

- President of the Australia and New Zealand Society for Palliative Medicine, 2002 to 2004
- Chairman of the Chapter of Palliative Medicine at the Royal Australasian College of Physicians, September 2004 to September 2006

In 2006 I was awarded the Bethlehem Griffiths Research Foundation medal for research in palliative care. I hold a conjoint position as professor of palliative care, Faculty of Health Sciences, University of Tasmania, and teach bioethics, palliative care and grief and loss in the Bachelor of Medicine and Bachelor of Surgery (MBBS) course. I am a member of the International Working Group on Death, Dying and Bereavement (IWG) and am a former vice-president and currently a director and board member of the Australian Centre for Grief and Bereavement (ACGB). I sat on the Governing Council of Tasmanian Health Organisations (THO) South 2014-2015.

I have research interests in law, ethics and the humanities as they apply to care and decision-making at the end of life, to advance care planning, and to pain and symptom management. I have an interest in psychodynamics as they apply to death, dying, loss and grief, and how these impact on organisational culture and behaviour. I attended the 2015 Tavistock Leicester Conference and am an associate member of Group Relations Australia.

During my time as leader of the Palliative Care Clinical Network I developed a health promotion project entitled 'Healthy Dying', a broad-based approach to dealing with end-of-life issues engaging the health professions and the wider community. This included the replacement of not-for-resuscitation (NFR) forms by 'Goals of Care', which provides a framework for decision-making and documentation of limitations to be made on medical treatment, especially as death approaches.

I am currently editor in chief of the Journal of Bioethical Enquiry, an editor of the Journal of Palliative Care and the journal Mortality, and a reviewer for a number of other national and international journals.

I have provided submissions to parliamentary committees in South Australia, Victoria and Tasmania and to the Australian senate. I have given expert testimony to superior courts in Canada (Carter) and New Zealand (Seales) and to several Australian courts and tribunals.

Key points of this submission

1. *Specialist palliative care services (SPCSs) are well established and embedded in Tasmania. Primary care capacity is dependent on generic local resources. There is a need for ongoing work to clarify relative roles and models of care to meet increasing demand and a need for continuing investment in specialist and primary workforces.*
2. *Specialist services are focusing future developments on shared and consultation care models.*
3. *Hospital Palliative Care Teams (HPCTs) need to be supported and developed in all locations to improve care and decision-making at the end of life and to make linkages with all parts of the health system.*
4. *Replication of the South Australian Consent to Medical Treatment and Palliative Care Act (1995, amended 2014) and Advance Care Directives Act (2013) would address medical anxiety about double effect (for example perceptions about hastening death as a side effect of pain relief) and provide statutory force for advance care directives. However, such legislative change will be mainly educational in its effect, and good outcomes will still be mainly reliant on adequate knowledge, experience—and hence confidence—in dealing with death and dying.*
5. *Tasmania has developed innovative approaches in the fields of goals of care and advance directives, and any new legislation or policy (whether federal or state) should take these into account.*
6. *The process of dying does need to be explicitly recognised in both law and medical practice.*
7. *Open public discussion of death and dying is needed, based on the health-promoting palliative care approach seen in the 'Healthy Dying' Initiative. Euphemism and avoidance will not help, and assisted dying cannot be ignored.*
8. *Ongoing sustained investment in the development and delivery of high quality experiential communication skills learning programs is essential to improve care planning and medical decision-making at the end of life.*

Matter of palliative care generally

Services

Specialist palliative care services (SPCSs) and the model of care (MOC)

Specialist palliative care services (SPCSs) have evolved in Tasmania over the last three decades in line with perceived local need, opportunities, leadership, and in line with national and international trends, policy and evidence. These services are mature, well embedded and of high quality.

The Tasmanian Health Service presently operates the following services:

- A ten-bed inpatient facility, the JW Whittle Palliative Care Unit, at the Repatriation Centre, Hobart
- Funding for four public palliative care beds at Calvary Healthcare's St Luke's Campus in Launceston and beds in rural facilities in the region
- Hospital Palliative Care Consultation Teams
- Community Palliative Care Services (North, North West and South) providing consultation, monitoring and support to primary healthcare providers and patients
- Volunteer service provides trained volunteer support to families and people in need of palliative care across all health care settings
- Equipment provision or brokering

The growing needs of an ageing community with rising cancer, dementia and chronic diseases pose challenges for the whole health system, including palliative care. SPCSs therefore face rising referral numbers and greater client and social complexity. There is a need for continual review of how SPCSs are positioned in a high-demand health system with high 'churn' and limited capacity.

There are approximately 4000 deaths per annum in Tasmania. Specialist palliative care services, from their inception in the early hospice movement in the UK and elsewhere, were clearly never intended to 'take over' all death and dying, and nor is it necessary that they do so. These services were always designed to work with primary care, hospital and other health services. For instance, in southern Tasmania just under 50% of people who die in a registered bed have accessed SPCSs, and in total the SPCSs receive approximately 1500-2000 new referrals a year across the state.

To address the recommendations from the Review Report (2004) and to align with the national standards, a palliative care service delivery model was developed for Tasmania. Not all people with a life-limiting illness need the same level of access to specialist palliative care during the course of their illness. The model ensures that clients and their families receive palliative care and support in such a way that ensures that they have access to an appropriate level of care when and where it is required. The model provides a framework for palliative care service providers (primary and specialist) to work together for the benefit of patients and their families in the provision of quality integrated palliative care services.

The Commonwealth-funded Better Access to Palliative Care (BAPC) projects in Tasmania have produced evidence of the need for better role definition of, and greater communication about, the model of care and how to access it.

The BAPC project has undertaken a review of the model and aims to clarify relative roles in the system and ensure that all contributions from primary care and the community, both formal and informal, are recognised, understood and integrated.' BAPC is also working on workforce, IT and community engagement activities, has funded key development positions in medicine, nursing, pharmacy and allied health, and the Hobart District Nursing Service in the Hospice@Home project.

Palliative care beds

There are well-established dedicated public specialist hospice/palliative care beds in Hobart and Launceston. Designated beds in other facilities are also available in rural and residential aged care facilities.

Specialist community palliative care

The state has three regionally based multidisciplinary teams that provide a combination of direct and shared care, consultation, education and policy work. They work with primary care providers and all parts of the health system to ensure the best quality of care for patients and their families.

Hospital palliative care teams (HPCTs)

Despite the fact that people when well state that death at home is their preference, the majority of Australians still die in institutional settings, mainly in public hospitals. A substantial proportion of the last few weeks or months of life may be spent in hospitals, often with fluctuating needs, multiple episodes and admissions. Many of the major transitions in illness trajectories occur in the acute setting. Some patients prefer to stay (and therefore die) in an acute hospital setting, or have no choice in the matter for medical or social reasons, or are in hospital prior to discharge for ongoing palliative care at home, or are awaiting a place at a nursing home.

HPCTs can help to generate earlier referrals, contribute to the 'supportive' care of patients with incurable cancer earlier in their journey, and promote an engagement in chronic diseases management, especially increasingly now also for non-malignant conditions. These trends allow longitudinal follow-up of patients through their illness trajectory from the initial assessment of progressive and incurable illness until death, regardless of diagnosis.

HPCTs assist hospital units to deliver palliative care appropriate to patient needs and wishes in the ward or outpatient environment. This can range from advice or information to full terminal care and complex symptom management. They improve standards of palliative care in the acute setting by staff education, collaborative clinical work, participation in policy and procedure formulation, and staff orientation.

Societal, policy, ethical and legal issues

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. There needs to be an improved common recognition of the process of dying, in its contemporary spiritual and social contexts, by the public and by medicine, ethics, public policy and the law.

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'. Based on the assumption that you cannot initiate talk of death because patients and families do not want it and that 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 and politics. Nonetheless, preparation for death is an intrinsic spoken or unspoken part of most cultures and religions across time and place, and a societal imperative at this time.

The modern palliative care and death awareness movements have been working on these issues across the world for over 50 years. Changes in societal and professional attitudes have been evolving slowly to improve care and decision-making at the end of life. Kellehear has shown that a health-promoting palliative care approach based on Ottawa charter principles is effective in engaging everyone in 'compassionate cities' and 'caring communities' where policy and practice can be inclusive of dying and grieving people. These principles have been adopted in Tasmania by the 'Healthy Dying' initiative and by the work of the peak body TAHPC (now Palliative Care Tasmania), including their work with BAPC.

It is essential for this work that we adopt a long-term social change strategy, with a whole of government and whole of community approach.

One way to address some of these barriers is by making provision for advance care directives. If advance care planning is to be successful, it needs designated human resources in each major hospital and associated community programs.

Much hope has been invested in advance directives to improve decision-making at the end of life. These aspirations will not be realized unless public expectations change, and clinicians are able and empowered to have these challenging conversations with patients while they still have capacity. Investment in the development and delivery of high quality experiential communication skills learning for medical students and for doctors in established practice, as well as for other health professionals, is necessary. Dr Robyn Thomas has led a program of very successful patient-actor workshops for a wide range of health workers and students in Tasmania, with national and international collaboration via the Royal Australasian College of Physicians.

Advance care directives

Advance care directives motivate people to contemplate incapacity and mortality. It is well documented that people who lack decision-making capacity have tended to be subjected to more aggressive and futile care at the end of their lives.

Tasmania has been active in the field of advance care planning and decision assistance for people who have lost capacity, including advance care directives. The principal milestones have been:

- **1995. Passage of *Guardianship and Administration Act*.** Makes provision for the appointment of an Enduring Guardian (EG). The EG can make medical decisions on behalf of a person who has

lost capacity. The document of appointment has a space provided to instruct the EG on any specific directions. The act also makes provision for a Person Responsible, and provides a hierarchy of relationships to the principal of persons who can fulfill this role. This is a valuable default structure for substitute decision making for the majority of people who do make any kind of formal legal provision. Even if an advance directive has been made, it is essential for engaging those closest to the person who has lost capacity, whether 'next of kin' or unrelated close friends and/or informal care givers.

Tasmania therefore has a sensible and well administered *Guardianship and Administration Act (1995)*. Appointment of an EG under these provisions is the most legally robust position for the management of potential future capacity loss. This is best reinforced by a clear advanced care directive to guide the EG which meets the challenge of limitation of medical treatment and the dying process head-on.

- **2005-7. Respecting Patient Choices Pilot Project, Royal Hobart Hospital.** This project was part of a national pilot project coordinated through Austin Health, Melbourne. It provided increased knowledge and awareness of advance directives in the hospital and education in the RHH and community. The EG form was amended for the duration of the project to include some specific written directions.
- **2010-2015. Healthy Dying Initiative.** Based on the principles of health-promoting palliative care, this initiative aimed to empower the whole community, including the health sector, to deal with death in a more direct, open and therefore 'healthy' way. Clinical decision making at the end of life was identified as a priority for policy and procedural reform. There were three initial components of the Healthy Dying Initiative: (1) Goals of Care, (2) advance directive redesign and promotion, and (3) encouragement of health-promoting activities relating to death. The initiative had full Department of Health and Human Services (DHHS) backing after briefing of the Secretary and DHHS executive, and direct support from both the Chief Health Officer and Chief Nurse, who provided two part-time project officers. Extensive community education was undertaken by the two project officers, the peak body TAHPC, and members of the SPCS. Details of the tools and policies are available on the DHHS website:

<http://www.dhhs.tas.gov.au/palliativecare>

http://www.dhhs.tas.gov.au/palliativecare/advance_care_planning_for_healthy_dying

Goals of Care

'Goals of Care' (GOC) is a framework and process for documenting limitation of medical treatment in encounters with the health system. It is informed by a thorough clinical assessment, patient wishes—including any advance directive—and the input of a Person Responsible or Enduring Guardian where capacity has been lost. Decision-making is based on determining the goals of care for the patient, whereby the patient's situation is assigned to one of three phases of care according to a realistic assessment of the probable outcomes of medical treatment at this stage of their illness trajectory. The phases are:

- curative (full life support measures - Goals of Care category A; or some specific patient-initiated limitation, category B)

- palliative (limitation of medical treatment appropriate to patient's medical condition, needs and wishes, category C)
- terminal (preparation for imminent death, category D)

Patients move from one category to another during their illness trajectory. For some patients, cure is never an option, even at presentation, and others only present in the terminal phase; many are somewhere between these extremes. The key questions for clinicians at each ward round or consultation are (1) what are the goals of care for this patient today? and (2) is the patient and/or person responsible aware and fully informed and engaged? The 'no surprises' approach is also very useful: 'would you be surprised if the patient died in the next year/month/week?'

The project started in 2010, with the appointment of a six-month part-time project officer position as part of the statewide Healthy Dying Initiative. In 2014, the experience at the Royal Hobart Hospital, in partnership with Northern Health in Melbourne, was reported in the Medical Journal of Australia together with some initial audit data.

There is ongoing evaluation and 'post-marketing surveillance' of this innovation. Five audits have been undertaken so far. The first two—before and after introduction of the initial form and protocol—comparing NFR order completion rate (34%) with GOC completion (75%) in an acute medical assessment unit (APU) were undertaken in 2009 and 2011.

Three subsequent audits have been undertaken—in 2012, 2013 and 2015—as part of ongoing quality activity and recent hospital accreditation processes. On 6th September, 2012, a one-day point prevalence audit of GOC form completion was undertaken across the Royal Hobart Hospital (excluding pediatrics). This found completion rates of 84% (124/146) in medical wards, 32% (22/68) in surgical wards and 4% (2/44) in areas of the hospital where completion was not required by the protocol, such as psychiatry, obstetrics and day cases.

For the six-month period January to July 2013, an audit of hospital deaths was undertaken. There were 352 deaths in total, 290 had a GOC (82%), and this rose to 94% once sudden deaths were excluded. The categories chosen for these patients prior to death were GOC 'C' or 'D' in 86% of patients. Once GOC was assigned to 'D', 78 % of patients died within 72 hours.(Edwards 2015)

In November 2015, a quality and safety audit was undertaken to measure compliance with the requirement of completing a GOC. This showed form completion compliance rates of 82% for all medical patients and 52.17% for all surgical patients.

These data show that this approach has found widespread acceptability by clinicians in practice and that the tool is now a routine part of hospital practice. Compliance is high and rising. There have been no serious incidents where it has been causal in adverse outcomes. These data also indicate that clinicians are indeed able to diagnose impending death with a reasonable degree of accuracy if they are open to the realities of the situation and thereby implement timely and appropriate terminal care.

The Goals of Care approach has been rolled out across the state, and is recommended to health organisations that do not yet have it, as a replacement for existing NFR forms and as an inclusive framework for all patients to ensure that patient needs and wishes are appropriately met by the health system. A number of health services outside Tasmania have replicated this framework or are considering it.

It is clear that good communication and focus on patient wishes and needs is paramount. It is essential to clearly differentiate between operational medical 'orders' and the patient voice—whether from patients themselves, through substitute decision-makers or via advance directives. It is a clear responsibility of clinicians, especially senior ones, to ensure that the patient 'is given voice' through the medical order, such as through the Goals of Care form, and not the other way round.

Desirability of replication of South Australian legislation in Tasmania

Replication of the *Consent to Medical Treatment and Palliative Care Act (1995, amended 2014)* (CMT & PCA) and the *Advance Care Directives Act (2013)* presumably explains the Select Committee notice's sub-headings (ii) and (iii). The CMT & PCA replaced and consolidated all statutory law about medical consent into one Act in South Australia. The consent provisions are not, therefore, palliative care specific. Palliative care practitioners observe the same legal requirements and ethical framework as all other practitioners, including respect for the so-called Gillick competence concept for children and teenagers under eighteen. Therapeutic privilege for life saving treatment is not specifically relevant for palliative care practice, but a proposal has been made to allow it to also be used for relief of suffering for imminently dying persons of all ages (see below).

CMT & PCA has the advantage of addressing the issue of giving statutory recognition to the doctrine of double effect. A recent Victorian parliamentary report recommends this be enacted in that state, with particular reference to the saving provision about the chain of causation.

The formal statutory recognition of palliative care and clarity about limitation of treatment and death causation might be useful, largely as an educational and decision-support tool for the underpinning of treatment abatement and to address the ongoing concerns about causation when curative or life support cessation is contemplated, or to support medication and palliative measures during the dying process. Palliative care everywhere, including Tasmania, has undergone another two decades of community and professional development since the 1995 Act in South Australia. Incremental improvements in care decision-making at the end of life have been occurring, but negative legal and ethical perceptions do still linger.

A perceived threat of legal action as result of treatment abatement decisions and palliative-care drug treatment is still widespread, and, although empirical data are lacking, the anecdotal evidence is powerful. Doctors, nurses, allied health personnel, substitute decision-makers, and family and friends may have causal 'anxiety', anxiety that the death in question has been caused by treatment withdrawal or non-initiation, or by opioid pain relief or sedative drug administration during the dying process— notwithstanding that opinion polls indicate a majority of Australians agree with assisted dying.

Health professionals usually have a narrow empirical view of causation, and they should be made aware that the law takes a common sense and multifactorial view, and indeed will often not even apply a causal analysis, focusing more on legality of actions and presence or absence of duties instead. Clarification of what law and ethics really say about death causation in the setting of the care of dying people will show that causal anxiety is largely misplaced, inflated and inappropriate. There is no basis for fear of legal sanction by health professionals when dealing with dying persons if the prevailing standards of palliative care are adhered to.

However, legislators in South Australia felt they still needed to give statutory force to the common law adoption of the doctrine of double effect, and dealt specifically with causation.

Ongoing public and professional education and research will be required to better understand and deal with these deeply engrained fears. Clear jurisdictional messages about the primacy of comfort and dignity in the dying process over length of life will always be helpful, provided that new legal obstacles are not thereby created. It should be noted that the so-called doctrine of double effect, with its origins in catholic moral theology, is a contested concept in law and ethics.

Statutory force for advance directives will be helpful by giving doctors more confidence about absence of legal sanction when they follow the instructions in advance directives. However, common law and medical ethics already require advance directives to be respected by health professionals. It is clearly established internationally that the conversation about advance care planning is more important than legal procedure. People must first contemplate illness or accident, ageing, incapacity, death and dying, and then talk to those around them about their values and wishes. Most of all, they need to be clear about unacceptable outcomes and ensure that their families and regular health attendants know about their wishes. Focus on values and outcomes is often more effective than naming specific treatments, unless these are clearly foreseen and articulated (for example, 'I have kidney failure and I would never want to have dialysis').

It is of note that CMT & PCA does *not* give a definition of euthanasia, and makes it clear that assisted dying in any form is not lawful.

Statutory recognition that doctors are not required to continue life-prolonging treatment for dying persons and must stop any such treatments if instructed to do so by an Enduring Guardian or Person Responsible is potentially useful. However, palliative care workers usually work through a process of negotiation, and a robust appeals process must also exist, even if virtually never used, in the rare case where a doctor feels that the agent is acting against the best interests of the person concerned.

The key to the provision of better care when death is imminent ('terminal' care) is recognition of the dying process in medicine, clearly and consistently underpinned by ethics and law.

The onus is on medical practitioners to communicate with and consult with the patient first and foremost, and with the appropriate and available substitute decision-maker(s) when capacity is lost. If need be, in rare contested circumstances, they will also have to demonstrate to a tribunal or court that the dying process was underway. 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 that any legally perceived requirement for medical provision of hydration and nutrition, or any other life-sustaining medical treatment, is also dismissed. All medical, nursing and allied health care should be focused on comfort and dignity.

It is not suggested that need for consent and respect for personhood and autonomy lapse before life ends, nor that we should restore some kind of medical ascendancy or paternalism. Rather, this is a proposal for 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' on end-of-life care provides transparency. It provides appropriate, timely and necessary terminal

care consistent with what is known of the dying person and the realities of the situation. It is an approach framed in ethics rather than avoidance of potential legal sanction (see Ashby 2016).

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