



Chisholm Health Ethics Bulletin

Drawing on thorough research, the best of human insight and the strengths of Catholic teaching, we offer an ethical vision to inform modern health care. We strive to guide our readers to greater knowledge and deeper understanding about issues in health care, and to assist all people in their search for insight and wisdom.

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In this issue

Welcome to the Summer 2016 Edition of the Chisholm Health Ethics Bulletin as I hope we find you basking in the blessings of Christmas.

In our first article, we heed the words of the Catholic Bishops of Victoria:

We, the Catholic Bishops of Victoria, condemn domestic violence in the strongest possible terms, and call on parishes, church organisations and people of faith to play a part in its elimination.

Domestic violence is a crisis in Australia – each week a woman dies at the hands of her partner or ex-partner. It is estimated that one in four children experience the fear and distress of witnessing their mother being abused.

In addition to this physical violence, domestic violence can also be emotional, financial or spiritual. The roots are abuse of power and the control of one person over another.

While men also suffer domestic violence, women and children form the great majority of the victims of domestic violence.

This statement is addressed to the whole Church community ⁱ

as researcher Dr Dilinie Herbert's article explores domestic violence juxtaposed against the Christmas Story by exploring the concept and experience of "no room at the Inn."

Also in this issue, in the interest of keeping our member services up to date with new legislation, we undertake a new concept in condensing the Medical *Treatment Planning and Decisions Act 2016*, a 104 page document, to a concise article which provides a general overview of the Act and serves as a map for your further exploration of the Act.

The associated ethical issues will be discussed in further editions of the Bulletin.

This year of 2017 will see much occur in Australia in relation to physician assisted suicide and/or voluntary euthanasia. In our final article for this edition, Dr Dilinie Herbert explores the concept of "the slippery slope effect" a logic term often used to describe the effect of change to a first premise for example, life is always worth living to life is sometimes worth living. The "slippery slope effect" is a contentious term used to describe the subsequent chain of related events in this transition, usually culminating in negative effect, because it is impossible to avoid the significant limitations of imposed safeguards. Will an acceptance of voluntary euthanasia ultimately lead to an acceptance of non-voluntary euthanasia?

We close with these powerful words of Howard Thurman to remind us that Christmas is a journey rather than a destination as we wish you well in welcoming the New Year of 2017.

When the song of the angels is stilled,
When the star in the sky is gone,
When the kings and the princes are home,
When the shepherds are back with their flocks,
The work of Christmas begins:
To find the lost,

To heal the broken,
To feed the hungry,
To release the prisoner,
To rebuild the nations,
To bring peace among people,
To make music in the heart.

Maureen Waddington &

¹ Catholic Bishops of Victoria *Domestic Violence Statement, 2016,* http://www.css.org.au/Portals/51/documents/ BishopsDomesticViolenceStatement2016.pdf

About the Caroline Chisholm Centre for Health Ethics

The Caroline Chisholm Centre for Health Ethics is a Catholic bioethics centre:

We research and publish about health care issues.

- We provide education and training about health ethics to health professionals and the general community.
- Over the phone or face to face, we assist any person who seeks help in making decisions about health care.
- We contribute to community discussion and debate by making public comments about important matters related to health care.
- We also assist health care institutions in the development of policies, protocols and procedures, particularly in areas which might be ethically contentious.

Making room in the Inn for those less fortunate

Christmas is a special time in the Christian calendar. The Christmas story begins with a heavily pregnant Mary riding on the back of a donkey alongside her husband into the city of Bethlehem. Their search for board to see them till the morning is futile. A somewhat kind Inn keeper shows them to his stable, where the animals are accommodated. That night Mary gives birth to baby Jesus and she lays the newborn down in a manger. The Inn is symbolic of prosperity for those fortunate to share in its comforts. To have to reside instead in the stable reflects that there is not space in the Inn and some people, for not immediately apparent reasons, live on the outside.

Homelessness in Melbourne is a growing issue, as more and more people are sleeping rough on the streets in the CBD. On a piece of used packaging is scrawled a narrative that is not unlike the Christmas story, a place at the Inn not forthcoming, instead the side of the footpath is the only space available to sleep till morning. For the purpose of this article I will focus on women and how domestic violence has left them without room in the Inn. I will summarise the findings from the recent Domestic Violence Commission¹ and how McAuley Community Services for Women is making a significant difference in the lives of women who are living in despair from the mental and physical anguish caused by domestic violence, through an initiative to educate workplaces about responding to domestic violence.

... Homelessness in Melbourne is a growing issue, as more and more people are sleeping rough on the streets in the CBD ...

I have caught the train to and from Flinders Street Station for over a year now, but I have always been a public transport commuter since studying and working in the city for a large part of my adult life. A few years ago, my husband and I moved to East Melbourne where we lived for nearly two years, before moving back into the suburbs to be closer to our families. In all the time that I have spent in the city, mostly walking through and other times sharing a meal with friends, I have seen Melbourne – the most liveable city – become home for men, women and

youth sleeping rough on the streets. Most remarkably the number of people setting up makeshift shelters along Flinders Street station where only a short time ago was footpath only. Amongst the trendy food trucks are soup kitchens on wheels and last month I saw a bus that had been transformed into a portable shower with bathroom facilities. I wondered where all these people came from, but maybe I was naïve to think this and perhaps they have always been there.

... In all the time that I have spent in the city, mostly walking through and other times sharing a meal with friends, I have seen Melbourne – the most liveable city – become home for men, women and youth sleeping rough on the streets ...

According to the Homelessness Australia website, 1 in 200² people will be without a permanent address tonight, sleeping rough and away from family. Why are there so many people homeless in our community? There are various reasons and it is important not to oversimplify these complex issues. However, there are two broad explanations that can contribute to homelessness; "one associated with structural economic and policy conditions, such as poverty, unemployment and shortage of affordable rented housing, and the other featuring personal incapacity, vulnerability and behaviour".3 To properly explore the nuances of the social context of homelessness is outside the scope of this article; however I am interested in reporting on the second of these two characteristics of homelessness - the "personal incapacity, vulnerability and behaviour issues" and in particular domestic violence amongst women that are homeless.

Mary the mother of Jesus is a pillar of strength as we read about her presence in Jesus' life and upbringing. Providing what she could and ensuring that her family had enough food, shelter and clothing. As far as we know, she was fortunate to not be subjected to the violence that women during her time received. The lived experience of violence in the home has been recognised since antiquity and is now commonly referred to as domestic and/or family violence. It is a complex situation that is compounded by an unequal power relationship that renders one person vulnerable to physical or emotional abuse. This person is usually the woman⁴ in the relationship, and has the added

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responsibility of caring for the children and domestic aspects of the home environment. burdensome instances of abuse can impact on work related responsibilities, domestic and sometimes resulting in the woman or victim leaving the relationship and/or the family home.⁵ There is evidence to suggest that a significant repercussion of domestic violence is homelessness, perhaps due to the lack of financial resources that women have when they find themselves searching for alternative housing arrangements. Until permanent housing is made available, women and their children are housed in temporary housing or rental arrangements.⁶ The personal stories of women who are victims of domestic violence are unique, therefore identifying and developing resources to better help them is a growing challenge.

... There is evidence to suggest that a significant repercussion of domestic violence is homelessness ...

Addressing the issues associated with domestic violence has been a mainstay of the Victorian Government for the last two years. The Royal Commission Domestic Violence (the Commission) exposed the trauma and grief of the lived experience of domestic violence. Women more frequently are victims of indiscriminate acts of violence perpetrated by an intimate partner, sometimes resulting in fatalities but mostly it is physical and emotional scars that remain. The task of Commission was multifaceted, including identifying the causes of domestic violence, addressing the shortcomings of current services,

protecting the victim, developing new programs and evaluating their progress.⁷ The cause of domestic violence is complex and is probably best described as a cycle. Perpetrators can sometimes be victims of family violence themselves, and as adults they perpetuate those same behaviours.

Victims can be subjected to domestic violence throughout their lives and not have the skills to break the cycle as adults. The Commission has been a positive move towards better understanding and addressing some of the complex issues, implementing new services and better resourcing existing services. Coming to a point where victims feel empowered to report and move away from violent partners and

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perpetrators, and receiving the support and resource to refrain from continuing to harm those around them, could be considered the best outcomes of the Commission. However, recognising and acting appropriately when domestic violence is encountered, particularly by community service providers and health care professionals, is a difficult aspect of keeping victims of domestic violence safe.

There are support services that are available to women seeking to escape from domestic violence. McAuley House Community services for women is one example. McAuley House "supports women who are homeless or at risk of homelessness on their journey towards recovery and independence by providing medium term accommodation, meals and intensive and individualised case management support." Of the women that seek refuge at McAuley House, 37 per cent are escaping domestic violence. Started in 2008 by the Institute of Sisters of Mercy of Australia and Papua New Guinea, McAuley House is a testament to the work started by Catherine McAuley in Dublin Ireland nearly two centuries ago. McAuley house strives to provide compassionate care, hospitality,

justice and sense of community to all its residents, in order to empower women that enter its facilities to return into the wider community without fear and with greater strength.

An initiative started by McAuley House is educating workplaces on the impact of domestic violence on productivity as well as physical and emotional health of women called "Engage to Change". This program is providing a platform for opposing domestic violence in the community and demonstrating, especially in the workplace, how recognising cases of domestic violence is a positive step towards helping victims. McAuley House notes that the Engage to Change sessions are well attended, but participants express some concern about knowing how to respond appropriately to cases of domestic violence as they arise. In order to address these concerns, a suite of training models are available including face-to-face training, e-learning references applications. Based on the extensive experience of McAuley House staff caring for women effected by domestic violence, they developed the Triple R program: to recognise domestic violence; then respond in a sensitive manner that acknowledges the needs of the women and staff member; and refer them to appropriate counselling or support services.9

Domestic and family violence is having a significant impact in our community. Alarming statistics indicate that it is contributing to a growing number of women finding themselves homeless. The protection and solace of a space that is one's own provides a sense of value. A home or residence should be such a space surrounded with people that nurture growth, show respect and have dignity towards one another. When these foundations are dismembered, women, men and children feel vulnerable.

As a broader community we should not cover up the after effects of domestic and family violence, walking by as these family members sleep rough in our city streets. The Commission heard the stories of victims and perpetrators to show the different dimensions of this issue. It summarised the pertinent issues and provided a series of recommendations that are being translated into practical and policy measures to better manage cases of domestic and family violence. The valuable work of McAuley Community Services for Women is a demonstration of a grassroots organisation that is providing a home to those women, finding themselves homeless due to domestic violence. They are providing women with the resources to gain employment and financial assistance along with the motivation and skills to be better able to negotiate future challenges.

I continue to catch the train at Flinders Street Station.

Making my way to the Swanston Street entrance I still read the stories scribbled on the brown cardboard. I cannot make better the lives of all the people who are sleeping rough or even begin to understand the circumstances that have led to them to only be able to find shelter by the side of a train station. However I can support those services that are assisting them to get back on their feet, a hand up to no longer be homeless. There should always be space in the inn for everyone in our community and to make this the reality requires us to work together.

...An initiative started by McAuley House ... "Engage to Change" ... is providing a platform for opposing domestic violence in the community and demonstrating, especially in the workplace, how recognising cases of domestic violence is a positive step towards helping victims...

ENDNOTES

¹ Victorian Government, *Royal Commission into Family Violence: Summary and recommendations*, March 2016, Parliament of Victoria, http://files.rcfv.com.au/Reports/Final/RCFV-All-Volumes.pdf.

"Homelessness Australia, Homelessness statistics, http:// www.homelessnessaustralia.org.au/index.php/about-homelessness/ homeless-statistics.

³ Maureen Crane et al., "The causes of homelessness in later life: findings from a 3-nation study," *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences* 60, no. 3 (2005): S152–S159 at S153.

⁴ Claudia Garcia-Moreno , Henrica AFM Jansen, Mary Ellsberg, Lori Heise, and Charlotte H. Watts. "Prevalence of intimate partner violence: findings from the WHO multi-country study on women's health and domestic violence." *The Lancet* 368, no. 9543 (2006): 1260-1269.

⁵ Ellen Malos, and Gill Hague, "Women, housing, homelessness and domestic violence," *Women's Studies International Forum*, 20, no. 3 (1997): 397–409.

⁶ Homelessness Australia, Keeping a home among the gum trees. Exploring risk of homelessness in 21st Century Australia: Who is 'at risk' and how are services working to mitigate that risk and keep people housed?, http://www.homelessnessaustralia.org.au/images/

 $\label{lem:condition} Keeping_a_home_among_the_gum_trees_Risk_of_homelessness_policy_paper.pdf.$

⁷ Royal Commission into Family Violence,

⁸ McAuley Community Services for Women, http:// www.mcauleycsw.org.au/our-services/mcauley-house.

⁹ McAuley Community Services for Women, Family Violence: it is your business. http://www.mcauleycsw.org.au/_literature_122548/ Engage_to_Change_Brochure. All online material accessed 6th December 2016

Dr Dilinie Herbert &

Summary: Medical Treatment Planning and Decisions Act 2016

In the Victorian Parliament, the Legislative Assembly, on 24/11/2016, agreed to the amendments made by the Legislative Council to the *Medical Treatment Planning and Decisions Bill 2016*.

The final part of the approval process, Royal Assent, was given on the 29th of November, 2016.

It is envisaged the provisions of the *Medical Treatment Planning and Decisions Act 2016* will come into effect, on or near, the 12th March, 2018.

The Medical Treatment Planning and Decisions Act 2016 (the Act) is designed to allow Victorians to make legally binding decisions about their future medical treatment and end-of-life care

The Victorian Council of Social Services describes the introduction of the Bill as follows:

The Act provides statutory recognition for advanced care directives. An advanced care directive allows a person to make binding decisions about consenting to or refusing future medical treatment while they have capacity to do so.

Advanced care directives are a form of advance care planning. Advance care planning involves planning for future care and medical treatment, so a person's preferences and values can guide clinical decisions if they become too unwell to make decisions themselves. It is usually related to preferences about end-of-life care.

The existing legislative arrangements for advanced care planning are complex and confusing for both people and their healthcare providers. They also restrict people from making decisions about future conditions.

The introduction of consistent definitions of capacity and medical treatment help clarify the legislative framework.¹

Legislation is a step in enabling and empowering people to be involved in important and often vital decisions in their lives, but it is only one step.

Advance Care Planning discussion and implementation has been occurring some healthcare systems for several years. These discussions highlighted have the essential requirement for building the awareness and capability of all participants; community, clinicians, patients, clients, family members, friends and carers who have been involved in Advance Care Planning, to be known as Advance Care Directive discussions; building their capacity for noticing the appropriate timing, knowing how to involve the right people; knowing how to facilitate and participate in these discussions, building health literacy whilst honouring the unique dignity of every person.

Part One of the Act

The main purpose of the Act is to:

"provide for a person to execute in advance a directive that gives binding instructions or expresses the person's preferences and values in relation to the person's future medical treatment;"

and to provide for the making of medical-treatment decision on behalf of persons who do not have decision-making capacity; to provide for a person to appoint another person to make medical-treatment decisions on behalf of a person without decision-making capacity; to provide for a process for obtaining approval and consent for medical research procedures for a person who does not have decision-making capacity; to repeal the Medical Treatment Act 1988 and to amend the Mental Health Act 2014 in relation to approval procedures for electroconvulsive treatment of adults who do not have capacity

Clause 4

Defines the meaning of *decision-making capacity*, the methodology of determining same, options if a person is without decision-making capacity, whilst acknowledging this capacity may fluctuate and providing safeguards for this consideration

Clause 5

Makes provisions for the *Victorian Civil and Administrative Tribunal* (VCAT) to make an order in relation to the decision-making capacity of a person and allows for VCAT to appoint a medical treatment decision maker

Clause 6

Defines the types of statements that can be included by a person with decision making-capacity in an Advance Care Directive; with the provision it may contain either or both an *instructional directive* and/or *values directive*

Clause 7

Sets out *principles* which must be held in regard by a person and VCAT when performing a function under the Act such as "the informed decision of a person

The main purpose of the Act is to:
"provide for a person to execute in advance a directive that gives binding instructions or expresses the person's preferences and values in relation to the person's future medical treatment;"

must be respected" and this respect should apply to a "person's culture, beliefs, values and personal characteristics."

Clause 8

Provides there is no capacity in the Act to compel a *health practitioner* to provide particular medical treatment or futile or non-beneficial treatment, a person may either consent or refuse to offered treatment but a health practitioner will continue to use their expertise to determine whether medical treatment are clinically indicated

Part Two of the Act

Concerns the Advance Care Directive and includes:

Clause 9

Which specifies *medical treatment* also includes a *medical research* procedure

Clause 10

Nothing in this Part affects any right of a person under any other law to refuse medical treatment

Clause 11

Allows the embracing of like treatments, related to those specified in an Advance Care Directive, with the acknowledgement a person cannot be expected to refer to treatments in technical and specific terms

Clause 12

Makes further reference to Advance Care Directive purpose i.e. *instructional directive* and/or *values directive* specifying a statement about *palliative care* must be interpreted as a *values directive* and does not require a health practitioner to obtain a medical treatment decision either by the person or the medical treatment decision maker for the person. The clause makes reference to the process of obtaining consent for a *special medical procedure* which is governed by the *Guardianship and Administration Act* 1986 and not this Act

Clause 13

Provides that any person *including a child* can make an Advance Care Directive if they have decisionmaking capacity

Clause 14

Determines inducement of an Advance Care Directive, through dishonesty or undue influence, will result in Advance Care Directive to be considered void, defines the inducement an **offence against law** and prescribes penalties

Clause 15

Defines knowingly-made false and misleading statements in relation to another person's Advance Care Directive as an offence against law and prescribes penalties

Clause 16

Sets out the formal requirements which must be met in order for Advance Care Directive to be considered valid e.g. must be written in English; must be signed; must be witnessed etc.

Clause 17

Determines the witnessing requirements e.g. two adult witnesses, one of which must be a registered medical practitioner or in the case of a child one of the witnesses must be a registered medical practitioner or psychologist with prescribed training and experience

Clause 18

Addresses the issue of inclusion of unlawful statements, i.e. a statement which would cause a health practitioner to contravene a professional code of conduct, would not necessarily invalidate the entire Advance Care Directive

Clause 19

Determines an Advance Care Directive is in force at the time it is signed and remains in force until any **expiry date specified** in the Advance Care Directive or it is revoked in accordance with the Act.

Clause 20

Stipulates an *amendment or revocation* must be done on the face of the original Advance Care Directive that it is amending; an Advance Care Directive is revoked by any later Advance Care Directive given by the person

Clause 21

Formal requirements must be met in giving, amending or revoking Advance Care Directives – Advance Care Directives which have not met formal requirements will not take effect as an Advance Care Directive but could be considered as an expression of

the person's values. The clause also gives VCAT power to order the document effect

Clause 22

Outlines the powers of VCAT in relation to the making, varying or revoking Advance Care Directives e.g. the advancement of a particular medical treatment results in the person no longer considering the outcome as unfavourable

Clause 23

Sets out matters for which VCAT must be satisfied for an order to be revoked, carried or suspended

Clause 24

Identifies parties to the proceedings before VCAT

Part Three of the Act

Relates to Medical Treatment Decision Makers and Support Persons and includes:

Clause 25

Advises *medical treatment* and includes *medical research*

Clause 26

Determines an adult who has decision-making capacity may appoint another adult as the person's appointed *medical-treatment decision maker* and this can occur at any time or at the same time as an Advance Care Directive is given

Clause 27 to 30

Makes reference to Parts 4 and 5 and the powers of the medical treatment decision maker; outlines the formal requirements of same; outlines the terms for acceptance of appointment; allows for revocation of appointment

Clauses 31 to 40

Allow the appointment of a *support person;* any person (including a child) who has decision making capacity may appoint another person (including a child) as the person's support person — only one person — with details of how appointment may occur and be revoked. A support person does not have the power to make a medical treatment decision in respect of the person making the appointment

Clauses 41 and 42

Define the offences and cite penalty of 5 years imprisonment for purporting to act as an appointed medical treatment decision maker or support person and makes an offence of using dishonesty and undue influence to induce a person

Clause 43

Allows VCAT intervention when validity is in question because of occurrences such as dishonesty or failure to comply with formalities

Clause 44

Defines terms under which VCAT can determine medical treatment decision maker or support person nomination may be invalidated

Clauses 45 to 47

Allow for consideration by VCAT of the person's "intention" despite non-conformance with formalities, with further consideration that VCAT must not make an order revoking an appointment, unless satisfied the person who made the appointment does not have decision making capacity to revoke appointment

Part Four of the Act

Relates to Medical Treatment Decisions

Clause 48

Provides that Part 4 does not apply to medical treatment for mental illness for a mental health patient or neurosurgery. These matters are all governed by the *Mental Health Act 2014*, nor does it affect the operation of section 24 of the *Human Tissue Act 1982*, which provides for circumstances in which consent is withheld, by person with decision making authority in relation to a child, protecting a registered health practitioner who delivers a blood transfusion to the child from criminal liability for doing so

Clause 49

States nothing in Part 4 affects any duty of care owed by a health practitioner to a patient

Clause 50

Before a health practitioner administers medical treatment to a person who does not have decision making capacity, the health practitioner must make reasonable efforts to ascertain if the person has either an advance care directive or a medical treatment decision maker. Failure to make these steps will amount to unprofessional conduct, which may be referred to the National Board

Clauses 51 and 52

Outline circumstances in which a health professional may refuse to comply with an instructional directive e.g. the circumstances have changed; and provides a health practitioner, who acts in good faith and without negligence, is not liable for unprofessional conduct or quilty of an offence

Clause 53

Provides for a health practitioner to administer medical treatment (other than electroconvulsive treatment) or a medical research procedure in what is considered an emergency situation unless the health practitioner is aware the person has refused the particular treatment, although the health practitioner is not required to search for an advance care directive in an emergency

Clause 54

A health practitioner may administer palliative care to any person who does not have decision making capacity for that care, despite the decision of the person's medical treatment decision maker, with regard to any preferences, values of the person and in consultation with medical treatment decision maker

Clause 55

Defines a person's medical treatment decision maker except if that person is a mental health patient

Clause 56

Requires a health practitioner to record certain matters in relation to medical treatment in the medical record

Clause 57

Cites Clause 57 to 63 does not apply to palliative care or special medical procedures, provision for which is set out in the *Guardianship and Administration Act* 1986

Clause 58

Defines consent, with the exclusion of palliative care and/or special medical procedure, if a health practitioner proposes to administer treatment to a person who does not have decision making capacity for that treatment

Clause 59

Sets out the circumstances, with the exclusion of palliative care and/or special medical procedure, in which a health practitioner may administer medical treatment to a person who does not have decision making capacity but is likely to recover decision making capacity within a reasonable time

Clause 60

Defines requirements of health practitioner in administering treatment to a person who has an advance care directive and does not have decision making capacity in respect of that treatment – contravention of which is deemed unprofessional conduct in the meaning of the Law

Clause 61

Outlines the framework for the making of a medical treatment decision by a medical treatment decision maker on behalf of a person who does not have decision making capacity

Clause 62

Instructs health practitioner to notify Public Advocate if medical treatment decision maker refuses significant treatment or the preferences or values of the person are unable to be known

Clause 63

Provides for a process of medical care decision making when there is no advance care directive and no medical treatment decision maker

Clauses 64 to 71

Set out the conditions determining who is eligible to apply to VCAT and the orders VCAT may consider necessary

Part Five of the Act

Considers Medical Research

Clauses 72 to 78

Outline the administration of a medical research procedure, to an adult who does not have decision making capacity in relation to a procedure; outlines the steps to take; the penalties for disregard of appropriate formalities; provides protection for actions in good faith; consent; Human Resources Ethics Committee (HREC)

Clauses 79 to 83

Addresses medical research procedures without consent; if the procedure would not be contrary to the person's values, having regard to the personal and social wellbeing of the person, the relevant HREC has approved in full knowledge of consent or absence; completion of certificate to identify treatment to individual, medical treatment decision maker and Public Advocate. Also identifies applications to VCAT for dispute resolution for same

Clauses 84 and 85

Create an offence of administering medical research procedure to a person who does not have decision making capacity in relation to the procedure unless the research project has been approved by relevant HREC

Part Six of the Act

Concerns VCAT jurisdiction

Clauses 86 to 92

Define VCAT jurisdiction and powers

Part Seven of the Act

Concerns general information

Clause 93

Provides that if a body corporate commits an offence against certain clauses of the Act, an officer of the body corporate also commits an offence if the officer failed to exercise due diligence to prevent the commission of the offence by the body corporate

Clause 94

Authorises a person's medical treatment decision maker or support person to access or collect health information about the person if relevant to a medical treatment decision to be made

Clauses 95 to 97

Provide for recognition of an advance care directive made in another State or Territory; recognition of medical treatment decision maker or support person appointment made in another State or Territory

Clauses 98 to 100

Place obligation on the operator of a health facility to take reasonable steps to ascertain whether any patient in the facility has an advance care directive or appointed medical treatment decision maker or support person and defines further obligations in regard to same

Part Eight of the Act

Addresses the repeal of the *Medical Treatment Act* 1988

Clause 101

Repeals the Medical Treatment Act 1988

Clauses 102 to 105

Sets out the savings and transitional arrangements following the repeal; preservation of refusal of treatment certificate in force under the Act; preservation of role of appointed agent under an enduring power of attorney (medical treatment) under the *Medical Treatment Act 1988*; preservation of role of person appointed under *Guardianship and Administration Act 1986*

Part Nine of the Act

Addresses the amendment of the *Mental Health Act* 2014

Clauses 106 to 122

Insert an additional person "other applicable person" into Division 5 of the *Mental Health Act 2014* i.e. a person who is not a patient and who is not a young person; amends Section 91 to provide for a course of electroconvulsive treatment to be performed on "other applicable person"; allows a psychiatrist to apply to the Tribunal to perform electroconvulsive treatment on "other applicable person" who does not have capacity to give informed consent and determines conditions of application of same

Clauses 116 to 122

Insert a new definition of *medical treatment* into the *Mental Health Act 2014* and repeals and amends other sections of the *Mental Health Act 2014* to consider values directive; to recognise medical treatment decision maker; to recognise instructional directive

Part Ten of the Act

Concerns the *Guardianship* and Administration Act 1986

Clauses 123 to 149

Repeal certain definitions and inserts new definitions i.e. *special procedure* has been changed to *special medical procedures*; amends the object of the *Guardianship and Administration Act 1986*; amends the function of the Public Advocate in the *Guardianship and Administration Act 1986* etc.

Clauses 150 to 152

Insert new definitions of *medical treatment* and *medical research procedure* into the *Powers of Attorney Act 2014* and amends the definition of *personal matter* to exclude any matter that relates to medical treatment or medical research procedures

Clause 153 to 161

Amends language in other relevant Acts

Access to the full Medical Treatment Planning and Decisions Act 2016 can be found at: http://www.legislation.vic.gov.au/domino/Web_Notes/LDMS/PubPDocs.nsf/ee665e366dcb6cboca256da4oo837f6b/c4016493339cd44dca258o2doo7d189e!OpenDocument.

The Caroline Chisholm Centre for Health Ethics would be very interested in your feedback on this style of article. Please send your feedback to maureen.waddington@svha.org.au.

¹http://vcoss.org.au/documents/2016/10/STM_161006_Medical-Treatment-Planning-Decisions-Bill.pdf.

Community attitudes shape palliative care: seeking a resolve to the slippery slope effect

As part of the Inquiry into End of Life Choices (The Inquiry), commissioned by the Victorian State Government on 7 May 2015, members of the community were invited to share their attitudes towards assisted dying by written submissions. The Inquiry also hosted a panel discussion with a few selected respondents. The final report prepared by the Inquiry is a comprehensive document that identified common themes relating to the benefits and concerns about a possible assisted dying framework. respondents used the opportunity to advocate in favour of palliative care services and advance care planning. There were other respondents that were apprehensive about possible changes to the law and wary that it could incite permissible practices of assisted death in Victoria which are in contradiction to existing ethical beliefs, values and norms. Their anxiety was in relation

... other respondents ... were apprehensive about possible changes to the law and wary that it could incite permissible practices of assisted death ... in contradiction to existing ethical beliefs, values and norms ... anxiety was in relation to a potential slippery slope effect ...

to a potential slippery slope effect of these laws in the future. In this article I will explore how the slippery slope effect has been used to criticise euthanasia legislation, using data from the Netherlands. Although there are indications that the slippery slope is apparent in the Netherlands, there are also contrary indications that are otherwise open for interpretation. I propose that the Inquiry was a valuable opportunity to reflect on community attitudes towards assisted death and that the recommendations to better resource palliative care services, is a positive outcome.

On 25 May 1995, the Northern Territory in Australia became the first place in the world to legalise euthanasia. However, the law was revoked by the Federal Government on 25 March 1997. The

Netherlands is therefore recognised as the first country in the world to legalise Euthanasia and assisted suicide on 1 April 2002. Since then, assisted death has been legalised in Belgium, Germany, Switzerland, France and various states in the United States of America. Since first instated, the law and incumbent safeguards created to protect patients and doctors have, in some countries, been compromised.

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The permissible action of some doctors under the guise of legalised euthanasia is sometimes referred to as the slippery slope effect. This raises some worrying questions concerning once autonomous, voluntary informed decisions possibly becoming non-voluntary or involuntary, and discriminating against citizens of a country based on sickness, level of disability or age.

Although a contentious issue in academic literature, there is anecdotal evidence that recognises the slippery slope effect in practice. This article will address the concerns of opponents of assisted death, which propose that the slippery slope is an inevitable repercussion of changing the law. It will also offer recourse, that through acknowledging community attitudes towards end of life decisions broadly and culturally, healthcare services such as palliative care can alleviate widespread concern that people have about dying with dignity.

Briefly here is a short summary of Euthanasia. Euthanasia is literally translated to 'good death'¹. Yet the way in which the word is used in ethical discourse and social debate is commonly related to how patients make decisions about their care at the end of life, as well as the intentions of doctors treating patients near death. Decision-making in this context is differentiated as either: voluntary active euthanasia, where a patient has made a decision to end their life and the request is acted upon by the physician, or non-voluntary euthanasia, where the patient is not able to provide meaningful consent or

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involuntary euthanasia, where the decision to hasten death is made against the wishes of the patient by either a doctor or a family member involved in their care.² In countries where euthanasia is legalised, patients with capacity can make a decision to end

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their life and either take the medication themselves or have their doctor administer it (this is referred to as physician-assisted euthanasia or also physicianassisted death). The safeguards written into laws are there to protect the patients, their doctors and the community. However, in countries where euthanasia is legalised, there is anecdotal evidence which suggests that these safeguards are being challenged to the point where patients that would not have otherwise been eligible for euthanasia or physicianassisted euthanasia, and those not wishing to end their life prematurely after a terminal diagnosis are being 'treated' under the euthanasia law. This is of concern for some community members and academics that denounce this practice and say it is evidence of the slippery slope effect. In order to explore the implications of a possible slippery slope effect, there needs to be some reflection of community attitudes, and more specifically, about why people feel disillusioned about their end of life care.

<u>Community attitudes towards end</u> <u>of life decision-making</u>

To explore the implication of the slippery slope effect, we need to define where this metaphorical slope actually begins. For the purpose of this article, it delineates from Catholic Social Teaching about death. Life itself is precious and human dignity is innate to our identity in the broader context of the Christian community. At the end of life, people may become particularly vulnerable and/or fearful. As immense as the struggles someone may feel at the end of life; love, compassion and human dignity nurture the person in these anxieties because in the Catholic faith we live and die together. An overt truth of the Catholic faith is that the choice to destroy one's own life is always morally wrong; and, the implicit cooperation of another in this action cannot be

condoned in any situation.³ This is the steadfast position that the Catholic Church has taken on suicide, which is unwavering since antiquity. It is strongly believed that any deviation from this platform, such as a law that sanctions suicide of any form –either physician-assisted or otherwise—is the tipping point that results in the 'slippery slope' effect.

Community attitudes about death and dying have changed throughout time. Where once an overtly existential experience framed by religion, has in recent time been shaped by patient autonomy and biomedical intervention. The Rights of the Terminally III Act (NT) 1995, was a significant shift in political and community attitudes towards death from traditional Australian values. A thorough discussion of the sociohistorical context of western society and beliefs about end of life is outside the scope of this article. However, an Australian academic provides some useful insights from her own research about how community attitudes shaped the political agenda in the Northern Territory.

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Professor Fran McInerney, from the University of Tasmania first wrote about the 'Requested Death Movement'. She wrote that community support for euthanasia and physician assisted suicide "principally concerned with the resisting state control of cultural matters, while reclaiming matters of identity, privacy and individual corporeality."4 This could be interpreted as patients generally and the community as a whole feeling disempowered at the end of their life. A second article she wrote in 2006 traced the print media reporting of the Northern Territory and The Rights of the Terminally III Act 1995. Employing a constructionist perspective to analyse the media reports at the time, McInerney found that "constructions of contemporary dying as horrific, intolerable and beyond the ameliorative powers of medicine and palliative care."5 It went on further to say that patients were the victims, and terminal illness was associated with suffering and physical decay. On the other hand, doctors and politicians were the heroes-"The voices of the dying themselves were

... There are some patients that feel overburdened and anxious at this time and express a wish to hasten death. This is however, rarely a choice to end their life, rather an invitation for family, carers and health care professional to engage in conversations about pain relief and perhaps pastoral care ...

rarely heard, as, arguably owing to their being near death, the requested death movement assumed the role of speaking for them."⁶

McInerney's work depicts the end of life as an "abject state from which the patient could be redeemed by the process of requested death." So if the patient is powerless, then euthanasia is strength to restore some of that lost power back to the patient. There is however contrary evidence from the literature and palliative care physicians. It is not unusual for patients to feel vulnerable at the end of life. There are some patients that feel overburdened and anxious at this time and express a wish to hasten death. This is however, rarely a choice to end their life, rather an invitation for family, carers and health care professional to engage in conversations about pain relief and perhaps pastoral care. 8

The slippery slope effect

The slippery slope effect is somewhat straightforward from a theoretical perspective and is commonly implicated in morally contestable debates about social change. In brief, the slippery slope effect can be summarised as:

Typically "slippery slope" argument claim that endorsing some premise, doing some action or advocating some policy will lead to some definite outcome that is generally judged to be wrong or bad. The "slope" is "slippery" because there are claimed to be no plausible halting points between the initial commitment to a premise, action or policy and the resultant bad outcome. The desire to avoid such projected future consequences provides adequate reason for not taking the first steps.9

Based on this premise, opponents of legalising euthanasia will contest that the misuse of euthanasia is inevitable if such laws are created. Also if we permit assisted death in a particular circumstance, then these provisions could be exploited in future to allow for a wider group of people to decide to end their lives, or more disconcertingly, granting authority for others to end the lives of those around them. To demonstrate this point I will refer to Professor John Keown's work and draw attention to euthanasia legislation in the Netherlands. This synopsis proposes how the slippery slope effect can be used in debates about euthanasia. It cannot however affirm inevitably that legislation of euthanasia is a proposition for permissible misuse in the future. I submit an alternative to circumvent community anxiety about the long term implications of assisted death legislation, to be guided by community needs and attitudes. In particular, addressing concerns through established palliative care services and working towards better resourcing these facilities would be beneficial. This notion was also expressed in the Inquiry's final report.

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John Keown is Professor of Christian Ethics at the Kennedy Institute of Ethics at Georgetown University. His work has been widely based on the ethical issues at the beginning and end of life. An important contribution he has made to the end of life debate, and specifically, the fallibility of legalising euthanasia, is related to justifying the slippery slope effect. Keown says that:

The "slippery slope" argument is often thought of as one argument but it is more accurately understood as comprising two independent yet related forms: the "logical" and the "empirical." In logical form, the argument runs that acceptance of voluntary euthanasia leads to acceptance of non-voluntary euthanasia.... Arguments for voluntary euthanasia rest on the judgement that some lives are not "worth" living Consequently, the alleged justification for voluntary euthanasia rests fundamentally not on the patient's autonomous request but on the doctor's judgement that the request is justified

because the patient no longer has a life "worth" living. If a doctor can make this judgment in relation to an autonomous patient, he can, logically, make it for an incompetent patient.... In its "empirical" form, the "slippery slope" argument asserts that even if a line can in principle be drawn between voluntary and non-voluntary euthanasia, a slide will occur in practice because the safeguards to prevent it cannot be made effective."¹⁰

In Keown's article, a large part is made up of evidence provided by the Commission appointed by the Dutch Government to oversee and review how citizens make decisions at the end of life. Keown begins by presenting the laws around euthanasia in the Netherlands. He questions whether the language used sufficiently safeguards patients from subjective interpretation, especially terms used to describe pain and informed decision-making such as "unbearable suffering" and "entirely free and voluntary request" respectively.

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The Commission surveyed general practitioners, specialists and nursing home doctors using three study designs that included qualitative and quantitative instruments with prospective and retrospective analysis. Interestingly, the incidence of euthanasia was different for each study but overall the Commission stated that where euthanasia is defined as "intentional, active termination of life at the patient's request" a total of 1.8 per cent of all deaths were caused by this practice. The report goes further to note that a further 0.8 per cent of the remaining deaths could be accounted for by doctors administering medications "with the explicit purpose of hastening the end of life without an explicit request of the patient."

Keown writes that using a standard definition of euthanasia, such as "when the death of a human being is brought about on purpose as part of the medical care being given to him", reveals a different estimate of the number of patient deaths as a result of euthanasia. Based on this supposition, Keown notes that the Commission underreported the

number of deaths, with 1 in 12 deaths (of a total of 129 000) in the Netherlands intentionally accelerated by a doctor. 11 Most have said, and Keown notes in his article, that the intention of the doctor and/or patient have not been acknowledged even though there was scope to explore this facet in the qualitative study. I don't think Keown's intention in publishing this report is to condemn the actions of doctors but to bring to light that the slippery slope effect is a contentious issue that could be used to interpret data on patient mortality. Keown also states that perhaps euthanasia is being used as an alternative to palliative care; although the evidence of this is outside the scope of this article and Keown's analysis. Since Keown's report, some academics have supported his conclusions.¹² However, there are other academics that refute the data and Keown's analysis as speculative, inconclusive and suspect due to the lack of baseline data. Also, the experience of one country cannot be superimposed onto the anticipated outcomes for another due to the cultural context, therefore the slippery slope effect to infer permissible misuse in the future remains open for debate.13

<u>Cultural aspects of community</u> <u>engagement</u>

Patients disenchanted by the care provisions at the end of life, in their community, or without familial networks for support, could inadvertently seek out ways to hasten their death in times of illness. I have shown previously that the wish to hasten death is not an explicit instruction to die but an expression for others including health care providers to engage in dialogue about pain management and care such as pastoral care.14 It is perhaps the gap in patient information together with limited or under-resourced palliative care services in such areas as the Netherlands that could provide some explanation for the high levels of patients seeking assisted death. Clearly, decision-making about end of life care is different to non-voluntary/involuntary euthanasia so I should emphasise the need for educating doctors and health care professionals about palliative care as well.

Community attitudes towards end of life decisions are

... It is perhaps the gap in patient information together with limited or under-resourced palliative care services ... that could provide some explanation for the high levels of patients seeking assisted death ...

... The cultural dimension of the experience at the end of life should also be sensitive to linguistic needs that need be negotiated at the provider level, an area that requires ongoing attention ...

an expanding area of research. The nuances inherent in community identity are dynamic and informed by social, cultural and ethical values. This in turn shapes how people within a community respond to and makes decisions about their end of life care, and whether to seek palliative care. Informed decisionmaking involves these values and in particular, cultural aspects. A literature review of how culture impacts on community needs of palliative care can be summarised according to three thematic areas which are applicable regardless of cultural group: that palliative care providers should attend to the physical, psychosocial and spiritual aspects of death and dying; that they demonstrate excellent knowledge and expertise about end of life care, which is respectful, genuine and compassionate; and, that they should include a range of resources that alleviate the potential burdens associated with end of life care. 15 The cultural dimension of the experience at the end of life should also be sensitive to linguistic needs that need be negotiated at the provider level, an area that requires ongoing attention.¹⁶

Conclusion

Inviting community consultation on important social issues in order to shape the political agenda is a valuable opportunity to learn about citizens' needs but also address any concerns they have about proposed laws and policy. End of life care is a pertinent social issue that is applicable to everyone in the community. The Inquiry was therefore imperative in learning whether changing the law in Victoria in favour of assisted death could raise significant concerns for the community at large. The final report supported allocating resources including funding into palliative care and advance care planning.

There were respondents to the Inquiry that expressed some misgiving about proposed changes to the law in light of the experience in the Netherlands and the permissible misuse of euthanasia legislation. The literature does acknowledge the slippery slope effect. It does however also show that the interpretation of research data in light of legalised euthanasia is as much responsible for over calculating as under calculating the incidences of voluntary, involuntary

and non-voluntary cases of assisted death. Therefore, identifying the social context and cultural values that shape community attitudes about death, is a far more important response to allocating resources and using palliative care to addresses any concerns before patients and families contemplate assertive action to die without due consideration for alternative care pathways. In the long term it will also help facilitate a health care framework that is shaped compassionate and holistic care.

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- ¹ Benedict M. Ashley and Kevin D. O'Rourke, "Suffering and death" in Health Care Ethics: A Theological Analysis, 4th edition. (Washington D.C: Georgetown University Press, 1997), 417.
- 2 Ibid., 411-419.
- ³ Kevin D. O'Rourke and Philip J. Boyle, "Assisted Suicide" in Medical Ethics: Sources of Catholic Teachings, 4th Edition. (Washington D.C: Georgetown University Press, 2011), 72-75.
- ⁴ Fran McInerney, "Requested death: a new social movement," Social Science and Medicine 50, no. 1 (2000): 137–154, at 137.
- ⁵ Fran McInerney, "Heroic frames: discursive constructions around the requested death movement in Australia in the late-1900s," Social Science and Medicine 62, no. 3 (2006): 654-667 at 664.
- ⁶ Ibid., 664.
- ⁷ Ibid., 665.
- ⁸ Dilinie Herbert, "Wish to Hasten Death," Chisholm Heath Ethics Bulletin 21, no.4 (Winter 2016): 7-11.
- ⁹ Walter Wright, "Historical analogies, Slippery Slopes, and the question of Euthanasia," The Journal of Law, Medicine & Ethics 28, no. 2 (2000): 176-186 at 177 In Penney Lewis, "The empirical slippery slope from voluntary to non-voluntary euthanasia," The Journal of Law, Medicine & Ethics 35, no. 1 (2007): 197-210.
- ¹⁰ John Keown, "Euthanasia in The Netherlands: sliding down the slippery slope?" Notre Dame Journal of Law, Ethics & Public Policy, 9, no. 2 (1995): 407–448 at 407–408. ¹¹ Ibid.,422–423.
- Raanan Gillon, "Euthanasia in the Netherlands down the slippery slope?" Journal of Medical Ethics 25, no. 1 (1999): 3-4.
- ¹³ Penney Lewis, "The empirical slippery slope from voluntary to nonvoluntary euthanasia." The Journal of Law, Medicine & Ethics 35, no. 1 (2007): 197-210 at 205.
- 14 Wish to Hasten Death
- ¹⁵ Harvey Bosma, Lars Apland and Arminée Kazanjian, "Cultural conceptualizations of hospice palliative care: more similarities than differences", Palliative Medicine 24, no. 5 (2010): 510–522.
- ¹⁶ A. Broom, P. Good, E. Kirby and Z. Lwin, "Negotiating palliative care in the context of culturally and linguistically diverse patients," Internal Medicine Journal 43, no. 9 (2013): 1043-1046.

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