



Submission to the Legal and Social Issues Committee

Inquiry into End of Life Choices

Approved by the Board of Palliative Care Victoria Inc.

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Inquiry into End of Life Choices Terms of Reference

On 7 May 2015 the Legislative Council agreed to the following motion:

That pursuant to Sessional Order 6 this House requires the Legal and Social Issues Committee to inquire into, consider and report, no later than 31 May 2016, on the need for laws in Victoria to allow citizens to make informed decisions regarding their own end of life choices and, in particular, the Committee should —

- (1) assess the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end of life, including the role of palliative care;
- (2) review the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian states and territories and overseas jurisdictions; and
- (3) consider what type of legislative change may be required, including an examination of any federal laws that may impact such legislation.¹

Executive Summary

Palliative Care Victoria welcomes the opportunity to contribute to this inquiry.

The values of compassion, dignity, respect and choice are important to us all and are integral to the provision of high quality palliative care and end of life care.

As a community, we must support people during the last stages of their lives. This involves being responsive to their needs and preferences so they can enjoy the best possible quality of life and die in comfort, with dignity, feeling valued and supported by family, friends and those providing care.

Our health and care services are not well-placed to achieve this outcome. Currently, there is significant unmet need for high quality palliative care and end of life care and forecasts indicate significant increases in need in the years ahead.

The terms of reference of this inquiry are focused on assessing any need for law reform to support decision making about end of life choices. We recognise that such a review is useful and that there is a need to improve the capacity to make known advance care wishes, including the refusal of treatment, for future as well as current health conditions.

We are very pleased that during the life of this inquiry, the Victorian Government has committed to undertake parallel work on appropriate improvements to palliative care services and associated funding through the health portfolio.

The Department of Health and Human Services has commenced work on an End of Life Care framework to replace the current palliative care policy framework expiring this year.

We hope this will result in a visionary, robust and sustainable strategy that includes appropriate community engagement, service provision, workforce, research, evaluation and funding strategies to respond to the immediate and longer term needs for palliative care and end of life care. Given its significance, we recommend that there be opportunities for public input into its development during the life of this inquiry.

Our submission considers the options of euthanasia and assisted suicide with reference to available information and evidence of these practices, particularly in the Netherlands, Belgium and Oregon. In all three jurisdictions, the evidence indicates an annual increase in the use of these options of 15% or more, with signs of more rapid increases as the scope of these practices broadens. In the Netherlands and Belgium euthanasia is now an option for children as well as adults, for people who are not terminally ill, for people with psychiatric or psychological conditions, and for people with current or anticipated disabilities. There is also a call to extend these options for people aged over 70 who are tired of life.

The practice of euthanasia and assisted suicide by health care professionals departs from the clear ethical foundations and practice boundaries of health care.

There is very concerning evidence that this is eroding trust in health professionals and health services and leading to cultural changes in normative health care practice.

The evidence also flags growing concerns about family pressure and social expectations impacting on requests for euthanasia or assisted suicide. This is relevant in the context of the known

incidence of elder abuse and family violence, which are often hidden, and the poor social status and value we accord to older people and people with disabilities in our society.

There is a real danger that legalising euthanasia and/or assisted suicide will lead to a growing sense of a duty to die.

Matters of life and death involve difficult and at times tragic choices. It is the responsibility of public policy and law to advance the public interest and to protect those who are most vulnerable.

There is no remediation available when euthanasia or assisted suicide results in the death of a person who could have lived with improved quality of life or died a good natural death had appropriate health care been given.

Palliative Care Victoria has given this issue in-depth consideration and does not support the legalisation of euthanasia or assisted suicide.

We sincerely hope that the Victorian Parliament will decide to not proceed with the legalisation of these options. If however, it does decide to do so, it must take urgent action to improve significantly access to high quality palliative care and end of life in all health and care settings across Victoria, with substantial increases in funding to support the comprehensive range of strategies that will be needed to achieve this in readiness for the implementation of such law.

We also recommend that any draft legislation impose very strict criteria and safeguards, include strong checks and balances, rigorous independent monitoring, and annual reporting to the Victorian Parliament and the community.

Importantly, we recommend very strongly that euthanasia and/or assisted suicide be strictly separated from all health and care services. They are not medical treatment and they should not be undertaken by health professionals. It is imperative that we do not cross the ethical barrier and allow doctors to kill patients. Health care must above all be a safe haven for people who are vulnerable and who are dying.

Summary of Recommendations

Palliative Care Victoria recommends that the Victorian Government:

1. accord a high priority to community engagement, service provision, workforce, research, evaluation and funding strategies that will significantly improve timely access to high quality palliative care and end of life care for all people with a life limiting illness and their families across Victoria;
2. provide opportunities for community engagement and input into the development of the End of Life Care Framework during the life of this inquiry;
3. allocate significant new funding for palliative care and end of life care in the 2016 Budget and forward estimates (such investment is likely to contribute to more effective use of health resources overall);
4. decide not to legalise euthanasia or assisted suicide; however, should it decide to do so, that any such practice be the responsibility of specifically trained staff in an independent and closely monitored service that is distinctly separate from all health and care services so that community trust in health professionals / services and the ethical foundations of health care can be maintained; and
5. provide opportunities for public input on any proposed law reforms related to end of life choices and decision-making.

Contents

Inquiry into End of Life Choices Terms of Reference	2
Executive Summary	3
Summary of Recommendations	5
Contents	6
Introduction	7
About Palliative Care Victoria	7
About this Submission	8
Terms of Reference	8
Informed Decision-Making about End of Life Care Choices	9
Health Care Choices	11
Priority to provide high quality palliative care and end of life care	11
Palliative Care	12
End of Life Care	14
Alleviation of Pain and Suffering	14
Refusal of Medical Treatment, Food & Fluids	17
Euthanasia and Assisted Suicide	18
Euthanasia and Assisted Suicide Are Not Health Care	18
End of Life Concerns Prompting Requests for Assisted Suicide	19
Legislation and Incidence of Euthanasia and Assisted Suicide	20
Concerns about Euthanasia & Assisted Suicide	22
Palliative Care Victoria's Position on Euthanasia & Assisted Suicide	29
Requirements IF Legalisation is Proposed	29
Endnotes	31

Introduction

Palliative Care Victoria Inc. welcomes the opportunity to make a public submission to the Legal and Social Issues Committee on this inquiry. We would also appreciate the opportunity to appear at a public hearing.

The values of compassion, dignity, respect and choice are important to us all and must continue to be integral to high quality health care and end of life care.

How well we support people to enjoy the best possible quality of life as they face their inevitable mortality and how well we support them to die in comfort, with dignity and supported by those close to them, are among the key challenges of the 21st century that will define the ethical character of our society.

There is no debate about the reality that we must and can do more to improve end of life experiences for the tens of thousands of Victorians who will die this year and the hundreds of thousands of Victorians who will die within the next decade, and beyond.

What this inquiry must consider and decide is how best to achieve this objective within a sound ethical, legal and moral framework that will provide sound and robust foundations for how our children, grandchildren and their progeny will die in the future.

Matters of life and death involve difficult and at times tragic choices. It is the task of public policy and law to advance the public interest and to protect those who are most vulnerable. Health care must above all be a safe haven for people who are dying.

About Palliative Care Victoria

Formed in 1981, Palliative Care Victoria is the peak body for palliative care in Victoria. Our vision is that all Victorians with a life limiting illness and their families are supported to live well, to die well and to grieve well.

Our current membership of 180 includes 87 organisations (health, palliative care and aged care) and 93 individuals (mainly health professionals). Our members have extensive expertise and experience in providing palliative care and end of life care. They cover the broad range of medical, nursing and allied health disciplines involved in the interdisciplinary provision of specialist palliative care and end of life care.

Palliative Care Victoria is also the 'go to' organisation for patients and families seeking to find out more about palliative care and how to access palliative care services. We hear directly from families and patients who are dealing with life limiting illness and seeking support to receive the care and support they need. We also work with communities to raise awareness of palliative care and to build community capacity in relation to dying, death, grief and loss.

About this Submission

This submission has been approved by the Board of Palliative Care Victoria.

It is based on consultations with our members, discussions with international colleagues, and reference to available evidence.

Terms of Reference

Legal provisions

Given Victoria's ageing population, the growing incidence of chronic disease and the associated increases in deaths over the coming decades, it is strategically and ethically important that we have the appropriate community engagement, legislative, policy, service, workforce, and funding arrangements in place.

The terms of reference of this inquiry are focused on assessing any need for law reform to support decision making on end of life choices. We recognise that such a review is useful and that there is a need to improve the capacity to make known advance care wishes, including the refusal of treatment, for future as well as current health conditions.

Although not explicitly mentioned in the terms of reference for the inquiry, we understand that consideration will be given to whether it is appropriate to legalise euthanasia or assisted suicide.

While there have been numerous public surveys on this matter and media coverage of proponents seeking these options, there has been little in-depth analytical reporting in the media that examines this complex ethical, moral, legal and practical issue and evidence based on experience in jurisdictions where these options are available.

Related strategies

Appropriate legislation to support informed decisions about end of life care choices must also be supported by the timely access to high quality palliative care and end of life care services that are responsive to their diverse needs and preferences.

The Victorian Government has committed to undertake work in parallel to this inquiry on appropriate improvements to palliative care services and associated funding through the health portfolio. To support this, the Department of Health and Human Services has commenced work on an End of Life Care framework to replace the current palliative care policy framework expiring this year.

Immediate and longer-term community engagement, service provision, workforce, research, evaluation and funding strategies are required to provide a visionary, robust and sustainable approach to increasing needs for palliative care and end of life care.

This will involve being responsive to the multi-dimensional aspects of human experience – physical, social, psychological, spiritual and cultural - that contribute to quality of life throughout our lives and at the end of life. The impeccable assessment and management of depression, hopelessness and other psychological suffering of people with a life limiting illness is required.

We also need strategies to improve the capacity of the general community and health professionals to have conversations about end of life care and to be better prepared to deal with dying, death, grief and loss. This includes discussing the likely success and the benefits and burdens of treatment options.

Recommendations

Palliative Care Victoria recommends that the Victorian Government:

- accord a high priority to community engagement, service provision, workforce, research, evaluation and funding strategies that will significantly improve timely access to high quality palliative care and end of life care for all people with a life limiting illness and their families across Victoria;
- provide similar opportunities for community engagement and input into the development of the End of Life Care Framework as are being offered for this inquiry;
- allocate significant new funding for palliative care and end of life care in the 2016 Budget and forward estimates (such investment is likely to contribute to more effective use of health resources overall).

Informed Decision-Making about End of Life Care Choices

Facilitating informed decision-making is a central requirement in the provision of all health care services. The ethical and legal issues are more complex in the context of life-threatening situations and end of life care and warrant careful consideration.

It is timely to review relevant Victorian legislation with reference to best practice approaches to support high quality end of life care and to manage the ethical and legal complexities. This includes provisions for informed consent, the refusal of medical treatment, the withdrawal of medical treatment, the withholding of medical treatment, supported decision-making, the appointment of substitute decision-makers and advance care plans/directives.

Queensland Health has produced implementation guidelines on end-of-life care decision-making, including for withholding and withdrawing life-sustaining measures from adult patients.² These guidelines outline four principles for decision-making about life-sustaining measures:

Principle 1: All decision-making must reflect respect for life and the patient's right to know and choose.

Principle 2: All decision-making must meet the standards of good medical practice.

Principle 3: All efforts must be made to obtain the appropriate consent through a collaborative approach.

Principle 4: There must be transparency in and accountability for all decision-making.³

They note the tensions that exist between the three major themes in the ethics of withdrawing and withholding life sustaining measures: the preservation of life, patient autonomy and good medical practice.⁴ They also refer to the four principles of autonomy, beneficence, non-maleficence and

justice that need to be considered in bio-ethical decision-making, and note that patient autonomy cannot be interpreted as an entitlement to requested medical interventions.⁵

Advance care planning

It would also be helpful to consider ways to strengthen alignment between Victorian legislation and the National Framework for Advance Care Directives developed by the Australian Health Ministers Advisory Council in 2011.

A recent survey of 1,166 Australians aged over 55 about their end of life care wishes found that the default position of “do everything to save life, no matter what” addresses the wishes of only a small minority of people. Sixty-one percent of people over 75 strongly oppose any intervention that either prolongs life in poor health or results in poor quality of life and this group has a strong aversion to being kept alive in the presence of dementia.⁶ It is important that end of life care preferences are discussed, regularly updated, recorded and available at the time of care delivery so that the care provided is in accordance with what the person wishes, if they are no longer able to speak for themselves.

The Victorian Department of Health and Human Services is in the process of implementing an advance care planning strategy. Work is underway to develop the capacity of health care professionals and health care systems and processes to support this. Initial work has also been undertaken to identify the needs for community education and engagement strategies to support advance care conversations and planning.

This work is still in its early stages and it will take time to influence attitudes, inform behavioural changes and develop appropriate systems and protocols. If advance care conversations and planning become a normative part of health care provision (especially for people with chronic or life limiting conditions) this will pave the way for a much closer alignment between the values and care goals of people as they approach the end of their lives and the health care services they receive.

Education is needed to develop the capacity of health professionals to consider the ethical implications of advance care plans. Further consideration and guidance is needed to consider the practical and ethical implications of end of life care decision-making in relation to advance care plans made by people who subsequently develop dementia and other cognitive impairments, given this is a relatively new area of practice.

There is also a need to consider ways to improve public awareness and understanding of the opportunities that exist in law and in health care practice to make informed decisions about health care and end of life care choices – as those issues arise and in respect of future situations.

While forms and information are available from the Office of the Public Advocate in Victoria, there is a need for more accessible information on end of life care decision-making that is part of a broader public health approach that does not assume good levels of literacy (in English or other community languages) or health literacy or death literacy. A series of randomised controlled trials on the use of videos to support patient decision-making on end of life care preferences has found

that these are much more effective than oral discussions alone in helping people to discern whether the end of life choices accord with their preferences and goals of care.⁷

There is also a need to consider ways to support community members who are appointed by relatives or friends as substitute decision-makers. These people can face onerous decision-making responsibilities unexpectedly and during a crisis, often with little understanding of the procedures or preparation for this role. The availability of trained volunteer mentors who have relevant experience in substitute-decision-making may be one helpful approach to consider.

The default responses for emergency assistance in hospitals and emergency systems also need to be aligned better with advance care planning. For example, we are aware of a recent situation in a Victorian hospital where an elderly patient had a request for non-resuscitation in her documented advance care plan held at the hospital. However, when she collapsed during a physiotherapy treatment, code blue was called and the emergency CPR response was applied.

Authorised Palliative Care Plans have been introduced by the NSW Ambulance Service in collaboration with relevant health services to support paramedic decision-making in meeting the needs of individual patients while respecting their palliative wishes. NSW Ambulance applies this protocol to palliative and end of life care when an ambulance responds to a patient with an endorsed Authorised Palliative Care Plan in place.⁸ It would be worthwhile considering the merits of a similar approach in Victoria, particularly in rural areas where access to health services is more limited.

Health Care Choices

Priority to provide high quality palliative care and end of life care

There is an urgent need to improve access to high quality palliative care and end of life care to better meet the care needs and preferences of people with a life limiting illness and those who are imminently dying.

This requires a whole of health approach by the Commonwealth and State Governments that will develop and support the capacity of primary, acute, specialist, aged, disability and paediatric care services to provide high quality care that meets the health care and support needs for people with chronic and life limiting illness in the last stages of their lives, as well as families and other people providing care and support.

A comprehensive End of Life Care Framework, as proposed by the Victorian Government, will provide an important vehicle for this. This will include facilitating a palliative approach to care where appropriate by generalist health care professionals, and further development of a strong specialist palliative care sector; both a palliative approach to care and specialist palliative care can play an important role soon after diagnosis of a life limiting condition and should not be limited to the last weeks or days of life.

Palliative Care

WHO Definition

The World Health Organisation defines palliative care as:

“An approach that improves the quality of life of patients & their families facing the problems of a life-threatening illness, through prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”⁹

Quality of Life Benefits of Palliative Care

Appropriately resourced palliative care will provide the best care possible to improve the quality of life of people with a life-limiting illness, to respond to their needs and preferences, and to support them to die with dignity and in comfort.

Extensive research studies¹⁰ have demonstrated a range of quality of life benefits for people receiving palliative care and their families, including:

- Improved management of pain and other symptoms
- increased likelihood of receiving care at their place of choice
- increased likelihood of dying at home, where this is their preference
- increased family support and satisfaction with the care provided
- greater emotional support
- improved communication with families and

- o significant improvements in quality of life and mood; and less aggressive care at the end of life but longer survival.¹¹

Palliative Care Services in Victoria

We provided a briefing about palliative care in Victoria to the Legal and Social Issues Committee on 10 June 2015. Our presentation (attached) highlighted issues pertinent to the availability of choices for end of life care for Victorians, including:

The need to respond to current unmet and growing needs for palliative care and end of life care

The current unmet need for palliative care in Victoria is in the range of 16% to 40%. Groups missing out on palliative care include: children, adults with non-malignant life limiting illnesses, including the rapidly increasing population with dementia, Aboriginal people and people from culturally and linguistically diverse backgrounds.¹²

Population growth and ageing, as well as the increasing incidence of chronic disease contribute to an anticipated growth in need of around 8% in the short term, with this increasing dramatically over the next 25 years.¹³

The need to improve community palliative care and support for carers

Although home is the preferred place of care and death for most people with a life limiting illness and their carers, most funding is provided for inpatient care. Increased investment in the availability of 24/7 community palliative care and support for carers is required.¹⁴

The need to increase community awareness and understanding of palliative care

A major community awareness and community engagement strategy, similar in scale to Beyond Blue, is needed to improve understanding of, and access to, palliative care and to build community capacity to deal with the issues of dying, death, grief and loss.¹⁵

A need to build the capacity of health services to provide high quality end of life care

Evidence indicates a need to improve the education of health professionals so they are better equipped to care for people who need a palliative approach to care and end of life care. This includes: developing the confidence and skills to have advance care conversations; identifying with triggers for referral to palliative care for specialist expertise; and providing high quality end of life care.

The need for a significant increase in funding for Victorian palliative care services

Palliative Care Victoria's Call to Action 2015-19 sought a modest increase of \$66 million during this period. Evidence indicates that investment in palliative care services improves the effective use of health resources and avoids costs associated with avoidable hospital admissions and non-beneficial treatments, which are more likely among patients who are dying who do not receive palliative care.¹⁶

The 2014 Grattan Institute report, *Dying Well*¹⁷, and the 2015 Victorian Auditor-General's report on the inquiry into palliative care¹⁸, also highlight the need to improve funding to support people to die well and align service provision with preferences to receive care and to die at home.

End of Life Care

Palliative Care Victoria welcomes the Victorian Government's intention to develop and implement an End of Life Care Framework, which will replace the current policy framework that concludes in 2015.

We look forward to contributing to consultations and the release of a visionary and robust policy and funding framework. While immediate actions are required in the short term, there is also a need for a sustained, longer-term strategy that builds the service and workforce capacity needed in the context of significant increases in the need for palliative care and end of life care over the coming decades.

Strong collaboration is needed between the Commonwealth and Victorian Governments if we are to provide universal needs-based access to health care and support services that provide the best care possible to people during the last stages of their lives. It is imperative that we provide consistently high standards of care to people who are dying, whether they are living in a hospital, an aged care facility, supported accommodation or at home in the community. It is very concerning that some of the most vulnerable people with some of the most complex needs are cared for in aged care services with much lower levels of qualified health professional staffing levels. We must also ensure that families and friends caring for people who are dying at home have timely access to appropriate professional support, including at night and weekends.

The "National consensus statement: essential elements for safe high quality end of life care", released earlier this year by the Australian Commission on Safety and Quality in Health Care¹⁹, outlines some guiding principles and essential elements that will be useful for Victoria's end of life care framework.

The End of Life Care Framework should also include innovative strategies and service models that can improve the responsiveness of services to the needs and preferences of people with life limiting illnesses and their families, and foster greater community and volunteering support.

Alleviation of Pain and Suffering

Pain and Symptom Management

Achieving the effective management of pain and other symptoms is a high priority in the care of people with a life limiting illness and people who are dying.

Where these symptoms are not readily alleviated by general health and care services, a referral to access the specialised expertise of palliative care services should be made.

In most cases, specialist palliative care teams are able to address the person's physical pain and other symptoms and to respond to their psycho-social, emotional, spiritual and cultural needs so that they are able to live and die well with dignity.

However, a small minority of patients experience refractory symptoms such as agitated delirium, difficulties breathing, pain and convulsions.

Refractory symptoms are defined as:

*"pain or other symptoms for which all possible treatment has failed, or it is estimated that no methods are available for palliation within the time frame and the risk-benefit ratio that the patient can tolerate."*²⁰

Management of Refractory Distress

A patient with refractory (unrelieved) distress "must have received skilled multidimensional management directed at the physical, psychological and existential dimensions of the symptom before a symptom is considered refractory."²¹

Prudent application of palliative sedation therapy may be used in the care of selected palliative care patients with otherwise refractory distress.

The European Association of Palliative Care (EAPC) defines palliative sedation as:

*"The monitored use of medications 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."*²²

The EAPC has outlined a 10-point framework²³ for the ethical use of palliative sedation therapy in the care of selected palliative patients with otherwise refractory symptoms at the end of life. This includes:

- pre-emptive discussion with the patient about the potential role of sedation in end of life care and contingency planning
- clear clinical indicators for its use in patients with intolerable distress due to physical symptoms
- evaluation and consultation procedures prior to initiating palliative sedation therapy
- consent requirements
- discussion of the decision-making process with the patient's family
- direction for the selection of the sedation method
- dose titration, patient monitoring and care
- guidance for decisions regarding hydration, nutrition and concomitant medications.

The EAPC framework indicates that the level of sedation used should be the lowest necessary to provide adequate relief of suffering:

*"The doses of medications should be increased or reduced gradually to a level at which suffering is palliated with a minimum suppression of the consciousness levels and undesirable effects, with documentation of the reason for changes and response to such manoeuvres."*²⁴

Only under exceptional circumstances is deep and continuous sedation required from initiation of palliative sedation therapy.²⁵

There is evidence that palliative sedation therapy does not hasten death.^{26 27}

Even if palliative sedation therapy were to have the side effect of hastening the death of an imminently dying patient, because the intent is to alleviate refractory symptoms through carefully titrated sedation, the doctrine of double effect would apply. This doctrine holds that:

*"...when a morally legitimate and good act results in unintentional and bad side effects, it is acceptable because the good outcome outweighed the bad side effect and the bad effect was not intended."*²⁸

Intention is an important consideration in the doctrine of double effect and is one of three characteristics that clearly distinguish palliative sedation therapy from voluntary and non-voluntary euthanasia and assisted suicide.^{29 30}

	Palliative sedation therapy	Euthanasia & Assisted Suicide
Intention	To relieve suffering through palliative means without intent to cause death	To end suffering by causing death
Method	The selection and carefully titrated use of drugs with palliative indications to relieve suffering at the lowest dose necessary.	The selection and use of drugs in appropriate doses to cause death quickly and effectively.
Outcome	Management of refractory symptoms to reduce suffering.	Death of the patient.

If clinicians sedate patients at the end of life with the primary goal of hastening or causing the patient's death, this is not palliative sedation therapy and is an abuse of the use of sedation.³¹ In such situations it transgresses the law and the professional bio-ethical principle of non-maleficence (do no harm). Intention is an important consideration in jurisprudence and in the case of palliative sedation therapy can be clearly discerned by the methods used and recorded.

Depression and Hopelessness

Depression is a major public health issue with lifetime incidence ranging from 2% to 25%.³²

It is estimated that 20 to 25% of cancer patients suffer often unrecognised and untreated long-term depression, contributing to a poor quality of life.³³

Depression is a disorder in which mood and vitality are lowered to the point of despair. Patients report that life is meaningless, and experience feelings of misery and hopelessness.³⁴

Depression limits the person's capacity to cope with the difficulties associated with incurable illness and can be experienced as a loss of dignity. It is a recognised risk factor for suicide and requests to hasten death.³⁵ With reference to the broader context, 65,000 Australians attempt suicide each year and of these 2,000 people die by suicide each year.³⁶

Studies show a higher perception of pain among people with depression and a higher incidence of depression among people with chronic pain than when these conditions are examined

individually. This suggests the need to treat both concurrently, as these conditions share biological pathways and neurotransmitters.³⁷

A study of 147 palliative care patients experiencing chronic pain (due to cancer and non-cancer conditions) found psychiatric morbidity was 67% with depression and adjustment disorders being the main diagnosis. There was a significant association between the worst pain perceived and psychiatric morbidity, which also impaired activity, mood, relationship and independence.³⁸

The impeccable assessment and management of depression and other psychological suffering of people with a life limiting illness is an integral part of high quality palliative care and end of life care.

One strategy is dignity therapy, which is “a brief psychotherapeutic approach with the aim of bolstering the patient’s sense of meaning and purpose, reinforcing a continued sense of worth within a framework that is supportive, nurturing, and accessible for those near death.”³⁹ This has been found to contribute to a significant reduction in symptoms of depression among terminally ill patients.⁴⁰

The wish to die

A range of studies have found that expressions of desire for a hastened death among terminally ill patients range from 17% to 45% (including those with a fleeting but not sustained wish to die). These studies have found a strong correlative relationship between the clinical manifestations of major depressive disorder and patients with a life-threatening illness expressing a desire for hastened death. The experience of hopelessness is also independently associated with the desire for a hastened death and there is also a link with the perception of the self as a burden to others. Pain specifically did not increase the risk of a desire to hasten death.⁴¹

Statements expressing a wish to die or to hasten death are often a means of communicating an intolerable internal or interpersonal state. Active listening and an exploration of the underlying needs and concerns are important in tailoring care to alleviate the distress.⁴² There is a danger that the literal meaning of expressions of a wish to hasten death are privileged in medical settings, without due consideration and investigation of the concerns underlying this form of communication.⁴³ With compassionate and appropriate care the wish to hasten death often disappears. Since the introduction of assisted suicide in Oregon, 35% of patients have chosen not to ingest the lethal medicine they were prescribed.⁴⁴ There is no second chance with euthanasia.

Refusal of Medical Treatment, Food & Fluids

The principle of respect for personal autonomy informs a widely held common law position that a competent adult has the right to refuse medical treatment, even if this is considered to be contrary to their best interests and may result in their death.

In Victoria, the Medical Treatment Act 1988 clarifies the law relating to the right of patients to refuse medical treatment. It establishes a procedure for clearly indicating a decision to refuse medical treatment in respect of a current condition and to appoint a person to refuse medical

treatment on their behalf in respect of that condition at a future date in the event that they are no longer able to make their own decision.

This Act excludes the refusal of palliative care, which is defined as “reasonable treatment for the relief of pain, suffering or discomfort and the reasonable provision of food and water.”⁴⁵

A Victorian Supreme Court decision in 2003 clarified that palliative care does not include artificial feeding through a PEG (percutaneous endoscopic gastrostomy) tube inserted directly into the stomach (hence this may be refused). While palliative care may include the provision of food and water, this does not involve requiring the person to accept food or water offered to them.

It would be appropriate to review the Act given community aspirations to have a stronger voice in determining the future medical care they may receive, both for current and future conditions. There is also the broader question of how this legislation relates to advance care planning and the need to strengthen supported and substitute decision-making.

Loss of appetite and refusal of food and fluids can also be a part of the natural dying process. The ability to swallow can become impaired and forcing food or fluid at this time may be harmful or painful to the dying person.

Euthanasia and Assisted Suicide

Euthanasia and Assisted Suicide Are Not Health Care

Health care

The World Health Organisation defines health care as:

“Services provided to individuals or communities by health service providers for the purpose of promoting, maintaining, monitoring or restoring health”⁴⁶

and a health goal as:

“An ultimate desired state of health towards which actions and resources are directed.”⁴⁷

The ethical principles of beneficence and non-maleficence have provided guidance on the goals and boundaries of health care since Hippocrates over 2,400 years ago.

We should not cross the ethical barrier and allow doctors to kill patients.⁴⁸

Euthanasia and assisted suicide

Euthanasia involves the deliberate intent to end the life of a person through the administration of a lethal agent sufficient to cause death. Voluntary euthanasia occurs where a decisionally competent person has given informed consent to be euthanased.

Assisted suicide involves providing the means (such as a lethal cocktail of drugs) to enable a person to end their own life through suicide.

Euthanasia and assisted suicide do not constitute health care and are directly at odds with the age-old and unambiguous prohibition on physicians not to kill or hasten death.⁴⁹

End of Life Concerns Prompting Requests for Assisted Suicide

The Oregon Public Health Division in its 2014 Annual Report provides a summary of the end of life concerns identified by 859 patients who have died from ingesting medications prescribed under Oregon's legislation permitting physician assisted suicide between 1998 and 2014 as follows:⁵⁰

Oregon patients who died by physician assisted suicide 1998-2014		
End of life concerns	N=859	%
Losing autonomy	782	91.5
Less able to engage in activities making life enjoyable	758	88.7
Loss of dignity	579	79.3
Losing control of bodily functions	428	50.1
Burden on family, friends/caregivers	342	40.0
Inadequate pain control or concern about it	211	24.7
Financial implications of treatment	27	3.2

This data shows that while inadequate pain control or concern about future inadequate pain control was one of the concerns among those who received assistance to die during this period, the most common motivating factors related to the need to remain in control and concerns about loss of quality of life, loss of dignity or being a burden on others. Some of these factors could have been related to depression and hopelessness.

The majority (78%) of these patients in Oregon who died as a result of physician assisted suicide in the period 1998 to 2014 had a form of cancer.⁵¹

Epidemiological data demonstrates that in general suicide is approximately 30% to 50% more likely among cancer patients and that depression is a primary motivation for suicide.⁵²

Depression

According to Ezekiel Emanuel⁵³, most studies examining what motivates patient interest in euthanasia or assisted suicide reveal that psychological distress, including depression and hopelessness, are significantly associated with patients' interests in hastening their own death through euthanasia or assisted suicide. He states:

"The empirical data strongly suggest that requests for euthanasia and or PAS [physician assisted suicide] are less like traditional requests for withdrawal or withholding of life-sustaining interventions than plain old suicide...

*Requests for these interventions tend to be guided by psychological distress than rational choices about a good death."*⁵⁴

A prospective cohort study conducted in the Netherlands among cancer patients with a limited life expectancy of three months or less found that patients with depressed mood (as assessed by the Hospital Anxiety and Depression Scale) were associated with a four times' greater risk of requesting euthanasia. The prevalence of euthanasia requests in the study sample (22%) was comparable with the prevalence of euthanasia requests among cancer patients in a nationwide study.⁵⁵

Psychiatric assessment is mandatory in some jurisdictions that allow euthanasia or assisted suicide, but not in others. In Oregon, a single psychiatric assessment is required but only 6% of Oregon psychiatrists felt confident that a single assessment could enable them to decide whether or not mental illness was influencing the person's request for physician-assisted suicide.⁵⁶

Legislation and Incidence of Euthanasia and Assisted Suicide

The following section provides information about the legislation and incidence of euthanasia and/or assisted suicide in four international jurisdictions.

Netherlands

Legislation

The Netherlands made voluntary euthanasia and physician-assisted suicide lawful in April 2002 but it had been permitted by the courts since 1984. The patient's request must be voluntary and carefully considered and the patient must be experiencing unbearable suffering with no prospect of improvement. A minor between 12 and 16 years requires parental consent and if aged between 16 and 17 years, the parent must be included in decision-making. The patient must be resident in the Netherlands.⁵⁷ The Dutch Paediatric Association is currently calling for the limit of 12 years to be removed: *"We feel that an arbitrary age limit such as 12 should be changed and that each child's ability to ask to die should be evaluated on a case-by-case basis."*⁵⁸

Available data on current practice

The 2013 Annual Report by the Regional Euthanasia Committees in the Netherlands reports that 4,829 people died as a result of euthanasia and assisted suicide in that year. This compares with 2,636 in 2009, indicating an average annual increase over the 5 year period of around 16%.⁵⁹ More recent data indicate that the numbers are continuing to climb and will reach 6,000 this year.⁶⁰

The majority of notifications (89%) of euthanasia and assisted suicide during 2013 were by general practitioners and 74% of patients who died through these means had cancer, followed by neurological disorders (6%), multiple geriatric syndromes (5%) and cardiovascular disorders (5%).⁶¹

Dementia was the primary disorder in ninety-seven of the notified deaths due to euthanasia or assisted suicide, compared with 42 in 2012. The report indicates that most of these patients were in the early stages and were deemed to be competent to make the decision. However, several of these patients were in an advanced stage of dementia and their lives were terminated on the basis of earlier discussions with their physician indicating this would be their wish (a written advance care directive is not required but is considered desirable).⁶²

Forty-two people with mental disorders died by these means in 2013, compared with 14 in 2012.⁶³

Belgium

Legislation

The Law on Euthanasia 2002 took effect in 2002. It permits voluntary euthanasia (and assisted suicide, although not explicitly included in the law). The patient must be competent and conscious at the moment of request and the request must be voluntary and well considered. The patient must be in a medically futile condition of constant and unbearable suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident. The patient must be resident in Belgium and 18 or over or legally emancipated if aged 15 or older.⁶⁴ [The section on monitoring and oversight issues below notes that the law is interpreted very loosely in practice].

Available data on current practice

According to a report drawn up by the Federal Commission for Control and Assessment regarding the implementation of the law on euthanasia, the total number of declared cases of euthanasia between September 2002 and December 2009 was 5,537. There were 235 deaths in 2003 compared with 1133 deaths in 2011.⁶⁵

In the report by the Federal Commission for Control and Assessment for 2008 and 2009, 8% of declared euthanasia cases were where death was not otherwise envisaged in the short term (predominantly for people with neuropsychiatric diseases, degenerative neuromuscular diseases and a combination of multiple pathologies). This report also indicates that 10% of medical practitioners who receive a request for euthanasia have not been trained in palliative care and that in 40% of these cases; a palliative care team was consulted.⁶⁶

Between 2002 and 2013 deaths from euthanasia increased from 0.4% to 1.7% of all deaths in Belgium. Between 2007 and 2013, the proportion of non-terminally ill patients increased from 7% to 15% of all cases of euthanasia.⁶⁷

Oregon

Legislation

The Oregon Death with Dignity Act 1994 was enacted in 1997. It legalises physician-assisted suicide for mentally competent patients aged 18 or over who are diagnosed with a terminal illness that will lead to death within 6 months. Candidates must be resident in Oregon.⁶⁸

Available data on current practice

The Oregon Public Health Division reports annually on the number of adults in Oregon who obtain and use prescriptions for self-administered, lethal doses of medications.

Since the Dying with Dignity Act 1997 (DWDA) came into force in 1998, 1,327 people have received DWDA prescriptions and 859 people have died from ingesting those medications. Deaths as a result of physician assisted suicide have increased by an average of 14% per year over the past 5 years.⁶⁹

Over the 17 year period, the majority of deaths were of people with cancer (79%) and neurodegenerative conditions (8%).⁷⁰

In 2014, 155 people received lethal prescriptions and of these 105 died as a result of ingesting them. Of those who died, three had been referred for a formal psychiatric or psychological evaluation. The median age at death was 72 years and 10% were aged between 18 and 54 years. Prescribing physicians were present at 14% of the deaths occurring in 2014.⁷¹

Switzerland

Legislation

The Swiss Penal Code (1942) decriminalised assisted suicide for legally competent adults, provided the assister does not have selfish motives. There are no requirements for residency.⁷² Guidance based on case law indicates that the patient must be capable of making the decision, the patient's wish has been well thought out, without external pressure, and the patient persists in the wish to die. For mentally ill persons requesting physician assisted suicide, a prior psychiatric examination is required.⁷³

Available data on current practice

Data published by Dignitas indicates that it was involved in accompanying 1905 people who died through assisted suicide in Switzerland during the period 1998 to 2014.⁷⁴ As other organisations are involved in assisting suicide, this is not the complete data.

Concerns about Euthanasia & Assisted Suicide

Broadening scope

The evidence during the last decade indicates both an extension of the circumstance in which euthanasia may be legally used (the logical slippery slope) and its abuse (the practical slippery slope).⁷⁵

The range of people who can elect to receive euthanasia or assisted suicide has broadened beyond decisionally competent adults experiencing unbearable suffering due to a terminal illness and now includes:

- people with mental disorders who are not terminally ill but suffering unbearably without prospect of improvement⁷⁶;

- people with early stage dementia or advanced dementia⁷⁷
- people experiencing unbearable suffering; there is no requirement that the medical condition should be serious or life-threatening⁷⁸
- psychological suffering due to failed gender re-assignment operations⁷⁹
- psychological suffering due to life imprisonment and no prospect of release⁸⁰
- newborn infants with a severe illness and very poor prognosis(the Groningen protocol)⁸¹

Reflecting on the broadening access to euthanasia, Boudreau and Somerville⁸² observe:

"When euthanasia is first legalized, the usual justification for stepping over the "do not kill" line is a conjunctive one composed of respect for individual autonomy and the relief of suffering. This justification is taken as both necessary and sufficient for euthanasia. But as people and physicians become accustomed to euthanasia, the question arises, "Why not just relief of suffering or respect for autonomy alone?" and they become alternative justifications.

As a lone justification, relief of suffering allows euthanasia of those unable to consent for themselves according to this reasoning: If allowing euthanasia is to do good to those mentally competent people who suffer, denying it to suffering people unable to consent for themselves is wrong; it is discriminating against them on the basis of mental handicap. So, suffering people with dementia or newborns with disabilities should have access to euthanasia.

If one owns one's own life, and no one else has the right to interfere with what one decides for oneself in that regard (as pro-euthanasia advocates claim), then respect for the person's autonomy as a sufficient justification means that the person need not be suffering to access euthanasia. That approach is manifested in the proposal in the Netherlands that euthanasia should be available to those "over 70 and tired of life".

Once the initial justification for euthanasia is expanded, the question arises, "Why not some other justification, for instance, saving on health care costs, especially with an aging population?" Now, in stark contrast to the past when saving health care costs through euthanasia was unspeakable, it is a consideration being raised."⁸³

Cultural changes in health care practice

The implementation of euthanasia and assisted suicide by health care professionals erodes the former clear ethical foundations and practice boundaries of health care delivery. This has the potential to seriously erode the trust patients have in health professionals and their confidence in a health care system that works within the parameters of beneficence and non-maleficence.

Boudreau and Somerville consider that the most dangerous aspects of legalising euthanasia are the unintended boomerang effects it will have on the medical profession. They ask:

"How will the involvement of physicians in inflicting death affect their thinking, decisions, and day-to-day practice? Given that euthanasia may be routinized

*and expedient, there is a distinct possibility that death will become trivialized and that avenues for dignity-preserving care will remain unexplored. What are the potential corrosive effects on hospitals of accepting the language of euthanasia and in implementing that mandate?*⁸⁴

Like all cultural changes, this can take time to become evident. The following examples illustrate concerning cultural changes that are emerging in which the legal parameters for euthanasia and assisted suicide are being broadened and applied in contexts outside the scope of the legislation and are beginning to inform normative medical practice:

a) **Ending patients' lives without request**

An initial justification for the introduction of euthanasia and assisted suicide was that it would lead to better regulation of practices involving the use of life-ending drugs without explicit patient request. However, available evidence indicates that this practice still continues. In one study in Flanders, 2% of deaths in the study were due to the use of life-ending drugs with the explicit request of the patient and 1.8% of deaths were due to the use of life-ending drugs without explicit patient request. Use of life-ending drugs without an explicit request mostly involved patients 80 years or older, those with a disease other than cancer and those in hospital. Of the deaths without an explicit request, the decision was not discussed with 77.9% of patients and, in those cases, the dosage was strongly increased in the last 24 hours in 45.8% of cases and the physician indicated it to be higher than needed to alleviate the patient's symptoms in 46.8% of cases.⁸⁵ The authors note the need for attention to protect patient groups from such practices, which are contrary to the law and go beyond the intent and scope of palliative sedation therapy.

b) **Belgian nurses acting beyond the legal margins of their profession:** a study of 1265 nurses in Flanders, Belgium, found 248 had been involved in administering life-ending drugs with the recognition that the death of the patient was intended. 120 nurses reported that the last patient in their care for whom a life-shortening end-of-life decision was made received euthanasia and 128 nurses reported that that the last person in their care for whom a life-shortening decision was made received life-ending drugs without his or her explicit request. Of the nurses whose patient received life-ending drugs without his or her explicit request, 4% reported that the patient had expressed his or her wishes about the decision to them. Nurses administered life-ending drugs at the physician's request in 12% of the euthanasia cases and 45% of the cases of life-ending without the patient's explicit request. The authors note that the administration of life-ending drugs by nurses is not regulated under Belgium's euthanasia law and is therefore not acceptable.⁸⁶

c) **The Belgian Society of Intensive Care Medicine** issued a statement in 2014⁸⁷ about the administration of sedative agents with the direct intention of shortening terminal care for patients not in a position to request euthanasia and with no prospect of a meaningful recovery. The paper notes that discontinuing therapies at the end of life in the ICU is performed in relation to more than 10,000 deaths per year, 10 times the number of individuals who die under euthanasia law. The Society states:

"This statement paper... is not about giving analgesics or sedative agents to combat pain or agitation, nor about the so-called double-effect, wherein analgesics given to alleviate pain may have the adverse effect of shortening the dying process. The discussion here is about the administration of sedative agents with the direct intention of shortening the process of terminal palliative care in patients with no prospect of meaningful recovery."⁸⁸

It further states:

".. we explain our belief in the concept that shortening the dying process by administering sedatives beyond what is needed for patient comfort can be not only acceptable but in many cases desirable."⁸⁹

The Statement indicates the cultural change that is occurring. Expediency and paternalism are beginning to take precedence over considerations of patient autonomy and the alleviation of suffering. The erosion of an ethical compass is evident in the following statement:

"There is no clear ethical distinction between withholding / withdrawing supportive therapy and increasing doses of sedative/opioid substances in patients in whom further treatment is no longer considered beneficial."⁹⁰

In relation to the decision-making process for such actions, the Statement clearly places the authority with the medical team, not the patient or the patient's substitute decision-maker:

"The plans for end-of-life care in each individual patient should be discussed with and understood by the relatives (or the patient's surrogate if one has been appointed). However it must be made clear that the final decision is made by the team and not by the relatives."⁹¹

There is also a concern that the option of euthanasia will become normative and inhibit learning from patients - rather than finding better approaches to alleviate patient suffering and to provide the best care and death possible, we will simply resort to euthanasia. Noting this danger, a palliative care physician in the Netherlands recounted the following experience in which he was able to provide symptom relief to a patient with bowel obstruction that the GP had been unable to resolve:

"I was giving consultations in several situations like this, when the GP was calling me about a patient with gastrointestinal obstruction. He said, 'The problem is that the patient is refusing euthanasia.' I said, 'What happened?' He said, 'In the past, all these kinds of situations, when people were intractably vomiting, I solved by offering euthanasia. Now this patient does not want it, and I do not know what to do.'"⁹²

Impact on health professionals

Stevens reviewed a substantial body of articles in medical journals, legislative investigations and the public press covering a twelve-year period and several jurisdictions to examine the impact on physicians who participated in physician-assisted suicide and euthanasia. This review identified a

consistent theme of adverse emotional and psychological impacts on a proportion of physicians in all of the jurisdictions examined. The study found:

*"Doctors describe being profoundly adversely affected, being shocked by the suddenness of the death, being caught up in the patient's drive for assisted suicide, having a sense of powerlessness, and feeling isolated. There is evidence of pressure on and intimidation of doctors by some patients to assist in suicide... Many doctors who have participated in euthanasia and or PAS [physician-assisted suicide] are adversely affected by their experiences."*⁹³

A qualitative study of 22 primary care physicians involved in euthanasia in the Netherlands found it was a drastic and sometimes even traumatic event for them.⁹⁴ One doctor stated:

*"We were crazy to do it, looking back. Who am I to do this? Euthanasia was put on my plate. It's a rotten job. I apparently felt, though, that it was normal that PCPs [primary care physicians] did this. How did we let ourselves into it in this way? I wanted to be important as well. I wish they would no longer ask me, but I'm scared to say so. Perhaps I will have the courage to say so in a few years' time. I feel very close to people, but I also feel angry: 'what do you think you can ask of me?'"*⁹⁵

Another primary care physician involved in euthanasia stated:

*"When euthanasia was not performed I found the deathbed a special aspect of the profession. It was an honour to be allowed to guide someone to his or her final moment. With euthanasia, I always feel: 'was that necessary'? I hate it. The patient is no longer granted the time for a natural dying process. He's saddled with the question 'when do I want euthanasia?' To have to decide about the moment of death has created enormous unrest around the deathbed."*⁹⁶

In 2014, the Belgian oncologist, Dr. Beuselinck, reported that the availability of euthanasia had created additional pressures on health professionals:

- In the case of one health centre where the director was known to support euthanasia, it began to get referrals simply for euthanasia, which changed the practice to the extent that a number of staff left.
- For those who are reluctant or unwilling to accede quickly to a request for euthanasia the time required for counselling and exploring alternatives adds to the work pressure.
- He also expressed concern that there were moves to restrict conscientious objection rights by making it a legal duty for individuals and institutions to refer someone for euthanasia.⁹⁷

Patient confusion and mistrust

The implications for palliative care and patients were highlighted in a recent conference considering what could be learnt from Belgium's implementation euthanasia and assisted suicide:

- Patients requesting euthanasia may be admitted to a palliative care centre for assessment; this has led to confusion among patients about the nature of palliative care and reluctance to accept a referral to palliative care because of opposition to euthanasia.

- Some patients are afraid to go to their doctor or hospital and some carry cards requesting that they not be euthanased.⁹⁸

Noting the fact that palliative care is not well understood by the general public, a palliative care consultancy team at a Swiss hospital where assisted suicide took place was concerned that their presence could be interpreted by the public, and promoted by the right-to-die organisations, as complicity or even active involvement.⁹⁹

There is also a concern that when doctors are ready to perform euthanasia, it sends a signal to patients in similar situations that they may be better off dead or even have a duty to die.¹⁰⁰

These concerns highlight the importance of clearly separating euthanasia and assisted suicide from palliative care and all health care services.

Family pressure and conflict

A qualitative study involving 20 hospice nurses and social workers in Oregon identified several dilemmas they experienced when asked to care for patients requesting physician assisted suicide. These concerns included whether helping patients to redefine quality of life impinges on their autonomy and whether to advocate for the patient or the family when the family does not support physician assisted suicide.¹⁰¹

Where a patient's request for assisted suicide is contrary to the views of the patient's family, health professionals in Switzerland found themselves in a difficult situation of either supporting the family's viewpoint or advocating for the patient's autonomy and right to decide, even though this may conflict with the health professional's own values.¹⁰²

Family pressure versus free will

There are also concerns about whether family pressure or social expectations influence the patient's decision to request euthanasia. For example:

A wife who no longer wished to care for her sick, elderly husband gave him a choice between euthanasia and admission to a home for the chronically ill. The man, afraid of being left to the mercy of strangers in an unfamiliar place, chose to have his life ended; the doctor, although aware of the coercion, ended the man's life.¹⁰³

Elder abuse and family violence

The issue of family pressure being placed on patients to choose euthanasia must be considered in the context of elder abuse, family violence and the poor social status of older and dependent people in our society. Studies in Australia and overseas estimate that at least 3% of people aged 65 years and over have suffered some type of abuse. The risk of abuse increases in situations of dependency, when there is a high and unacceptable burden of caring.¹⁰⁴

Unfortunately, pre-existing patterns of family violence continue to present significant risks even when a person is seriously ill and dying. In some cases, victims of family violence are receiving end of life care in the family home and the perpetrator has a key role in the provision of that care.¹⁰⁵

Ethical concerns about advance euthanasia directives

A focus on contemporary competence to make informed decisions is central to the concept and practice of personal autonomy.

However, Australia and Victoria are in the early stages of implementing advance care planning and dealing with the complex ethical, legal and practical issues that may arise when they are used to inform care and treatment decisions for persons who are no longer competent to make those decisions for themselves.

Advanced euthanasia directives are now legally recognised in the Netherlands (for up to 5 years) and are under consideration in Belgium.

It has been noted that these pose complex ethical issues because it is difficult for competent individuals to predict their interests in future treatment situations when they are incompetent because their needs, values and interests may have radically changed. The creation of an advanced euthanasia directive does not mean that it should be carried out in every case.¹⁰⁶

The right normally accorded to those seeking euthanasia to change their mind up to the very end is denied those who have compromised competence, unless their lived experience as the 'now self' prevails over the expressed wishes of the 'then self', according to Chris Gastman, professor of medical ethics.¹⁰⁷

No remediation available

There is no remediation available when euthanasia or assisted suicide results in the death of a person who could have lived with improved quality of life had appropriate health care been provided. This can have lasting negative effects on their family members, including complicated grief, as evident in a recent feature story in the New Yorker:

Godelieva De Troyer, a 63-year old Belgian woman, died by euthanasia in 2012. She had a history of periods of depression and another was prompted by the recent breakdown in the relationship with her partner. She met Dr. Distelmans, a leading Dutch advocate for and practitioner of euthanasia at that time and the following year decided to request euthanasia, which Dr. Distelmans carried out. Her adult son, Tom Mortier, found out the day after her death when he received an email written the day before by his mother stating that she had died from euthanasia the day before.¹⁰⁸

A preoccupation with euthanasia and assisted suicide can detract from the range of other opportunities to alleviate suffering. We must not forget those for whom euthanasia or assisted suicide precipitates suffering or is a misguided response to suffering that could have been alleviated through other means.

Reporting and oversight issues

The Netherlands has a legal requirement that health professionals notify all cases of euthanasia and assisted suicide to the relevant regional pathologist. A regional committee is responsible for reviewing every notification to ensure compliance with the law and for referring any breaches to

the public prosecution service for review. The problems with this approach is that it relies on voluntary reporting by those who if found to be in breach of the law are at risk of prosecution. In their Annual Reports for 2011 and 2012, the regional committees noted that they had been unable to keep up with the increase in notifications and that this had resulted in “unacceptably long periods of review, that often exceeded the statutory deadline for issuing their findings to the physicians concerned”.¹⁰⁹ Data is not readily available on the numbers referred to the public prosecution office but the delays in reviewing cases reflect an inadequately resourced monitoring system that is therefore limited in its capacity to ensure appropriate safeguards are met.

The Commission for Control and Assessment of Euthanasia in Belgium has acknowledged in several reports that it is not capable of “assessing the proportion of declared cases of euthanasia compared with the number of real cases which have actually taken place.”¹¹⁰

It has also been noted that “the Commission interprets the law very freely, even going so far as to void any control it is supposed to carry out with regard to some of the legal conditions mentioned below [pertaining to a written request and suffering from a life-threatening and incurable illness].”¹¹¹

Palliative Care Victoria’s Position on Euthanasia & Assisted Suicide

Palliative Care Victoria does not support the legalisation of euthanasia or assisted suicide.

We have reached this position following consultation with our members and international colleagues, a review of available evidence and in-depth consideration of the ethical, legal and practical issues that arise when euthanasia and/or assisted suicide are included in the range of options at the end of life.

We note that Professor Theo Boer, an academic in the field of ethics, who has been a Member of a Regional Review Committee of euthanasia notifications in the Netherlands since 2005, is now strongly opposed to euthanasia. He said that he was “wrong – terribly wrong, in fact” to have believed regulated euthanasia would work. Instead it is “on the way to becoming a default mode of dying for cancer patients” and he is also concerned by the extension to new classes of people, including those who are depressed and demented. “Once the genie is out of the bottle, it is not likely ever to go back in again,” he said.¹¹²

Reviewing the progress of euthanasia in the Netherlands, Dr Brian Pollard highlights two lessons:

“First, in legalising euthanasia, one has to contend with what has been described as ‘the tendency of a principle to expand itself to the limit of its logic’, and second, attempting to make law in the absence of a full understanding of its consequences is highly dangerous.”¹¹³

Requirements IF Legalisation is Proposed

While we sincerely hope that the Legal and Social Issues Committee and the Victorian Government will reject both euthanasia and assisted suicide.

Should that not be the case, we strongly recommend the actions and safeguards outlined below.

Improve access to high quality palliative care and end of life care

Urgent action is taken to improve access to high quality palliative care and end of life care in all health and care settings across Victoria with substantial increases in funding to support a comprehensive range of strategies that will be needed to achieve this.

Limited scope with strict criteria and safeguards

The evidence to date indicates significant difficulties in avoiding logical and practical extensions beyond the scope, eligibility criteria and target population initially envisaged under the legislation. This is most evident in the case of euthanasia, which appears to be driving cultural change within the provision of health care services to the extent that hastened death without explicit consent is no longer an ethical boundary that health professionals in Belgium and the Netherlands do not cross.

Assisted suicide requires demonstrated voluntariness by the recipient to take effect and those people have the opportunity to change their minds.

As we do not support these options, we find it difficult to propose appropriate limits and safeguards. Our submission has highlighted the issues and risks that must be given deep consideration in framing any legal proposals that would then be put to the Victorian community for further consultation and feedback.

Excluded and separate from all health care and care services

Palliative Care Victoria strongly recommends that should the Victorian Government decide to legalise euthanasia or assisted suicide that this is separated very clearly from palliative care, aged care, and all health and care services in Victoria.

It is vitally important that these are not labelled as medical treatments or included in the concept of health care.

This is essential to safeguard the ethical principles and foundations of health care, as well as public trust and confidence in all health care professionals and services. The principles of beneficence and non-maleficence must continue to define the ethical boundaries in which health care professionals and services operate. Hastening death and killing patients are outside the parameters of health care.

This approach is strongly advocated by Boudreau and Somerville who, while opposing these options, argue that if they are to be legalised they must be strongly separated from medical treatment and health care services. They suggest that euthanasia and assisted suicide could be undertaken completely independently of health services and health professionals by staff that are recruited, screened and trained for this role. They suggest 24 weeks of training would be required.¹¹⁴

A mobile euthanasia unit with trained staff to perform this function and relevant equipment could be established as part of an independent service operated by the Victorian Government that has full responsibility for implementing the legal provisions. A designated and specially trained unit

would make it easier to ensure that the requirements and safeguards of the legislation are met and maintain a clear separation of this practice from health and care services.

Independent checks and reporting to the Victorian Government and community

Strong legislative checks and balances would be required and these would need to be monitored independently on a rigorous basis. The use of single dedicated service would make this much more achievable.

Independent and transparent reporting should occur on at least an annual basis, to the Victorian Government and the Victorian community.

Criminal sanctions should apply where the legislative provisions are transgressed.

Recommendations

Palliative Care Victoria recommends that the Victorian Government:

- decide not to legalise euthanasia or assisted suicide; however, should it decide to do so, that any such practice is the responsibility of specifically trained staff in an independent and closely monitored service that is distinctly separate from all health and care services so that community trust in health professionals / services and the ethical foundations of health care can be maintained;
- provide opportunities for public input on any proposed law reforms related to end of life choices and decision making.

Endnotes

¹ Parliament of Victoria, Inquiry into End of Life Choices Terms of Reference, <http://www.parliament.vic.gov.au/lsic/article/2608>

² Queensland Government, Implementation Guidelines End of Life Care: Decision-making for withholding and withdrawing life-sustaining measures from adult patients, Part 1: Legal Framework and Clinical Considerations; <https://www.health.qld.gov.au/qhpolicy/docs/gdl/qh-gdl-005-1-1.pdf>

Part 2: End-of-life care: Decision-making for withholding and withdrawing life-sustaining measures from adult patients, <https://www.health.qld.gov.au/qhpolicy/docs/gdl/qh-gdl-005-1-2.pdf>

³ Ibid, Part 1, p5

⁴ Ibid, Part 1, p4

⁵ Ibid, Part 2, p16

⁶ <https://theconversation.com/end-of-life-care-no-we-dont-all-want-whatever-it-takes-to-prolong-life-41495>

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⁹ World Health Organisation <http://www.who.int/cancer/palliative/definition/en/>

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- d. Casarett, D; Pichard, A; Bailey, F A; Ritchie, C; Furman, C; Rosenfeld, K; Shreve, S; Chen, Z; Shea, J A; 2008 "Do Palliative Care Consultations Improve Patient Outcomes?" *Journal of the American Geriatric Society*, 2008 No 56 pp593-599
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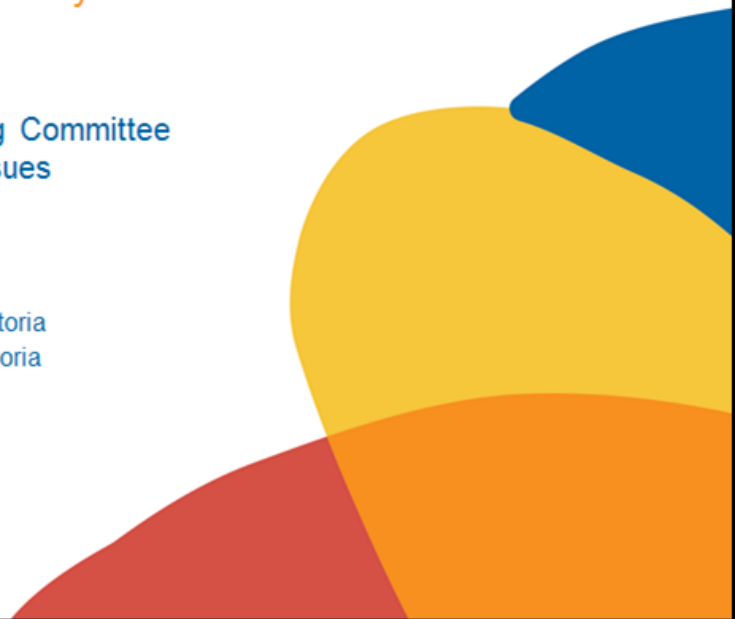
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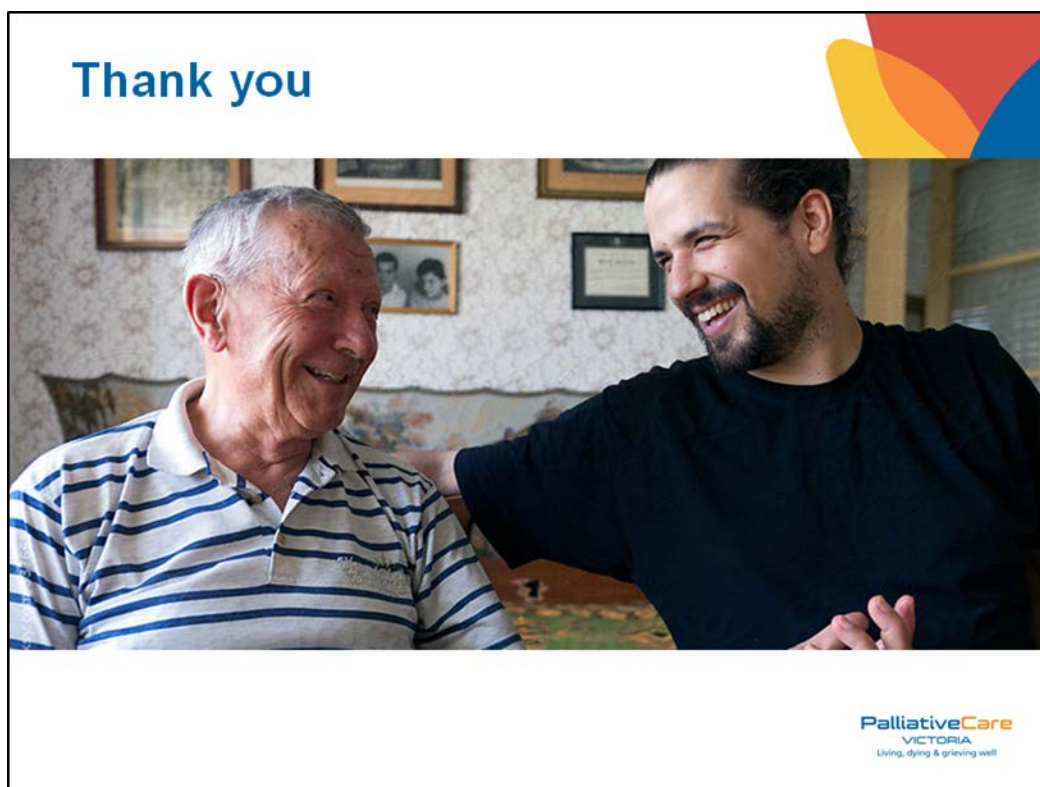
Services that support quality of life

Victorian Parliamentary Standing Committee
on Legal and Social Issues

Michael Bramwell, Chair, Palliative Care Victoria
Odette Waanders, CEO, Palliative Care Victoria
10 June 2015

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Good evening everyone. My name is Michael Bramwell and I am the Chair of Palliative Care Victoria. Joining me is Odette Waanders, the CEO.

Thank you very much for the invitation to provide you with an introductory briefing about palliative care and its role in supporting Victorians with life-limiting illnesses and their families to live, die and grieve well.

Please feel free to ask us questions during our presentation tonight, and at any time during your deliberations.

We have brought an information pack, which we hope will be useful.

This includes:

- a copy of our presentation
- a booklet about palliative care
- Palliative Care Victoria's Call to Action for 2015-19
- Some stories of people with a life limiting illness and palliative care volunteers
- Copies of the Dreamers are also available for those who would like to read it. This includes photographs of 40 people receiving palliative care and their reflections on life, death and dreams.

The slide features a white background on the left and a large abstract graphic on the right composed of overlapping yellow, orange, and pink shapes. The title 'Overview' is in a large blue font. Below it is a bulleted list of five topics. The Palliative Care Victoria logo is in the bottom left corner.

Overview

- About Palliative Care Victoria
- About Palliative Care
- Palliative Care Services in Victoria
- Key issues
- Questions & discussion

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Broadly, these are the topics we will cover this evening. If questions arise or matters you wish to discuss, please raise them and don't feel you need to wait until the end.



Palliative Care Victoria

- Not for profit, peak body, established 1981
- 180 members, 87 organisations
- Vision: all Victorians with a life-limiting illness and their families are supported to live, die and grieve well
- Strategic priorities 2013-2016
 - Strong, innovative sector delivers high quality care
 - Community awareness & capacity
 - Access and responsiveness for diverse communities
 - Strengthen palliative care volunteering


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Palliative Care Victoria was formed in 1981, early in the development of palliative care services in Victoria. We represent palliative care services – 87 organisations are among our members – as well as people with a life limiting illness and their families, and those with an interest in palliative care.

As the peak body, our roles are both community and sector facing. We are the 'go to' organisation for people seeking information and services at a very vulnerable stage in their lives.

Our strategic priorities include raising community awareness of palliative care, building community capacity to deal with issues of dying, death, grief and loss and improving access and responsiveness for diverse communities – including Indigenous Australians and people from culturally and linguistically diverse communities.

We also undertake activities to ensure a strong, innovative palliative care sector, including information and education, advocacy and policy development and collaboration with other key stakeholders.

Palliative Care Victoria is a founding and current member of Palliative Care Australia.

Origins of palliative care

"You matter because you are you,
and you matter to the end of your life.
We will do all we can not only to help
you die peacefully, but also
to live until you die."



Dame Cicely Saunders
Founder St Christopher's Hospice, UK 1967

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Palliative care was founded by Dame Cicely Saunders in the UK. She established St Christopher's Hospice in 1967 and her vision was to provide holistic care that promotes quality of life, supports the person and their family and enables people to receive care and die at home or in homelike environments.

Palliative care was initiated in Victoria by charitable organisations – the Melbourne City Mission and the Order of Malta. Most palliative care services in Victoria are provided by public health services and community charities.

In 2001, Palliative Medicine was recognised as a specialty in Australia.

Palliative care is still a relatively new specialty and area of service provision, with significant variability in its development across Australia. This means that there is still work to be done in Victoria and Australia to ensure it is fully integrated and available across the health and care sectors.

What is palliative care?

*“Palliative care is for the living.
It helped us get our lives back
on track.”*

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The purpose of palliative care

Palliative care aims to:

- Support personal control, informed choices
- Respect person's wishes and goals of care
- Promote quality of life and maintain dignity
- Maximise comfort and freedom from pain
- Care for the whole person; physically, emotionally, socially and culturally
- Support family carers, including through bereavement



Palliative care focuses on promoting the person's quality of life and dignity. The presentation notes include a definition from the World Health Organisation. A key element of palliative care philosophy and practice is that it does not intend to hasten death.

The World Health Organisation has defined palliative care as:

"An approach that improves the quality of life of patients & their families facing the problems of a life-threatening illness, through prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and
- includes those investigations needed to better understand and manage distressing clinical complications."

What does palliative care include?

- **Care planning:** values, goals & choices
- **Personal comfort and wellbeing:** pain & symptom management, physiotherapy, etc.
- **Emotional support:** counselling, spiritual & cultural care
- **Quality of life:** to make the most of life; volunteers provide support



The starting point of palliative care is a comprehensive holistic assessment of the person with a life limiting illness as well as the support needs of their carers.

Impeccable needs assessment includes identifying and discussing their needs, understanding what is important to them and discussing their goals of care.

This process and conversation informs the care that is provided by the palliative care team, which is reviewed with the ill person and their carers on a regular basis and as the need arises.

Help for carers and families

- Respite care
- Advice on how to provide care and counselling
- Help to find appropriate legal and financial assistance
- Practical assistance - equipment, travel to appointments
- 24 hour access to phone support



This slide shows the kinds of support available to assist carers who provide the mainstay of care. The majority of people prefer to receive care at home.

So a key focus of palliative care is supporting and partnering with those carers throughout the person's illness and providing support through bereavement.

The recent report by the Victorian Auditor General on the inquiry into palliative care identified the need to improve access to respite care and 24 hour support.

Personal experiences of palliative care

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Moira & George Lund

“Palliative care is a gift of life for Moira, extra life.

I’m convinced we wouldn’t be together now if we hadn’t gone for it.”

A photograph of an elderly couple, Moira and George Lund, sitting closely together on a dark leather couch. Moira, on the left, is wearing a yellow and white striped sweater and grey trousers. George, on the right, is wearing a green button-down shirt and light-colored trousers. They are both smiling at the camera. The background is a plain, light-colored wall.The logo for Palliative Care Victoria, featuring the text "PalliativeCare" in blue and orange, "VICTORIA" in blue, and the tagline "Living, dying & grieving well" in a smaller font below it.A decorative graphic in the bottom left corner consisting of overlapping yellow, blue, and orange curved shapes.

Moira chose to participate in the Dreamers Project. This involved an interview with the project author, Pippa Wischer, about her reflections on life, death and dreams.

Palliative Care Victoria asked Pippa to include in four recorded interviews some additional questions about how they found out about palliative care and what difference it made to their life.

This is the completely unscripted response by Moira and George to those questions.

The video is available at:

<https://www.youtube.com/watch?v=RE8CJlthcsA>

Mamaduke Waring

“Pain relief in terms of the quality of life is absolutely critical. To be able to offer that sort of pain relief at home and almost to allow him to lead a normal life with his family was so important. With palliative care we had the opportunity to bring him home.”

Mamaduke's Dad, Simon Waring



Watch video at
bit.ly/Mamaduke-video

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If you have time, we would encourage you to watch some other short videos produced for Palliative Care Australia that illustrate the range of people who receive and benefit from palliative care.

The link to each video in youtube is below the photograph.

Mamaduke was diagnosed with cancer at 15 months of age. About 1 % of palliative care recipients are aged 14 years or under.

The Victorian Paediatric Palliative Care Program and Very Special Kids provide care to these children and their families in inpatient, community and hospice settings.

Kaye Sales

“Palliative care has provided me with incredible emotional support... I feel secure and safe and fully understand they will be supportive through this last period of my life.”

“From the moment a person is diagnosed with a life limiting illness would be the ideal time to link them to palliative care.”



Watch video at
bit.ly/kaye-video

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Kaye suffered from mesothelioma.

Bassam Abedalqader

“Palliative care is more important or as important as the treatment itself...”

Palliative care is not the end stage. They make your life comfy and you need it... Instead of being in agony screaming of pain... you are out and about, with your loved ones, you can go home. It gives you that chance to live life.”



Watch video at
[Bit.ly/bassam-video](https://bit.ly/bassam-video)

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Both Bassam and Kaye highlight the importance of palliative care being offered early in the disease trajectory. In Bassam’s situation his cancer was too advanced for treatment. He agreed to clinical trials but these were unsuccessful.

Effective pain management by the palliative care team enabled him to make the most of the remaining time with his family and friends.

Who can palliative care assist?

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Who can benefit from palliative care?

Palliative care assists people with life-limiting conditions who need specialist palliative care support, including

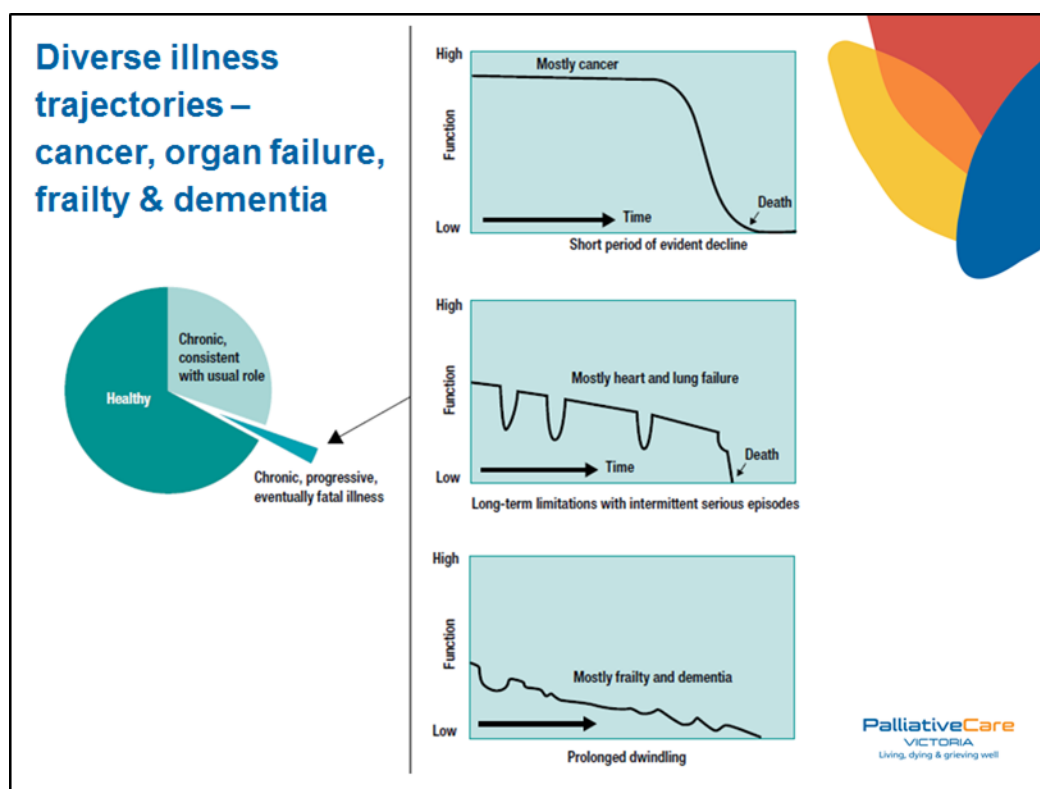
- People with cancer, end stage chronic diseases such as organ failure, dementia, degenerative conditions
- People of all ages, cultures and beliefs



This slide shows 4 people receiving palliative care who participated in the Dreamers Project. As you can see they represent a diversity of ages and backgrounds.

The benefits of palliative care are not limited to people with cancer or in the older age range.

Palliative care should be available to all people with a life limiting illness who have complex needs that would benefit from its holistic approach and focus on improving quality of life.



Palliative care originated with the care of people with cancer.

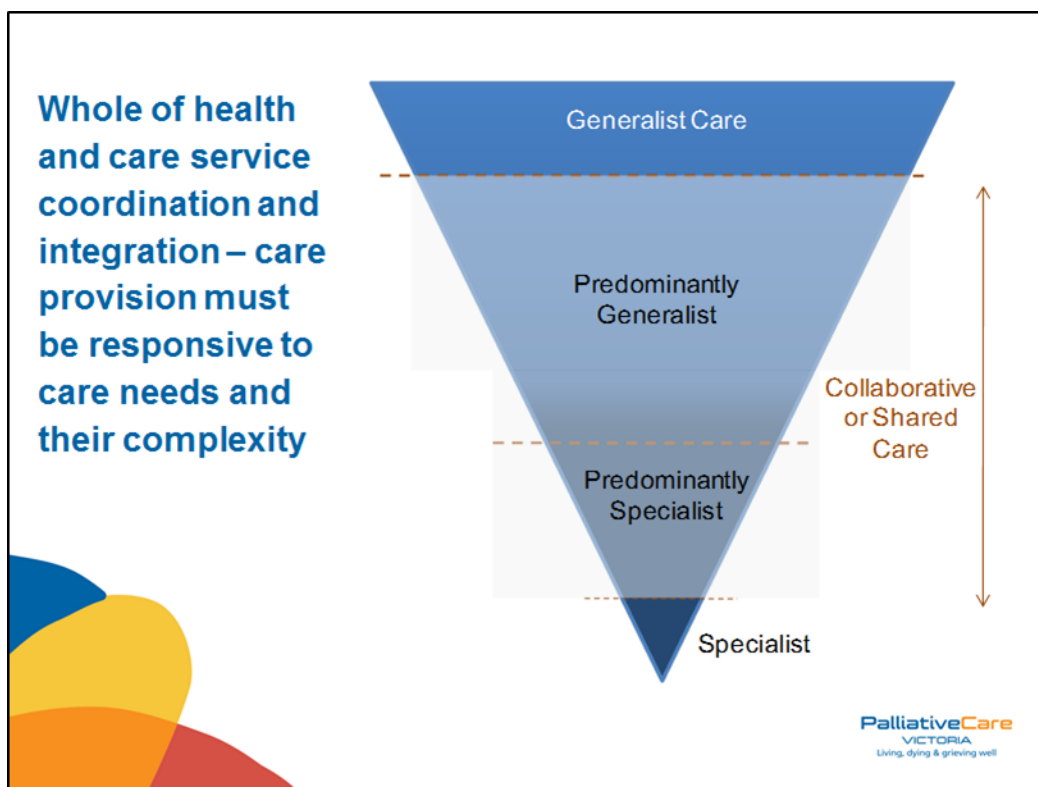
As you can see from the top diagram, cancer has a more sudden onset and shorter illness trajectory prior to death compared with other chronic conditions, although this is changing as cancer treatments become more effective in extending life.

Palliative care is also beneficial for other chronic and life-limiting conditions.

The middle diagram shows the illness trajectory that is typical for heart and lung failure – both leading causes of death. There is a steady decline with periods of acute deterioration. It can be difficult to give a prognosis regarding the person's remaining length of life.

The bottom diagram shows the prolonged trajectory of deteriorating health status due to frailty and dementia. Given the duration of the illness, it can make it more difficult for health providers to know when to refer to specialist palliative care. This is particularly challenging in aged care settings where the ratios of qualified health professionals are relatively low and it can be difficult to get good GP coverage.

In Victoria, palliative care services provide consultancy support to aged care facilities, as well as some education, but this is an ongoing challenge given the high levels of staff turnover and limited funding for provision of complex care.



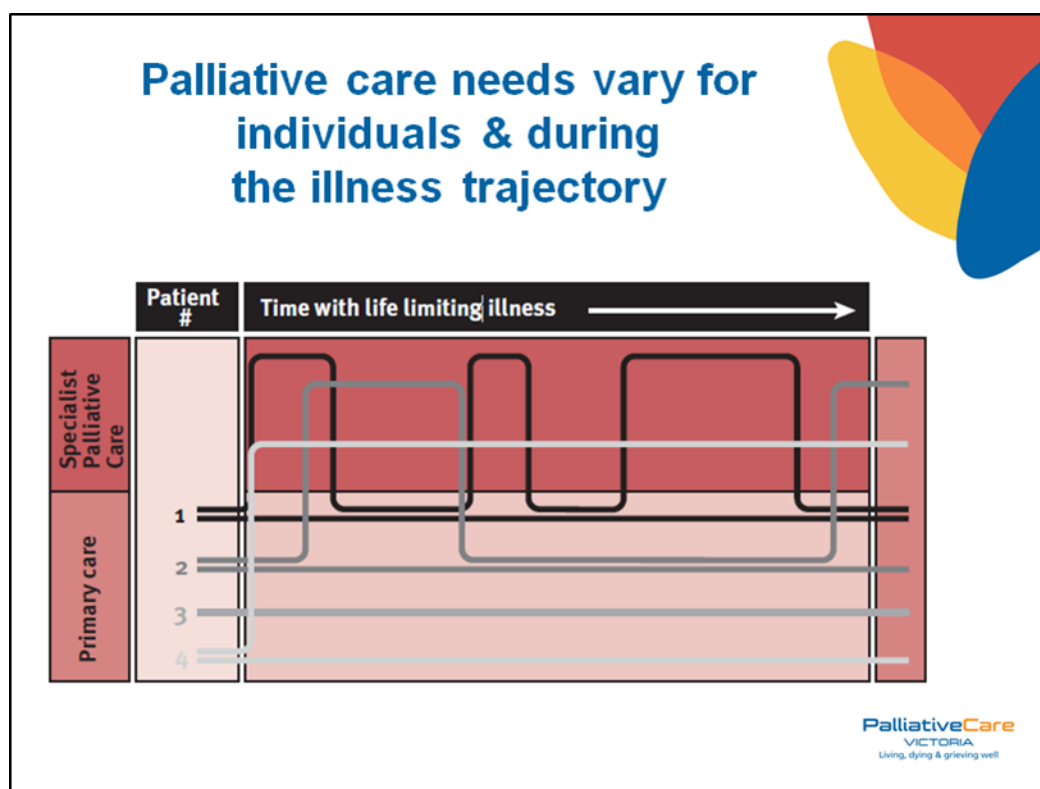
Specialist palliative care can be provided alongside active treatment and it is advisable to refer people to palliative care earlier in the disease trajectory.

Palliative care offers specialist support that complements the care provided by the person's GP, and other specialists and health providers.

The Australian Commission on Safety and Quality in Health Care recently released the National consensus statement: essential elements for safe and high-quality end-of-life-care (<http://www.safetyandquality.gov.au/publications/national-consensus-statement-essential-elements-for-safe-high-quality-end-of-life-care/>)

One of the triggers is if the physician would not be surprised if the person were to die within the next 12 months.

There is a need for education of health professionals to identify triggers for referral to palliative care and to ensure the person receives the best end of life care possible.



The role of specialist palliative care varies depending on the needs of the person and their family, the trajectory of the illness and the capacity of other health and care services to meet their needs.

For example, a person with a life limiting illness with well-controlled symptoms may experience a sudden deterioration and require admission to a palliative care program for assessment and symptom management until their condition stabilises and they can be discharged to ongoing care in the community.

Some people may have a complex range of physical and psycho-social needs that require ongoing support by appropriate members of the specialist palliative care team.

The level of support provided by palliative care may be daily, weekly or much less frequently, depending on the needs of the person and their family.

In other cases, the persons palliative care needs may be able to be met by their primary health care providers, as in scenario three in the diagram.

Palliative care services in Victoria

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There are three main types of palliative care services in Victoria:

Inpatient, community – which includes care delivered to the person’s usual residence or at a day hospice, and consultancy.

There was an 80% increase in the number of people who received palliative care in the community in 2012-13 compared to 2008-09.

19 palliative care consultancy services provide consultancy in acute and community settings.

Four state-wide programs focus on special populations: paediatric, motor-neurone disease, HIV/Aids and Australian Centre for Grief and Bereavement.

Who provides palliative care? A team.



Peter enjoys art activities with Ros, a palliative care volunteer

The palliative care interdisciplinary team includes physicians, nurses, allied health staff, social work and pastoral staff, and trained volunteers.

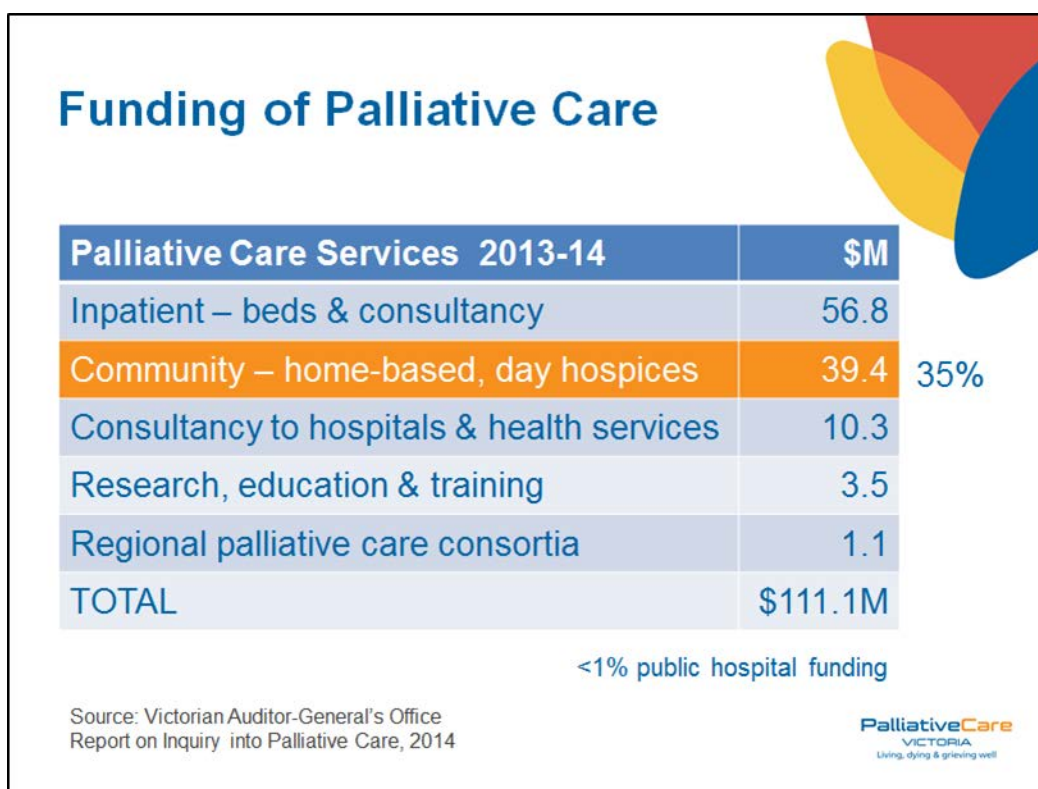
A shared care approach is used involving the ill person and their carers, the GP and other specialist, health and care providers.

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A 2013 study of the Victorian palliative care workforce indicates that around 11% are physicians, 63% are nurses and 8% are allied health professionals. They work together as interdisciplinary teams.

Victoria is fortunate to have around 2000 trained palliative care volunteers. Around two-thirds of them contribute directly to supporting the quality of life of patients and their carers.

Your information pack includes 8 stories about people with life limiting illness and palliative care volunteers who support them. These were produced by Palliative Care Victoria for National Volunteers Week and National Palliative Care Week in May. To date, 6 stories have been published in community papers with a combined circulation of over 265,000, plus on ABC online and 774 radio.



In his report on recent inquiry into palliative care, the Victorian Auditor General noted that although most people would prefer to receive care and to die at home, only 35% of the palliative care funding is directed to community palliative care services.


International evidence shows that palliative care not only contributes to improved quality of life but also contributes to more effective use of health resources (see papers at "bit.ly/pcvlibrary-election2014").

Increased investment in palliative care (which currently is less than 1% of expenditure on Victorian public hospitals) would benefit the Victorian health system as well as people with a life limiting illness and their families.

Access to palliative care

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How to access palliative care



Community palliative care

- Self, family, GP, specialist can refer

Inpatient palliative care

- GP or specialist must refer

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Most referrals to palliative care are from the acute hospital setting. Unfortunately, many are very late in the disease trajectory.

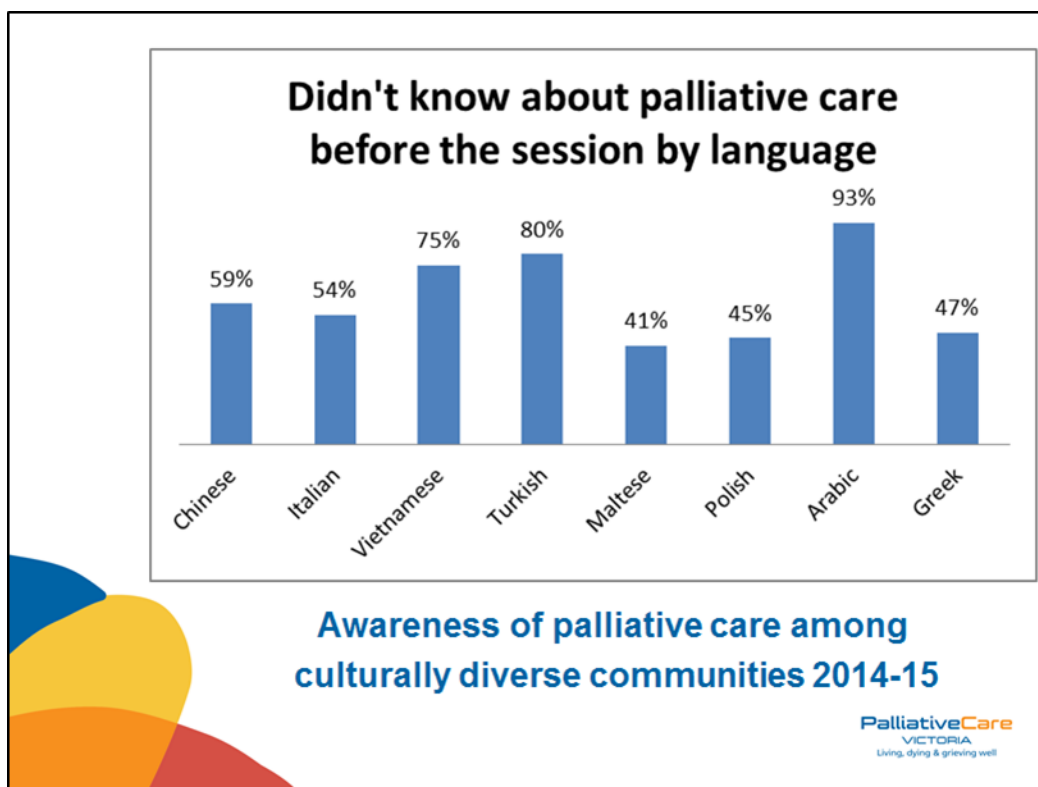
Raising community awareness of palliative care will assist people to ask their doctors for information and referrals at an earlier stage.

Palliative care recipients in Victoria

- Majority (>75%) have cancer
- Mainly older population
 - 1% 0-24 years
 - 36% 25-69 years
 - 63% 70+ years
- Limited cultural diversity compared with Victorian population



Low rates of use of palliative care services by people from culturally and linguistically diverse communities spurred the culturally responsive palliative care strategy undertaken by Palliative Care Victoria, the Ethnic Communities Council of Victoria and other partners over the past 2 years, with the support of a large philanthropic grant and some Government funding.



Between February 2014 and April 2015, 89 education sessions about palliative care were delivered in community languages to 2,280 participants from 8 ethnic communities in Melbourne.

Overall, 64% had no prior knowledge of palliative care and 90% reported that they learned new information about palliative care.

This work is continuing until 30 June, when the project funding ends.

Palliative Care Victoria is seeking further funding to enable this work to continue.

Michael recently gave a presentation at the 4th International Public Health and Palliative Care Conference in Bristol about this strategy.

It sparked considerable interest among the delegates particularly given its scope, the level of community engagement and success to date.





International evidence on the benefits of palliative care

- Improved management of pain & other symptoms
- More likely to receive care and to die at place of choice
- Increased family support and their satisfaction with care
- Greater emotional support
- Improved communication with families
- Reduced frequency and duration of hospital admission
- In some cases, increased length of life

Refer to papers citing evidence at:
bit.ly/pcvlibrary-election2014

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There is now a significant body of international evidence on the benefits of palliative care which include those listed in the slide.

There is scope for considerable improvement in our capacity to support people to die at home, the preferred location for around 70% of people. However, in Victoria 52% die in a public hospital.

This will require more adequate investment in community palliative care and support for carers. This could be done on a cost-neutral basis by reducing avoidable and unwanted admissions to hospital.

Further information about this evidence is available via the link indicated on the slide.



Feedback from patients, carers & bereaved carers

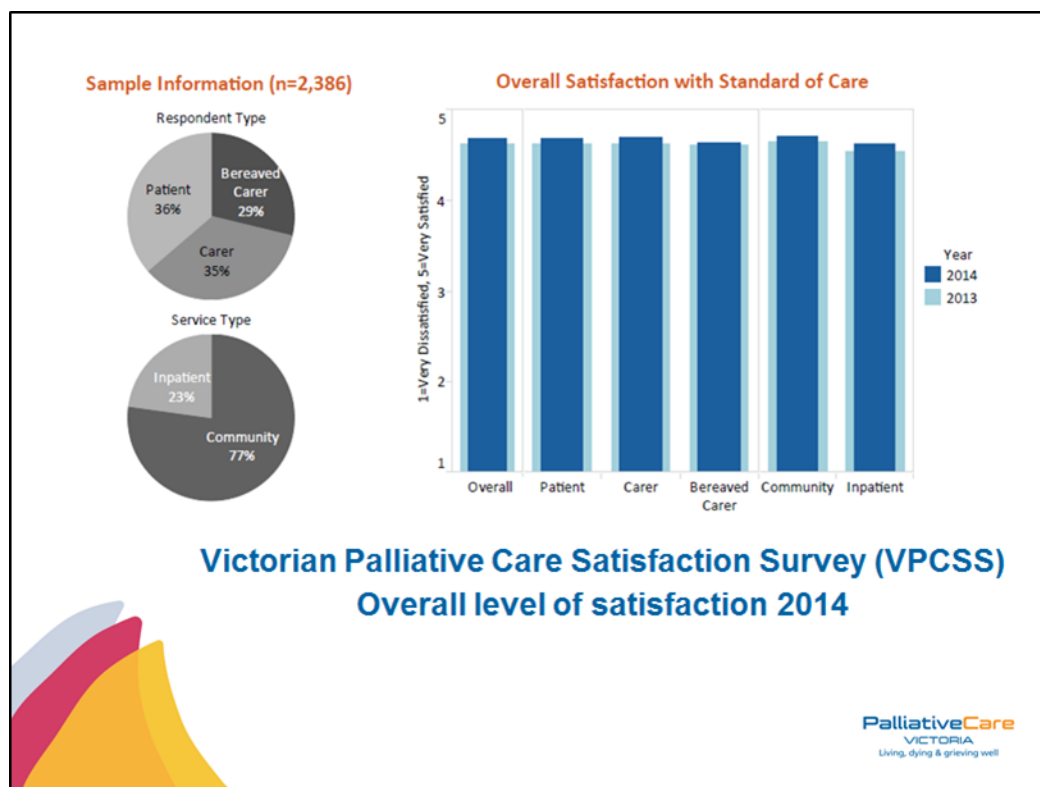
Victorian Palliative Care Satisfaction Survey

- Funded by the Victorian Government, Department of Health
- Annual survey between February and May
- Conducted over 5 years, 2010-2014
- Unique in Australia and internationally
- 11,000 patients, carers and bereaved carers provided feedback over the 5 year period
- Average overall satisfaction > 4.6 out of 5

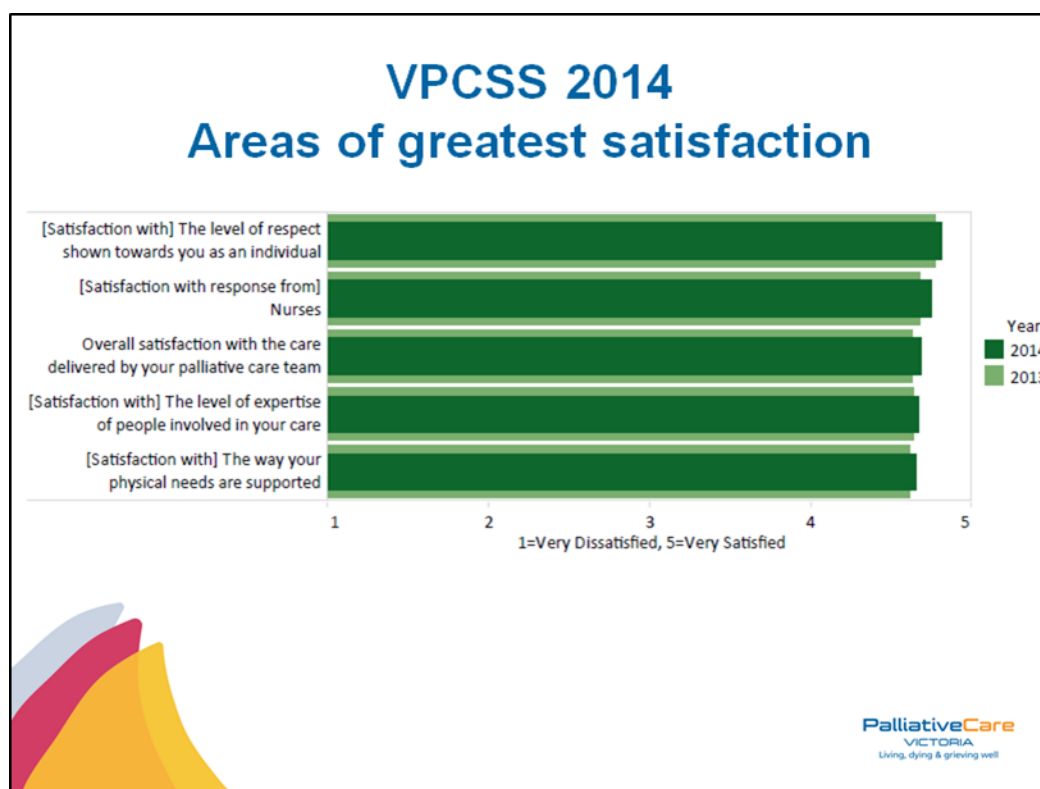
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Around 11,000 Victorian palliative care patients and carers have contributed voluntary and anonymous feedback about their experiences of palliative care through the Victorian Government funded Palliative Care Satisfaction Survey over the last 5 years and the average overall satisfaction is was consistently rated very highly at 4.6 or more out of a maximum of 5.

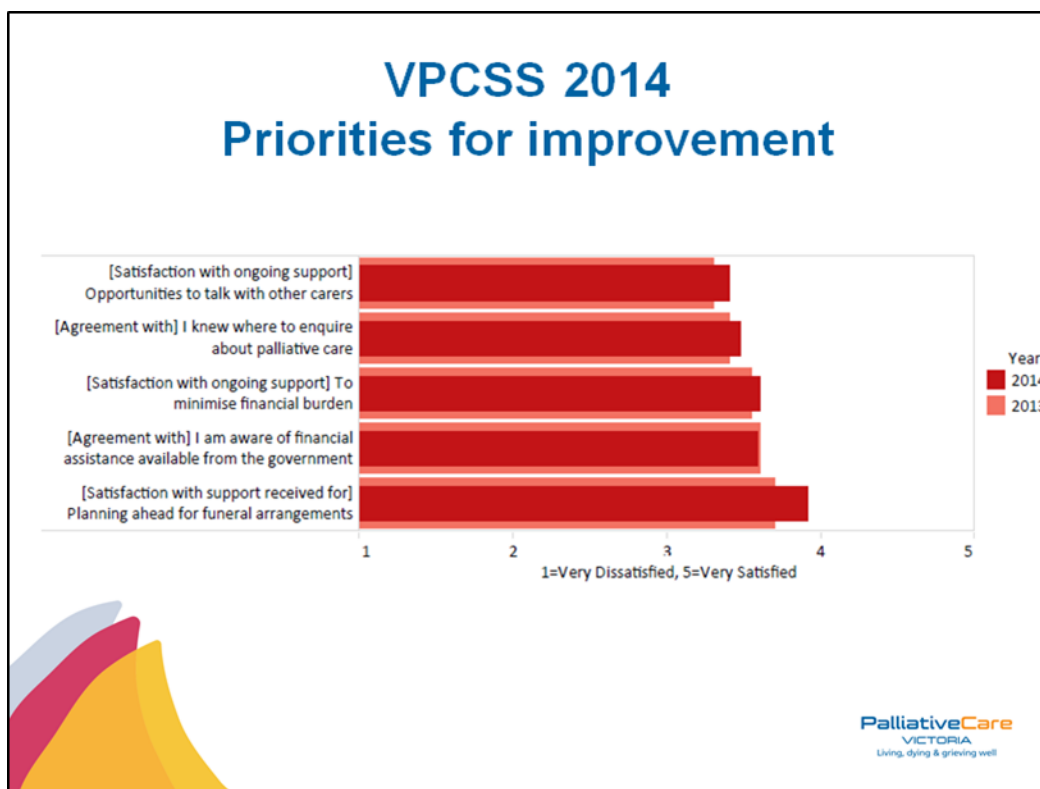
There is no survey in 2015 but the Department has indicated that an experience survey will be developed to replace it, hopefully in 2016.



The overall level of satisfaction reported in 2014 shows consistent and high levels of satisfaction by patients and carers and for inpatient and community palliative care.



The areas of greatest satisfaction reported by respondents in 2014 included “The level of respect shown towards you as an individual” (top bar) and the care delivered by the palliative care team and their level of expertise.



This chart shows the overall priorities for improvement.

One of these priorities is to make it easier for people to know where to enquire about palliative care.

Palliative Care Victoria has received a \$100K grant each year for the past four years to raise awareness of palliative care. Unfortunately, this grant ends on 30 June 2015.

Most palliative care in Victoria is delivered free of charge to the patient and family. The exceptions are charges for equipment loan and charges for some medications and supplies not covered by the PBS.

Nonetheless, there are significant financial burdens associated with the loss of income due to illness and the caring role.



Future directions

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Current unmet need for palliative care

Palliative care provision in Victoria is currently between 16% and 40% less than required to meet current need, based on these population benchmarks:

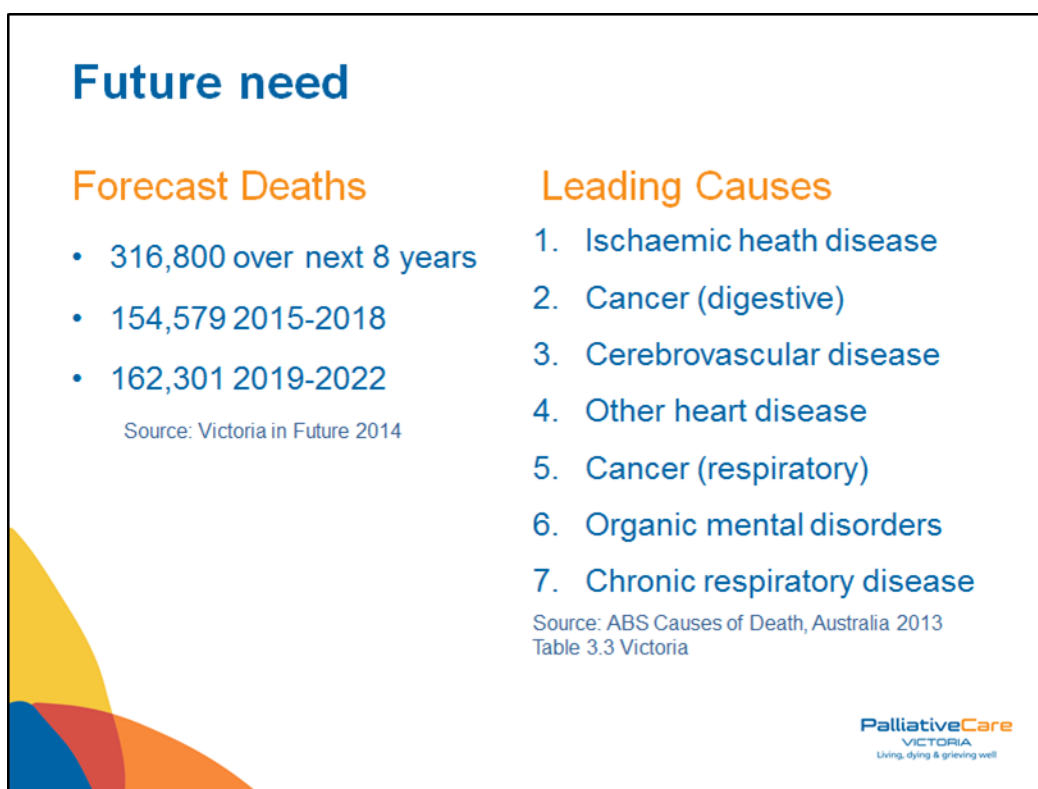
- World Health Organisation (2011) need for palliative care:
 - 378 people per 100,000 aged 16 plus
 - 63 children per 100,000 under 16 years
- UK Government study (2011) 75% of all deaths are likely to require palliative care input.



As this slide indicates, palliative care provision is currently between 16% and 40% less than the actual need based on these international population benchmarks of need.

The main population groups that are under-represented in palliative care service provision are:

- People with non-cancer life-limiting conditions, such as organ failure
- People with neuro-degenerative conditions, particularly dementia
- People from diverse backgrounds



Victoria's growing and ageing population and the increasing incidence of chronic disease will also contribute to an increase in the need for palliative care.

We estimate a growth rate of around 8% over the next 4 years.

Over 150,000 Victorians will die within the next 4 years. The seven leading causes of death in Victoria are all chronic conditions that would benefit from palliative care.

Policy directions & priorities

- Current policy framework expires 2015
- DHH&S developing an End-of-Life Care Framework by 1 July 2017
- Palliative Care Victoria - 6 key priorities in Call to Action 2015-2019



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The Victorian Auditor General noted that the palliative care policy framework for 2011-2015 provided a clear and ambitious agenda and that good progress had been made but that time required to deliver some of the complex goals had been under-estimated.

In its response to the Auditor-General's report, the Department of Health indicated that it is developing an End of Life Care Framework that will be completed by 1 July 2017.

Given the need to avoid a policy vacuum, we hope that progress can be made so that it can be launched in 2016 and funded in the 2016 State budget.

Palliative Care Victoria supports its development as a priority and will contribute constructively to ensure the top 6 priorities we have identified are addressed.

6 Key priorities

1. Increase community palliative care services
2. Expand palliative care consultancy services
3. Close the gap in palliative care for Indigenous Australians
4. End of life care is a priority
5. Increase community awareness and capacity
6. Improve health care experience and performance

A summary of these 6 key recommendations is included in the information folder.

Significant work is underway to build the capacity of Victorian health services to undertake effective advance care planning.

It is important that this is complemented by community engagement activities that build capacity to discuss issues of dying, death, grief and loss and also to raise awareness of palliative care and end of life care provisions so that they are able to participate fully and in an informed way in advance care planning.



Palliative care funding

- 2011-2015 \$34.4M new funding
- 2015-19 ?

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At this stage we are uncertain about the funding available for palliative care for the next four years. Growth funding is needed to ensure palliative care services do not lose ground and are well placed to meet growing demand.

We are optimistic that there will be some positive announcements about increased funding for palliative care in 2015-16 and the following years.

There is recognition among all the parties in Victoria's government that palliative care is important.

The Special Minister of State, Hon. Gavin Jennings, when he proposed the reference to this Committee in Parliament on 7 May, placed on record that the Premier and Minister for Health would during the life of this inquiry put in place appropriate improvements to palliative care, including a responsive, appropriate home-based palliative care model.

The Minister for Health indicated on 13 May at the Public Accounts and Estimates Committee that there are some significant investments in the budget around palliative care.

This will be most welcome in assisting the palliative care sector to address unmet need and the growing numbers of people with a life limiting illness and their families to receive the care and support they need to live well, to die well and to grieve well.

Questions & discussion

Thank you

Palliative Care

V I C T O R I A

Specialist health care and practical support

STATE ELECTION 2014

CALL TO ACTION
2015-2019

To assist Victorians with a life limiting illness
and their families to live, die and grieve well

A detailed supporting paper is available at:
<http://bit.ly/pcvlibrary-election2014>

Approved for distribution by the
Board of Palliative Care Victoria
10 June 2014

CALL FOR ACTION SUMMARY

Increase investment in palliative care by \$16.45 million a year:

Service Growth - \$14.25 million a year

See recommendations 1, 2 & 3

Effectiveness & Efficiency - \$2.2 million a year

See recommendations 4, 5 & 6

Allocate funding to improve equity of access and outcomes, as well as efficiency.

DESIRED OUTCOMES

- Palliative care services are responsive to the growing need and care choices.
- An increasing trend in home deaths and an associated decline in hospital deaths.
- Improved support for caregivers, including after-hours respite.
- Improved access to palliative care by groups currently missing out.

Positive Case Examples

Palliative care reduces use of hospital emergency

Moira is in her 70's and is cared for at home in regional Victoria by her husband, George. She suffers from end stage chronic obstructive pulmonary disease. George says before palliative care Moira struggled - they would call the ambulance and end up in hospital a couple of times a month. The palliative care team prescribed medication, provided equipment, taught them helpful practices, visit regularly and can be called at any time. As a result, there have been no more ambulance calls or emergency admissions to hospital. George says that getting respite one afternoon a week and for a few days every couple of months enables him to re-charge his batteries and re-dedicate himself to caring for Moira. "Without that, I probably couldn't exist under the strain," says George.

View video at <http://bit.ly/moiraandgeorge>

Achieving the wish to die at home in rural Victoria

Jan was a 73 year old with advanced ovarian cancer who lived three hours' drive from the closest palliative care service in Gippsland. She did not have any family or extended network and wished to die at home. The palliative care nurse practitioner candidate (NPC) developed a care plan with Jane that involved utilising the remote area nurses. A trained volunteer who lived close by was enlisted to provide support to Jane. The NPC provided support to the remote area nurses caring for Jane and the volunteer. Jane died at home with her volunteer holding her hand.

Gaps in palliative care services make it difficult to achieve these outcomes in many situations. For example, one metro palliative care service found that short-term overnight respite for 15% of their patients would have enabled them to continue to receive care and die at home at a much lower cost to the health system, had the funding been available.

Recommendation 1: Increase community palliative care services.

Need: Population growth, ageing and the incidence of chronic disease will increase the need for palliative care. Increasing the availability of palliative care services will: improve equity of access and quality of life outcomes, assist more people to receive care and to die at their place of choice (for most people this is at home), and contribute to more effective use of limited health resources.

Actions: 1.1 Increase the overall supply of palliative care services to address the unmet and growing need for palliative care and end of life care.

1.2 Support the provision of community palliative care on a 24/7 basis, including greater capacity to provide in-home care and respite (including overnight) by appropriately trained staff and improved access to out-of-home respite and end of life care options in metro and rural areas and for particular population groups such as children and young adults.

Investment: \$9.5 million per year

Recommendation 2: Expand palliative care consultancy services

Need: Victoria has less than half the recommended number of palliative medicine specialists and more are required to meet the anticipated growth in need for palliative care. Gaps in these services contribute to avoidable hospital admissions, difficulties in accessing advice after hours, and diminished access to expert advice for GPs involved in end of life care.

Action: Increase capacity to provide specialist palliative care consultancy services. Priorities include: patients receiving palliative care in the community; 24/7 access to address complex / urgent needs; gaps in rural provision; state-wide services including children and young adults.

Investment: \$4.3 million per year

PALLIATIVE CARE IN VICTORIA

- Community: 15,323 people received palliative care at home in 2012-13 – **80% increase** since 2008-2009. Average cost per patient \$2,570; 174 days average duration of care.
- Inpatient: 8,035 palliative-care related separations (94,384 patient days) in 2012-13. Average cost per patient separation (12 days) \$5,995.
- Funding for palliative care in 2013-14 is \$109.5M; **<1% of public hospital expenditure.**

Recommendation 3: Close the gap in palliative care for Indigenous Australians.

Need: In spite of higher rates of morbidity and mortality, Indigenous Australians have lower rates of use of palliative care services due to concerns about cultural safety. Indigenous Australians prefer to receive care and to die at home, connected to land and their extended family network. Research indicates that it is preferable for palliative care to be delivered under the auspices of an Aboriginal Health Service and in collaboration with mainstream palliative care services.

Action: Provide a culturally safe model of care whereby Aboriginal Health Liaison Workers at Aboriginal Health Services assist patients to access specialist palliative care and provide support, advocacy, and care coordination. Adjunct education, clinical placement and resource development will build the capacity of Aboriginal Health Services and palliative care services to provide culturally responsive palliative care.

Investment: \$450,000 per year

Recommendation 4: End of life care a priority for all Victorian Government funded health services

Need: Over 300,000 Victorians are expected to die during the next 8 years; the majority will receive care in hospital and up to 52% will die there. Most health professionals have not received adequate education in care of the dying or discussing advance care wishes.

Actions: 4.1. Include high quality end of life care in the Statements of Priorities for all Victorian Government funded health services.

4.2. Provide education on palliative care and communications skills, including the use of key clinical triggers for referral to palliative care, to health professionals in Victorian Government funded health services. A priority focus should be health professionals working with patients with chronic illnesses that are leading causes of death.

Investment: \$50,000 per year

REASONS FOR ACTION

- Current unmet & growing need for palliative care
- Lack of community awareness of palliative care
- Preference to receive care and die at home
- Integration of palliative care within health services a priority
- Improve health outcomes and resource use
- See overleaf for more information.

Recommendation 5: Increase community awareness and capacity

Need: Lack of awareness of palliative care and lack of physician referral to palliative care services are common barriers to accessing these services.

Action: A community engagement program to raise awareness of palliative care, to build community capacity in dealing with issues of dying, death, grief and loss, and to encourage people to discuss and document their advance care wishes. This would include delivery of peer education sessions by trained and supported volunteers in partnership with COTA Victoria, as well as train the trainer education to build this capacity in other volunteer programs. A range of media, engagement events and communication channels would be used, including those relevant to specific target populations.

Investment: \$400,000 per year

Recommendation 6: Improve health care experience and performance

Need: To improve equity of access and quality outcomes for consumers, as well as health system performance.

Actions: 6.1 Fund priority palliative care research projects in Victoria to improve consumer outcomes, responsiveness to under-served populations, and provide evidence of cost-effectiveness.

6.2 Strengthen palliative care clinical and research expertise through continuation of post-graduate scholarships and 3 new PhD scholarships/ placements.

6.3 Continue an annual survey of palliative care patients, carers and bereaved carers as this assists in measuring consumer outcomes and continuous quality improvement.

6.4 Seed, share and spread innovative approaches to improve referral pathways, fast track hospital discharge and enable people to receive care and die at home.

Investment: \$1.75 million a year

REASONS FOR ACTION

Increasing Need for Palliative Care Services

Population growth, ageing and chronic disease will continue to drive significant increases in the need for palliative care. There is also a significant level of current unmet need among specific populations.

Over 300,000 Victorians will die within the next 8 years. Unless current trends are turned around, 52% will die in Victorian hospitals and most without the benefits of palliative care.

More Effective Use of Health Resources

International and Australian evidence indicates that palliative care not only improves the quality of life of patients and their families, it also contributes to more cost-effective use of health resources.

A conservative analysis of available data indicates that the cost of palliative care services can be between 40% and 300% less expensive than care in an acute bed or intensive care bed.

Palliative care a health care priority

The World Health Assembly passed a unanimous resolution on 23 May 2014 calling for the integration of palliative care into healthcare systems. Palliative care is an increasing health priority that can deliver improved patient and carer outcomes as well as contributing to improvements in the overall performance of the health system.

Support more Victorians to die at home

Home is the preferred place of care and place of death for most Victorians. However, only 25% die at home. Community based palliative care services need the capacity to provide clinical advice and carer support/respite on a 24/7 basis as required to support patient choice to die at home.

Community awareness of palliative care

Lack of awareness of palliative care and physician referrals to palliative care are key barriers to access. Community engagement will enable more people to be aware of the options and to discuss and document their advance care wishes.

Research, education and innovation

Investment in palliative care research, education and service innovation will assist Victoria to address forthcoming challenges arising from an ageing workforce and ageing population and the need to deliver better health outcomes more efficiently.

Further information and evidence

A detailed supporting paper is available at <http://bit.ly/pcvlibrary-election2014>

ABOUT PALLIATIVE CARE

What is Palliative Care?

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (World Health Organisation)

Who Can Benefit from Palliative Care?

Palliative care is beneficial for people of all ages with a wide range of life limiting conditions, including cancer, end stage organ failure, dementia, other neurodegenerative conditions and genetic disorders. It is provided on a needs basis from diagnosis and including bereavement.

PALLIATIVE CARE VICTORIA

Palliative Care Victoria is an independent not-for-profit peak body in Victoria. Established in 1981, we represent palliative care providers, consumers and their families, and those with an interest in palliative care in Victoria. We are a member of the national peak body, Palliative Care Australia.

Our desired outcomes:

Caring communities that are supportive and resilient in responding to life limiting illness, death, grief and loss.

Equity of access to quality palliative care when and where it is needed.

High quality palliative care achieved through a capable and compassionate workforce and a strong, innovative and effective service system.

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