Managing End of Life

Summary
This submission advocates a number of changes to the legislative framework for healthcare at the end of life, and consequently to the ability of individuals to exercise their preferences for the way their end of life is managed.

- Legislative change is needed to support and improve the ability to make informed decisions regarding care at the end of life and to have those choices respected. The following discussion of relevant legislation includes consideration of change in respect of
    - national consistency
    - recognition of substitute decision makers appointed in other states
    - removal of limits in refusal of treatment certificates
    - indication of consent as well as refusal
    - accessibility of advance care planning documents
    - symptom relief hastening death
    - palliative sedation
    - withdrawal of futile treatment
    - euthanasia and assisted suicide

The submission proposes that current practices in health care mean that the recommended legislative changes need to become operational in a context of greater awareness of rights in health care and of more accessible palliative care so it also considers

- The current lack of knowledge about healthcare rights and the need for effective education of both providers and consumers of health care services in order to increase awareness and understanding of healthcare rights and relevant law

- The unmet need for accessible high quality palliative care

Managing End of Life

Change is needed to increase the ability of Victorians to make informed decisions regarding their end of life care and to have those choices respected. The complex and inconsistent legal requirements in Australian states and territories relating to advance care planning and decision-making at the end of life create confusion and uncertainty, affecting both patients and care providers. People are free to make decisions at the end of their life about what kind of health treatment and care they wish to have or not have, but action is required to encourage and facilitate such decisions and to have those decisions honoured. We are now less likely to die when we are young and we are more likely to experience a period of chronic disease and disability prior to death. The predictability of death may vary but it is greater than it was in the past and we now have greater opportunity to make end of life choices. Legislative change is needed in the interests of both those wanting to exercise their preferences for managing their end of life care and those providing such care.

The number of Victorians dying each year is increasing and will continue to do so. The Australian population is growing and ageing, with the proportion of older people in that population increasing. Approximately two-thirds of Australians die between the ages of 75 and 95,[1] and ABS projects that the percentage of the population aged 65 and over will increase from 14% in 2012 to 20% by 2040. Similarly, the number of people aged 85 years and over is projected to almost triple by 2040.[2]

Decision making about end of life care and treatment is not simple for the care providers, nor for the care recipients. People have very different notions of what constitutes a good death and in the Victorian health care system people do not always approach the end of their life in the way that they would wish. Some may prefer symptom control and supportive care directed at optimising quality of life rather than interventions directed at prolonging life, but they do not always achieve this. They may prefer end of life care to be provided at home, but there are many factors that affect decisions about the location for care at the end of life and it is acknowledged that it is not always feasible for a patient to choose the place where they will die. However, when good end-of-life services are available, people are much more likely to die at home.[3] The type of care that is preferred at the end of life varies and we may not be in a position to communicate our wishes when that time comes, so if we are to have our needs and aspirations met we need to indicate our wishes in advance and to make them known to people we trust to act in our best interests in the

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[1] Australian Bureau of Statistics (ABS) 2013, *Deaths Australia, 2012*.

[2] ABS 3222.0 - *Population Projections, Australia*, 2012 to 2101.

[3] Jordhøy, M., Fayers, P., Saltnes, T., Ahlner-Elmqvist, M., Jannert, M. and Kaasa, S. (2000) 'A palliative-care intervention and death at home: a cluster randomised trial', *The Lancet*, 356(9233), p 888-893

future, should we become unable to make our own choices about health care and treatment.

Legislative Change

THE NEED FOR EFFECTIVE ADVANCE CARE PLANNING
The right to participate as fully as we wish in decisions about our care and treatment is included in the Australian Charter of Healthcare Rights in Victoria[4] and the fact that patients "need to know and exercise their healthcare rights and be engaged in their health care and treatment decisions" is also included in the National Safety and Quality Health Service Standards.[5] There is also a common law right for a competent adult to consent to or to refuse medical treatment.

All Australian states and territories provide a framework for advance care planning but there are significant differences between the ways it functions in different states. There is a National Framework for Advance Care Directives[6] but it is aspirational, rather than reflecting current law and practice. It comprises a code for ethical practice and a set of best practice standards and it recognises that there are challenges for those writing, interpreting, applying and abiding by advance care directives.

A competent adult's right to autonomy means that they have the right to refuse treatment, but it becomes more difficult if a patient no longer has the capacity to exercise this right. However, an advance care directive can give effect to a person's right to autonomy if they no longer have legal capacity by providing a means to ensure control of medical treatment and health care. Such directives must be informed and while it is not possible to predict all future health issues and circumstances, discussions with medical practitioners are worthwhile, as issues and outcomes that are likely to arise can often be predicted in broad terms at least. Careful consideration can be given to what the individual values, to choices that may have to be made for them in the future and to what would be an acceptable outcome for them in different circumstances.

While an individual's right to autonomy is not absolute those who are at the end of life have the same right to participate in decisions about their health care as other patients. However, although most people have clear preferences for the care they want at the end of life, very few people discuss those preferences for end of life care with health professionals[7] which means that those deciding on appropriate medical interventions may have no knowledge of the wishes and values of the person concerned. Some would prefer end of life care to be focused on managing symptoms and enabling them to live as well as possible until their death, rather than on achieving a cure, or prolonging life. Advance care planning is an important component of this palliative approach to end of life care. It can assist care

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[4] Australian Charter of Healthcare Rights in Victoria, Australia Commission for Safety and Quality in Healthcare, Dept Health & Human Services (http://health.vic.gov.au/patientcharter/), 2011.
[5] Australian Commission on Safety and Quality in Health Care, *National Safety and Quality Health Service Standards*, 2011.p.6.
[6] Clinical, Ethical and Technical Principal Committee, Australian Health Ministers Advisory Council, (AHMAC) *National Framework for Advance Care Directives* September 2011, p. 6.
[7] Swerissen, H.,& Duckett S., *Dying Well,* Grattan Institute, 2014. p11.

providers to identify and respect the wishes of a patient, improve such care from the perspective of both patient and family, and reduce the likelihood of stress, anxiety and depression in surviving relatives.[8] Advance Care Plans are "one of the central pillars of effective palliative care" and "more needs to be done to promote and embed them across the health system".[9]

The current law concerning the ability of people to give binding directions in relation to future medical decisions is complex and there is a need to strengthen the legal framework both for the appointment of substitute decision makers and for the indication of values and wishes for future health care.

SUBSTITUTE DECISION MAKERS:

The Guardianship and Administration Act 1986 (Vic) provides for the "person responsible"[10] to make decisions about medical treatment on behalf of a person who cannot indicate their wishes, but in the absence of the formal appointment of a substitute decision maker there may be significant problems. An increasing number of older people now live alone and ABS suggest that more than 900,000 people aged 75 or over will be living alone by 2026.[11] Many of these may have no appropriate family member to act as 'Person Responsible' unless they appoint someone as an Enduring Power of Attorney (Medical Treatment).[12] A family member who is acting as a 'person responsible' may or may not have been close to the patient, they may or may not be the person the patient would have chosen, and they may or may not know what the patient's choices would be. The absence of a legally appointed substitute decision maker creates potential for increased stress for all involved, for fraught decision making and for serious family disagreement.

Currently in Victoria an appointed agent with an Enduring Power of Attorney (Medical Treatment) has power to refuse treatment but other substitute decision makers who act as 'person responsible' have power to withhold consent are not similarly authorised to refuse treatment. This is confusing for health professionals and the general public. All lawful substitute decision makers should have the power to refuse treatment, as they do in Queensland.

Simplifying Victoria's power of attorney laws is one of the purposes of the Powers of Attorney Act 2014 which comes into operation in September 2015.[13] However change to the Medical Treatment Act 1988 which provides for appointment of an agent (Enduring Power of Attorney (Medical Treatment) to act on behalf of the donor when they no longer have capacity is also necessary. Laws governing the appointment of such agents should be nationally consistent. The "high level of variability makes it difficult for one jurisdiction to legally recognise an [Advance Care Directive] from elsewhere".[14] Legislation such as the

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[8] Detering, K., Hancock, A, Reade, M. Silvester, W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial., *BMJ.* 2010; 340: c1345.

[9] Victorian Auditor-General's Office (VAGO) *Report on Palliative Care*, 15 April 2015. Summary, Conclusions, p X

[10] Guardianship and Administration Act 1986 (Vic) s. 37

[11] ABS projections Series 11, 3236.0 - *Household and Family Projections, Australia, 2001 to 2026*

[12] Medical Treatment Act 1988 (Vic) s.5A

[13] Power of Attorney Bill 2014 (Vic) Explanatory Memorandum 25/6/2014)

[14] Clinical, Ethical and Technical Principal Committee, AHMAC, op cit., p.1

Advance Care Directives Act 2013 in South Australia[15] would support recognition of substitute decision makers who have been lawfully appointed in another State or Territory. The Victorian option of appointing an alternate agent to act if the first appointee is unavailable has great merit and should be retained and adopted in the other states and territories.

REFUSAL OF TREATMENT CERTIFICATE

There is need for change to the legislation which provides the Refusal of Treatment Certificate.[16] A Refusal of Treatment Certificate may be completed by the person or by their agent if the person does not have capacity, but in both cases the refusal of treatment certificate is limited to treatment of conditions already diagnosed at the time of completion.[17] Treatment of a condition that may occur in the future cannot be included and a person not diagnosed with a 'current condition' is excluded, even if they are ageing and frail and have clear preferences in regard to their future medical treatment. Similar legislation in some other Australian jurisdictions does not limit the refusal of treatment to current conditions.[18] In some jurisdictions the autonomy of the person is restricted by limits on when the refusal of treatment that has been documented can become active. In the Northern Territory the person must be suffering from a terminal illness,[19] whereas in South Australia it is necessary to be in the terminal phase of a terminal illness.[20] There should be no such requirement in Victorian law for the condition to be current or terminal. The law should allow for a correctly completed and witnessed Refusal of Treatment Certificate to cover future conditions and should not limit when it can become operational.

DOCUMENTING THAT VALUES AND PREFERENCES HAVE BEEN DISCUSSED

Inclusion of a statement that the wishes of the donor have been discussed with the appointed agent would not guarantee that it was done, but could reduce the incidence of the appointment of individuals with little knowledge of the preferences of the donor as substitute decision makers. However, failure to include such a statement should not render the certificate invalid.

ACCESSIBILITY OF DOCUMENTS

Advance Care Directives need to be readily accessible when needed. A register of advance care directives (ACD) and lawfully appointed substitute decision makers could facilitate access to the appointed decision maker and increase confidence that the authority of the agent would be recognised. The National Framework for Advance Care Directives argues that such registers are expensive to establish and to run, and that evidence indicates that they are not an effective means of ensuring that an advance care directive will be found when needed.[21] However, if the use of advance care directives becomes commonplace and health care providers are educated to expect to those in their care to have one, then a

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[15] Advance Care Directives Act 2013 SA s33(2)

[16] Medical Treatment Act 1988 (Vic) s.5.

[17] Medical Treatment Act 1988 (Vic) s5 & 5a

[18] Advance Care Directives Act 2013 SA, Advance Personal Planning Act 2013 NT.,

[19] Natural Death Act 1988 (NT)

[20] Consent to Medical Treatment and Palliative Care Act 1995, (SA) s 17 (2)

[21] Clinical, Ethical and Technical Principal Committee AHMAC, op cit. p.35

voluntary register of advance care directives and substitute decision makers which can be easily accessed by health professionals would be useful. Alternatively, recording the appointment and identity of a substitute decision maker in a electronic health record system such as E Health[22] could also assist. However, if a registration system, or inclusion in a national electronic health record system is adopted it must not become a compulsory component of advance care directives, Failure to register should not render the advance care directive or the appointment of a substitute decision maker invalid.

WITHOLDING OR WITHDRAWING TREATMENT

While there is common law backing for acting according to the person's expressed wishes about medical treatment and care when a person is no longer competent the absence of legislative support for their advance care plan weakens their ability to have their right to autonomy recognised and respected. U.K. courts have accepted that "where a competent patient makes it clear that he does not wish to receive treatment which is, objectively, in his medical best interests, it is unlawful for doctors to administer that treatment",[23] and if a patient who is sentient but not competent is suffering extreme pain, discomfort or indignity, and has demonstrated no wish to be kept alive, then a doctor may have no duty to keep that person alive.[24] Certainly legislation to support the ability to make binding ACD's would increase confidence in advance care planning and would clarify the legal obligations of care providers. It would benefit both those who wish to make an ACD and those providing treatment and care. It would also support regular review and updating of advance directives.

There is some Australian case law relating to refusal of treatment, with some of it relating to the previously expressed wishes of a person who is no longer competent. For example Morris J has stated that medically administered nutrition and hydration can be refused by an agent on the patient’s behalf.**[25]** Kourakis J declared that H Ltd’s duty of care did not include an obligation to overcome a valid refusal of sustenance or medical treatment as J’s lawful direction removed that duty.[26] McDougall J found that the Area Health Service would be justified in complying with Mr A’s wishes as expressed in his advance directive even though withdrawal of dialysis would hasten death.[27]

Legislative support for advance directives would increase certainty. While "the Parliament recognises that it is desirable".........." (e)to state clearly the way in which a patient can signify his or her wishes in regard to medical care",[28] the substitute decision maker who refuses treatment in Victoria must be satisfied one of two things apply; either the medical treatment would cause unreasonable distress to the patient or there are reasonable grounds for believing the patient if competent, would consider the treatment unwarranted.

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[22] Commonwealth of Aust. Dept Health, E Health. (www.ehealth.gov.au/)

[23] Burke, R (on the application of) v General Medical Council & Ors [2005] EWCA Civ 1003 at 30

[24] Airedale NHS Trust v Bland [1993] 2 WLR 316 at 398

[25] Gardner re BWV [2003] VSC 173 at 76

[26] H LTD v J & ANOR [2010] SASC 176 (15 June 2010

[27] Hunter and New England Area Health Service v A [2009] NSWSC 761.

[28] Preamble to the Medical Treatment Act 1988 (Vic)

Legislation should make it clear that a substitute decision maker has both a right and an obligation to refuse treatment that they believe the principal would refuse if competent.

CONSENT IN ADVANCE

The ability to give consent in advance would also add strength to an advance care directive. Indicating treatments that a person would accept as well as some that they would refuse would add clarity. Residents of Queensland can give specific instructions about certain medical treatments - for example whether they would want to receive life-sustaining measures such as tube feeding to prolong life.

The ability to give consent in advance would mean that a person could indicate, for example, that they wish to be kept free from pain and other distressing symptoms even if that means that they are extremely drowsy, or even unconscious. Palliative sedation is accepted as a method of symptom control in patients with intractable symptoms at the end of life[29] and is an option in the uncommon case where a patient has refractory symptoms and severe suffering. Health professionals sometimes voice concerns about such treatment and a clear formal indication that such treatment would be an acceptable part of terminal care would be of value to both the patient and those providing care. However it needs to be clear that the absence of any such advance consent to a particular treatment does not of itself constitute refusal.

SYMPTOM RELIEF AND DOUBLE EFFECT

There are consistent calls for care that ensures comfort and dignity at the end of life but active euthanasia is not the only way to achieve this. Symptom treatment that leads to an earlier death is legal under Australian law, provided that hastening the death is not the intent. The relief of suffering is one of palliative medicine's key values. However, there needs to be a clear legal framework for such care and decision making at the end of life. There may be use of narcotic medication to relieve pain and sometimes it is deemed necessary to administer medication to reduce awareness or even to induce unconsciousness in order to relieve intractable suffering. It needs to be clear that palliative sedation, defined as “the monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the burden of otherwise intractable suffering in a manner that is ethically acceptable to the patient, family and health-care providers in patients that are imminently dying”,[30] is a legal and acceptable method of symptom control in patients with intractable symptoms at the end of life.

The administration of medication to relieve severe pain and distress may lead to the unintended, but foreseeable consequence of hastening death. Foreseeing death as a probable consequence of an action is generally regarded as constituting intent, however if the intention is to relieve pain rather than to cause death, and the administration is compatible with standards of good medical practice then the doctrine of double effect

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[29] Braun T.C, Hagen N.A, Clark T. Development of a clinical practice guideline for palliative sedation. *J Palliative Med.* 2003;6:345-350.

[30] Cherny, N,& Radbruch L, Board of the European Association for Palliative Care European Association for Palliative Care (eapc) recommended framework for the use of sedation in palliative care. *Palliative Med.* 2009;23:581–93.

would apply. It may be argued that doctors are already protected in law where the double effect principle is applied if their actions are consistent with best medical practice and the intention was to relieve pain and symptoms. However, while the double effect doctrine is likely to be recognized as being part of Australia's common law, there have been no Australian cases to test this as yet.

South Australia provides the legislative defence in the Consent to Medical Treatment and Palliative Care Act 1995 that a medical practitioner responsible for someone in the terminal phase of a terminal illness, or a person participating in the care of such a person, incurs neither civil nor criminal liability by administering medical treatment with the intention of relieving pain or distress, if it is done with consent of the patient or their representative, in good faith and without negligence and in accordance with the standards of palliative care, even though an incidental effect of the treatment is to hasten the death of the patient.[31]

Victoria and other states should also adopt such a legislative defence. The same South Australian Act also makes it clear that there is no duty to continue life sustaining methods to prolong life in a moribund state or a persistent vegetative state. Up to eighty percent of patients who die in intensive care units do so following withholding or withdrawal of treatment deemed to be futile,[32] and it needs to be clear that discontinuing life sustaining measures in such circumstances does not constitute cause of death. Such legislation throughout Australia would increase certainty for those providing the care making it more likely that the care given and the death will be in accordance with the preferences of the dying person.

ACTIVE EUTHANASIA AND ASSISTED SUICIDE

Many of the ongoing calls for the right to exercise preferences at the end of life refer to 'dying with dignity' and call for voluntary euthanasia and/or assisted suicide. Any discussion of possible change to the legislative framework for healthcare at the end of life must include some consideration of this option.

A number of arguments are commonly used against legalising assisted suicide and voluntary euthanasia. For example some believe that such laws would damage our society and that it would be difficult and costly to regulate euthanasia to minimise abuse. Some argue that such policies show no regard for the inviolability or sanctity of life and that some lives will inevitably be seen as being of less value than others. It is argued by some that legalising euthanasia means that there would sometimes be a duty to kill, and that it will lead to involuntary euthanasia. However, while many of the arguments against euthanasia and assisted suicide can be countered the argument that it is not possible to effectively regulate to protect the interests of vulnerable groups is extremely difficult to rebut.

When euthanasia or assisted suicide is proposed the community is reassured that effective measures to prevent abuse can be provided. However there is an "insoluble ethical conflict between meeting individuals' demands for therapeutic death and ensuring that incapable,

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[31] Consent to Medical Treatment and Palliative Care Act 1995, (SA) s17

[32] Brieva, J.L, Cooray P, Rowley, M. Withholding and withdrawal of life-sustaining therapies in intensive care: an Australian experience. *Critical Care and Resusc.* 2009 11(4):266-8

vulnerable, or voiceless patients will not have lethal treatment prescribed as their best interest".[33] Legalising euthanasia can expose vulnerable people to pressure to end their lives. The old and frail or those with severe disabilities may feel pressured to request euthanasia so that they are not a burden to anyone. The ratio of requests for physician assisted suicide because of "being a burden" have risen from 1:5 to 1:3 in Oregon since its Death with Dignity Act was implemented.[34] 'Lives Worth Living', a rights based group of Australians with a disability, is concerned that utilitarian approaches to life and death do not recognise the inherent value of people with a disability.[35] Its convenor, Craig Wallace, argues that "disability advocates throughout the Western world need to see euthanasia as inimical to everything we stand for and unite against it".[36]

Those with mental illness are particularly vulnerable. A 2001 US study found that "depressive symptoms, hopelessness, and other psychological factors" appear to motivate patients' requests for euthanasia and [physician assisted suicide]".[37] Breitbart, Rosenfeld & Pessin also found there was an association between clinical depression and the desire for hastened death, with patients with depression being 4 times as likely to have a desire for hastened death than those who were not depressed. (47% vs. 12%).[38] We are assured that steps would be taken to protect such people, but in 2007 none of the people who died by lethal ingestion in Oregon had been evaluated by a psychiatrist or a psychologist.[39] In 1998 25% of patients requesting euthanasia in the Netherlands received psychiatric consultation, but in 2010 none did.[40]

The UK's House of Lords Select Committee on Medical Ethics concluded in 1994 that it would be "virtually impossible to ensure that all acts of euthanasia were truly voluntary and and that any liberalisation of the law in the United Kingdom could not be abused".[41] I see no evidence that this situation has changed. In 2014 Lord Sumption in the UK Supreme Court stated that "it is one thing to assess someone's mental ability to form a judgment but another to discover their true reasons for the decision which they have made...."and that he very much doubted "whether it is possible in the generality of cases to distinguish between those who have spontaneously formed the desire to kill themselves and those who have

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[33] George ,R., Finlay, I., & Jeffrey, D., Legalised euthanasia will violate the rights of vulnerable patients, *BMJ.* 2005 Sep 24; 331(7518): 684–685

[34] Oregon Department of Human Services. *Fifth annual report on Oregon's death with Dignity Act*. (http://egov.oregon.gov/DHS/ph/pas/docs/year5.pdf.)

[35] Lives Worth Living, (http://livesworthliving.com.au/?page_id=7)

[36] Lives Worth Living, Wallace, C., op. cit.

[37] Ezekiel J. Emanuel Euthanasia and Physician-Assisted Suicide A Review of the Empirical Data From the United States, *Arch Intern Med,* Vol 162, Jan 28, 2002.

[38] Breitbart W, Rosenfeld B, and Pessin H. et al. Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *JAMA.* 2000 284:2907–2911

[39] Oregon Department of Human Services (DHS) Death with Dignity Act. Portland, OR: DHS; 2007. (www.oregon.gov/DHS/ph/pas/ors.shtml)

[40] Hendin H., Seduced by death: doctors, patients and the Dutch cure. *Issues Law Med*. 1994;10:123–68. [PubMed].

[41] Lord Walton in speech to House of Lords May 9, 1994 in Euthanasia: Present law protects doctors and patients, BMJ 1994;309:471.

done so in response to real or imagined pressure arising from the impact of their disabilities on other people".[42]

It has to be acknowledged that there are instances where a competent and informed individual would choose to die if they had the means and the physical ability to do so. In such circumstances the person may not have a right to access assistance to die but they do have a right to refuse measures to sustain life, including medical interventions and food and fluids. They also have a right to good palliative care, to treatment of symptoms to control suffering and to palliative sedation if necessary. The right to autonomy is not absolute and the inability to protect the vulnerable means that assisted suicide or voluntary euthanasia should not be made lawful.

Education

Change to the legal framework for end of life decision making and care will not itself enable people to exercise their preferences for the way they want to manage their end of life.. Strategies to increase awareness and understanding of the relevant law by the community are also needed. Few of us are comfortable talking about death and that includes health professionals, some of whom develop a range of skills to avoid doing so or to manage their discomfort when such conversations are unavoidable. Effective education is needed for both care providers and care recipients.

HEALTH PROFESSIONALS: Despite "Facilitating Advance Care Planning" being included in the Code of Conduct for Doctors in Australia,[43] lack of knowledge and uncertainty around advance care planning are recognised as being among the barriers to advance care planning in both practitioners and patients.[44] Critical gaps have been found even in the legal knowledge of some doctors who practise end-of-life medicine, and many doctors do not possess sufficient legal knowledge to determine whether an advance directive presented to them is valid**.**[45] **"**Limited understanding of the meaning, scope and associated administrative processes by practitioners contributes to hesitation towards raising and encouraging [advance care planning]".[46] Doctors are not the only providers of care who have demonstrated inadequate knowledge about the law as it applies to end of life care. A study commissioned by Alzheimer's Australia which surveyed 236 family carers and 783 care professionals, including registered nurses, enrolled nurses, and direct care workers as well as general practitioners and specialists, found that a number of care professionals did not know or were unsure of the fact that people have the right to refuse food or fluids (29 per cent), refuse antibiotics at end of life (22 per cent) or refuse medical treatment or have existing interventions withdrawn (14 per cent).[47]

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[42] R v Ministry of Justice [2014] UKSC 38 229.

[43] Medical Board of Australia *Good Medical Practice, A code of Conduct for Doctors in Australia*, March 2014.

[44] Boddy J, Chenoweth L., McLennan, V., Daly M., (2013) It's just too hard! Australian health care practitioner perspectives on barriers to advance care planning. *Australian Journal of Primary Health* 19, 38–45.

[45] , B. White, L. Willmott, C. Cartwright, M.H. Parker and G. Williams, Doctors' knowledge of the law on withholding and withdrawing life-sustaining medical treatment. *Med J Aust* 2014; 201 (4): 229-232.

[46] Boddy et al, op cit. p 7.

[47] Egan, Natasha, Knowledge lacking on end-of-life rights, February 12, 2014, *Consumers, Industry, Research & Clinical.*

Knowledge of the law as it relates to end of life care may be somewhat inadequate but there is particular need for education about advance care planning. Medical practitioners who are confused about the legality of advance care directives and the authority of substitute decision-makers or who are unaware of the wishes of the patient, may choose active treatment that would have been refused had the patient had capacity. Many patients undergo interventions at the end of life that are of little or no benefit at all, and where the harm outweigh potential benefits.[48] In the absence of an advance care plan, the patient's family may be equally uncertain and may by default give consent.

Further education and training about the legal framework for end of life care is needed for all health professionals, and not just for medical practitioners. Nurses also need to receive such education. They are often the first point of contact, and are sometimes trusted with information not yet shared with other members of the health care team. For advance care planning to become a usual part of health care clinicians working in primary care, hospitals and nursing homes, and patients and their families must be effectively educated about its purpose and process. Excellent resources may already be available but for various reasons many practitioners do not access them. Active education is required and clinicians must be required to acquire and maintain knowledge of current law that is relevant to their practice.

There is also a need for ongoing education directed at maintaining and improving the communication skills of health professionals. Effective communication is essential for those involved in advance care planning and end of life decision making. Information needs to be tailored to individual needs and circumstances so that patients and their families can be genuinely informed about prognosis and options and can participate in decisions about treatment and care.

LEGAL PROFESSION: Legal practitioners are sometimes used by those wanting to appoint a medical power of attorney, usually when making a will or appointing a financial power of attorney. Involving a lawyer is seen by some as a way of adding strength and validity to their advance care plan. I am not aware of any formal studies of the topic but there is anecdotal evidence of incomplete and sometimes even incorrect information and services being provided by legal practitioners. For example, some members of the public have reported completing the appointment of an Enduring Power of Attorney (Medical Treatment) prepared by their lawyer without receiving any information about the need to discuss their wishes with the appointee. Education directed at increasing awareness in the legal profession of what is required for effective advance care planning and of the need to ensure that their advice is understood by the client is also needed.

GENERAL COMMUNITY: The Victorian Government Audit of Palliative Care[49]reported in April this year that there has been little progress in improving community awareness of advance care planning since 2011. Patients must be empowered to direct their own care, whenever

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[48] Walling A.M, Asch S.M, Lorenz K.A, Roth, C., Barry, T., Kahn, K., and Wenger, N.. The quality of care provided to hospitalised patients at the end of life. *Arch Intern Med* 2010; 170: 1057-1063.

[49] Victorian Auditor General's Office op. cit. p.25.

possible,[50] and education of consumers and their families about their health care rights and the law is necessary to achieve this. Most consumer education about end of life care and advance care planning has been directed at those who are unwell, who are hospital inpatients or who are living in residential aged care facilities. Consideration of health care preferences, particularly preferences relating to end of life care, is better if it is commenced well before choices have to be made. There are excellent resources available to members of the public, but many people are completely unaware of advance care planning, and of their need for information about it. Some who are aware of advance care planning have limited understanding of it and some even have incorrect knowledge of it.

Online materials and literature about advance care planning are often displayed at facilities providing services likely to be utilised by the older person, but there is also need for face to face education. Education programs which promote effective advance care planning and encourage people to consider their values and preferences are essential to increase the ability to manage end of life choices.

Some efforts are now directed at encouraging people to think and talk about death as part of the life cycle and to accept its inevitability but more action is required to raise awareness and prepare people for more focused discussions. Organisations such as 'Council for the Ageing', and 'Palliative Care Victoria' provide some education sessions. The Health Issues Centre is currently working with a number of other organisations on a one year project to assess consumer understanding and perceptions of advance care planning and, it hopes, Increase consumer capacity to discuss advance care planning.[51] In spite of limited resources some hospitals occasionally provide education about advance care planning in the community as well as to inpatients. For example, while the Respecting Patient Choices program at Austin Health is primarily directed at inpatients it also provides a service whereby a small number of volunteer speakers provide information to groups such as Probus or U3A, and to residents of retirement villages who wish to hear about advance care planning. Many are reluctant to talk about anything related to death and those in most need of the information are often the least likely to receive it. Many in the community are not aware of their need for information, much less of ways to obtain it.

Consumer education about end of life care, the right to refuse treatment and advance care planning is essential. However, before attention can be focused on rights and options in health care, and before there can be informed discussion about end of life care, we need to support conversations about death and grief. Most of us avoid talking about death and a national public education campaign to gradually increase comfort talking about death and grief would be a good start to the necessary community education. We do have 'Dying to Know Day,'[52] a national day of action dedicated to encouraging people to start thinking about what matters most when we approach the end of life, and to encouraging conversations about dying, but action to raise awareness needs to be ongoing rather than

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[50] Australian Commission on Safety and Quality in Health Care. *National Consensus Statement: essential elements for safe and high-quality end-of-life care*. Sydney: ACSQHC, 2015. p. 4.

[51] *Health Issues Centre,* Vic Gov. (http://www.healthissuescentre.org.au/government-policy/projects).

[52] *Australian Communities Foundation*, (http://www.communityfoundation.org.au/dying-to-know-day-campaign/)

limited to one day a year. It could start gently, utilise the media, and promote consideration of the thought that death is something that everyone will experience at some stage. The excellent short videos on the Department of Health Advance Care Planning website provide a light hearted introduction to the topic of advance care planning and such films should be shown to the public rather than just to those who are already informed enough to access a Victorian Government website with the title 'Advance Care Planning'. [53]

Palliative Care

Legislative change and education of providers and consumers of end of life care are both necessary but there is also need for action to systematically improve end-of-life care for patients receiving palliative care and their caregivers. Palliative care is traditionally thought of as an option for those with cancer, however many people with other chronic illnesses such as motor neurone disease, end-stage cardiac or respiratory disease, or dementia, are also increasingly seeking palliative care. There is a clear obligation to provide services for such chronically and terminally ill persons "sparing them avoidable pain and enabling them to die with dignity".[54] The population is ageing and growing and demand for palliative care is increasing. The benefits paid for all palliative medicine specialist services more than doubled over the five years to 2012-13.[55] There are challenges that will have to be addressed before high quality palliative care can be available to all who want it and some metropolitan community palliative care services are already struggling to cope with the demand.[56]

The evidence is that although people want to die at home most spending on health care in the last year of life takes place in hospitals or residential care. However, many who receive institutional care experience interventions toward the end of life that they would have rejected had they been aware of their right to refuse treatment and aware of the necessary action to ensure that their choices would be respected.

Obviously there are substantial costs involved in providing palliative care services at the end of life, whether in institutions or in the home. The goal of the multidisciplinary team providing care at the end of life should be to deliver care that is "appropriate to the needs and condition of the patient and aligned with their expressed wishes",[57] but care services at the end-of-life do not yet meet the recommended standards and are not equally available to all.[58] Several organisations have advised of the need for work to strengthen palliative care. The Senate Community Affairs Committee[59] which reviewed palliative care services recommended greater emphasis on research, training and capacity

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[53] Dept Health & Human Services, Vic Gov. *Advance Care Planning Aust.*, (http://www.health.vic.gov.au/acp/)

[54] UN Committee on Economic*, Social and Cultural Rights ESCR General Comment* 14 Para 25) Open Society Foundations Palliative Care as a Human Right 2011, (http://www.opensocietyfoundations.org/sites/default/files/palliative-care-human-right-20110524.pdf)

[55] Australian Institute of Health & Welfare, *Palliative care services in Australia* 2014. Cat. no. HWI 128. Canberra (http://www.aihw.gov.au/palliative-care-key-findings/)

[56] Victorian Auditors General's Office op cit, p X

[57] Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. op cit.. p 14

[58] Providing Palliative Care for all Australians. *Palliative Care Australia* May 2005 Appendix 1.

[59] Senate Community Affairs Committee 2012

building and on case management and service coordination. The Australian Commission on Safety and Quality in Health Care advised that significant cultural change was needed to develop successful and sustainable systems for delivering safe high quality end of life care.[60] The Victorian Auditor General's Office (VAGO) audit of Palliative Care reported that progress to improve community awareness about palliative care has been slow, and indicates that further work is required.[61] The National Consensus statement instructs health services to consider ways to work collaboratively to maximise the opportunity for patients to be cared for and die in their preferred place and to "optimise the co-ordination and delivery of end of life care**.**[62] In "Strengthening Palliative Care,: Policy and Strategic Directions, 2011 - 2015" the then Victorian Department of Health[63] committed to modelling demand for palliative care and developing a business case to support the sector to cope with a growth in service need, but the 2015 VAGO audit of Palliative Care[64] advises that this has not yet occurred.

The VAGO April 2015 report recommends that health services and the Department of Health and Human Services (DHHS) work to "understand barriers to accessing care, understand and respond to unmet demand, and engage communities who don't traditionally access palliative care. It advises that DHHS needs to "review service provision as a priority to understand gaps in the system, better forecast demand and inform future service planning" and to continue to invest in making palliative care accessible for all.[65]

Although there may be a substantial minority of patients and caregivers for whom home is not the first choice or who change their mind,[66] most people want to die at home. However, currently only fourteen percent do so, a much lower percentage than in some other countries, e.g. New Zealand or the United States.[67] The provision of palliative care services at home is more cost-effective than providing those services in hospital[68] and reducing demand for hospital and residential aged care services for the dying could achieve savings that could be diverted to home and community services. Duckett & Swerissen suggest that if the demand on hospital and residential aged care services declined in proportion to the increased number of people dying in the community costs would reduce by $324 million in acute and sub acute hospital sectors and $275 million in residential care institutions for an overall saving of $50 million.[69]

Palliative care may be provided in hospitals, hospices, aged care facilities and in the home. The multiple funding sources mean that arrangements for providing palliative care services are extremely varied. As a result the care is often fragmented and there are sometimes gaps between the services. A person with private health insurance may prefer to be cared for at

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[60] Australian Commission on Safety and Quality in Health Care. National Consensus Statement: op cit . p 14

[61] VAGO Report on Palliative Care, op cit p.26.

[62] Australian Commission on Safety and Quality in Health Care. National Consensus Statement op. cit.

[63] Vic Govt Dept Health, *Strengthening Palliative Care,: Policy and Strategic Directions*, 2011 - 2015, Aug. 2011

[64] VAGO Report on Palliative Care, op. cit. p.17

[65] VAGO Report on Palliative Care, op. cit. p.23.

[66] Gomes**, B.,** Calanzani**,** N., Gysels, M**,** Hall, S**,** & Higginson,I.J. Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliative Care* 2013, **12**:7 **)**

[67] Swerissen, H., & Duckett,S. J., What can we do to help Australians die the way they want to? *Med J Aust* 2015; 202 (1): 10-11.

[68] VAGO Report on Palliative Care, op. cit. p.X

[69] ibid

home but if the insurer does not fund such service in the home then the patient may opt to receive the more expensive and sometimes more aggressive treatment that will be funded in a private acute care hospital. There are a number of national palliative care services but the creation of a national palliative care agency within government that is responsible for linking existing resources and upholding standards of care and accountability is vital. Palliative care must be appropriately funded so that it can provide high quality services to all who want and need them, including those living in rural and remote areas. Targeted resources may be required to meet the needs of indigenous and culturally diverse populations who may have specific palliative care needs. A recent study which involved a comprehensive literature review of available international evidence on the costs and cost-effectiveness of palliative care interventions in any setting (e.g. hospital-based, home-based and hospice care) over the period 2002–2011 found that despite wide variation in study type, characteristic and quality, there were consistent patterns in the results. "Palliative care is most frequently found to be less costly relative to comparator groups, and in most cases, the difference in cost is statistically significant."[70]

Safe high quality end of life care requires the availability of skilled experienced multidisciplinary teams and there is need for education to increase both understanding of the palliative approach to care and development of relevant skills in all those who provide such services, whether in the home, hospital or residential aged care facility. Resources for palliative care need to be focused more on community based support and less on institutional care. District nurses and general practitioners supported by the specialist palliative care team need to be readily available, and equipped to provide good palliative care. Pastoral care must also be available and readily accessible. Patients and carers need to know and understand the support services that are available and how to access them when they need them.

Conclusion

Change is needed to enable Victorians to exercise their preferences for managing their care at the end of life. Active euthanasia is often advocated by those who have seen someone die in a distressing way, but while assisted suicide or voluntary euthanasia may be superficially appealing there are other options. There is a clear difference between acting to end life and abiding by wishes to refuse treatment as expressed in an advance care plan.

The right to refuse treatment must be understood and respected. The Medical Treatment Act 1988 (Vic) encourages community and professional understanding of changing the focus of treatment from cure to symptom relief and protects registered medical practitioners and those acting under their direction who act in accordance with a completed refusal of treatment certificate, but legislative change is needed to strengthen and standardise the legislative framework for end of life care. It needs to address problems relating to end of life

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[70] Smith, S., Brick, A., O'Hara, S., Normand, C., Evidence on the cost and cost-effectiveness of palliative care: A literature review, *Palliative Medicine,* February 2014 vol. 28 no.2. 130-150.

care, particularly those relating to the appointment and conduct of substitute decision makers and those relating to refusal of treatment.

Health services need to prioritise the implementation of advance care planning and education is essential if this is to be achieved. There is need for education in the general community and amongst health professionals and lawyers about the law relating to end-of-life care. Action is required to encourage and facilitate timely advance care planning and to have decisions to refuse treatment respected. Such action will only be effective if both care providers and care recipients are better informed. Community education needs to be provided to everybody rather than being limited to the elderly, to hospital inpatients and to those recently diagnosed with a serious illness. In addition to formal education simple strategies are needed to increase awareness of end of life issues and comfort discussing them.

There is an obligation to improve the standard of care available to both the dying person and the family. Palliative care is an ethical responsibility of health systems, and "end-of-life care for individuals is among the critical components of palliative care".[71] It should be respected, promoted and accepted as being able to provide quality care at end of life. Palliative care needs to be of the highest standard and needs to be available to all. It needs to be researched and evidence based, well-funded and adequately resourced.

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[redacted]

BIBLIOGRAPHY

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[71] World Health Organisation, Sixty seventh World Health Assembly, WHA67.19 Agenda item 15.5 24 May 2014 *Strengthening of palliative care as a component of comprehensive care throughout the life course* Ninth plenary meeting, 24 May 2014 A67/VR/9 (http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf)

Australian Bureau of Statistics (ABS) 2013, *Deaths Australia, 2012*.

ABS 3222.0 - *Population Projections, Australia*, 2012 to 2101.

ABS projections Series 11, 3236.0 - *Household and Family Projections, Australia, 2001 to 2026.*

Australian Charter of Healthcare Rights in Victoria, Australia Commission for Safety and Quality in Healthcare, Dept Health & Human Services 2011. (http://health.vic.gov.au/patientcharter/)

Australian Commission on Safety and Quality in Health Care, *National Safety and Quality Health Service Standards*, 2011.

Australian Commission on Safety and Quality in Health Care, National Consensus Statement : essential elements for safe and high quality end-of-life care Sydney ACSQH 2015.

Australian Communities Foundation, (http://www.communityfoundation.org.au/dying-to-know-day-campaign/)

Australian Institute of Health & Welfare, *Palliative care services in Australia* 2014. Cat. no. HWI 128. Canberra (http://www.aihw.gov.au/palliative-care-key-findings/)

Boddy J, Chenoweth L., McLennan, V., Daly M., (2013) It's just too hard! Australian health care practitioner perspectives on barriers to advance care planning. *Australian Journal of Primary Health* 19, 38–45.

Braun T C, Hagen N A, Clark T. Development of a clinical practice guideline for palliative sedation. *J Palliative Med.* 2003;6:345-350.

Brieva, JL, Cooray P, Rowley M. 2009, Withholding and withdrawal of life-sustaining therapies in intensive care: an Australian experience. *Critical Care and Resusc.* 2009 11(4):266-8.

Breitbart, W, Rosenfeld B, and Pessin H. et al. Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *JAMA.* 2000 284:2907–2911.

Cherny, N.I, Radbruch, L, Board of the European Association for Palliative Care European Association for Palliative Care (eapc) recommended framework for the use of sedation in palliative care. *Palliative Med.* 2009;23:581–93.

Clinical, Ethical and Technical Principal Committee, Australian Health Ministers Advisory Council, (AHMAC) *National Framework for Advance Care Directives* September 2011.

Dept Health, Commonwealth of Aust. E Health. (www.ehealth.gov.au/)

Dept Health & Human Services, Vic Gov.(http://www.health.vic.gov.au/acp/)

Detering,K, . Hancock, D. Reade, M. Silvester, W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial., *BMJ.* 2010; 340: c1345.

Egan, N. Knowledge lacking on end-of-life rights, February 12, 2014, *Consumers, Industry, Research & Clinical*

Ezekiel J. Emanuel, Euthanasia and Physician-Assisted Suicide A Review of the Empirical Data From the United States, *Arch Intern Med,* Vol 162, Jan 28, 2002.

George, R, Finlay, I, & Jeffrey, D. Legalised euthanasia will violate the rights of vulnerable patients, *BMJ.* 2005 Sep 24; 331(7518): 684–685

Gomes, B**.**, Calanzani**,** N.**,** Gysels, M, Hall,S & Higginson**,** I., Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliative Care* 2013, 12:7.

Health Issues Centre, Vic Gov. (http://www.healthissuescentre.org.au/government-policy/projects)

Hendin H., Seduced by death: doctors, patients and the Dutch cure. *Issues Law Med*. 1994;10:123–68. [PubMed]

Jordhøy, M. S., Fayers, P., Saltnes, T., Ahlner-Elmqvist, M., Jannert, M. and Kaasa, S. (2000) 'A palliative-care intervention and death at home: a cluster randomised trial', *The Lancet*, 356(9233), p 888-893

Lord Walton in speech to House of Lords May 9, 1994 in Smith, A.M., Euthanasia: Present law protects doctors and patients*, BMJ* 1994;309:471.

Medical Board of Australia, *Good Medical Practice* A Code of Conduct for Doctors in Australia, 2014 (http://www.medicalboard.gov.au/Codes-Guidelines-Policies.aspx)

Oregon Department of Human Services (DHS) Death with Dignity Act. Portland, OR: DHS; 2007. (www.oregon.gov/DHS/ph/pas/ors.shtml)

Oregon Department of Human Services. *Fifth annual report on Oregon's death with Dignity Act*. (http://egov.oregon.gov/DHS/ph/pas/docs/year5.pdf.)

Providing Palliative Care for all Australians. *Palliative Care Australia* May 2005 Appendix 1.

Power of Attorney Bill 2014 (Vic) Explanatory Memorandum 25/6/2014) (http://www.austlii.edu.au/au/legis/vic/bill_em/poab2014250/poab2014250.html)

Senate Community Affairs Committee 2012.

Smith, S. Brick, A, O'Hara,S., Normand, C., Evidence on the cost and cost-effectiveness of palliative care: A literature review, *Palliative Medicine,* February 2014 vol. 28 no. 2 **130-150.**

Swerissen, H. & Duckett, S, What can we do to help Australians die the way they want to,? *Medical Journal Aust.* 2015; 202 (1).

Swerissen, H.,& Duckett S., *Dying Well,* Grattan Institute, 2014

UN Committee on Economic*, Social and Cultural Rights ESCR General Comment* 14 Para 25) Open Society Foundations Palliative Care as a Human Right 2011.

(http://www.opensocietyfoundations.org/sites/default/files/palliative-care-human-right-20110524.pdf).

Victorian Auditor-General's Office (VAGO) *Report on Palliative Care*, 15 April 2015.

Vic. Govt Dept Health, *Strengthening Palliative Care,: Policy and Strategic Directions*, 2011 - 2015, Aug. 2011.

Vic Govt. Dept Health & Human Services (http://www.health.vic.gov.au/acp/)

Wallace C., Lives Worth Living, (http://livesworthliving.com.au/?page_id=7)

Walling A.M, Asch SM, Lorenz KA, Roth, C., Barry, T., Kahn, K., and Wenger, N. The quality of care provided to hospitalised patients at the end of life. *Arch Intern Med* 2010; 170: 1057-1063.

White, B., Willmott, L., Cartwright, C., Parker ,M., and Williams, G., Doctors' knowledge of the law on withholding and withdrawing life-sustaining medical treatment. *Med J Aust* 2014; 201 (4): 229-232.

World Health Organisation, Sixty seventh World Health Assembly, WHA67.19 Agenda item 15.5 24 May 2014 *Strengthening of palliative care as a component of comprehensive care throughout the life course* Ninth plenary meeting, 24 May 2014 A67/VR/9.

LEGISLATION

Advance Care Directives Act 2013 (SA)
Advance Personal Planning Act 2013 (NT)
Consent to Medical Treatment and Palliative Care Act 1995, (SA)
Death with Dignity Act 1995 (Oregon)
Guardianship and Administration Act 1986 (Vic)
Medical Treatment Act 1988 (Vic)
Medical Treatment Act 1988 (Vic
Medical Treatment Act 1988 (Vic)
Natural Death Act 1988 (NT)

CASES

Airedale NHS Trust v Bland [1993] 2 WLR 316
Burke, R (on the application of) v General Medical Council & Ors [2005] EWCA Civ 1003
Gardner re BWV [2003] VSC 173
H LTD v J & ANOR [2010] SASC 176 (15 June 2010)
Hunter and New England Area Health Service v A [2009] NSWSC 761.
R v Ministry of Justice [2014] UKSC 38 229