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WHPCA position paper on euthanasia and assisted dying

Purpose	To affirm the WHPCA position on euthanasia and assisted suicide
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Publication Date	May 2012
Audience	Palliative care personnel, national governments, international organizations
Circulation List	Regional and National Associations
Summary	This position statement clarifies the position on euthanasia and assisted suicide
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Review Date	1 st May, 2018

Introduction

The Worldwide Hospice Palliative Care Alliance (WHPCA) is a global network of organizations committed to the development of palliative care in order to improve accessibility and availability of palliative care services for people affected by life-threatening illness.

The WHPCA has identified the need to produce a position statement on euthanasia and assisted suicide that may be helpful to hospice palliative care organisations engaged in this discussion in their countries.

Summary of Recommendations

The WHPCA recommends that all governments:

- integrate palliative care into their country's health care system
- ensure training for health care workers in communication skills, bioethics and palliative care
- encourage advance care planning and discussion of preferences for end-of-life care

Value Statement

The goal of palliative care is to improve **quality of life** for patients and family members affected by life-threatening illness¹. Palliative Care affirms life, regards dying as a normal process and intends neither to hasten nor to postpone death. Euthanasia and physician assisted suicide are not part of palliative care practice².

Definitions

Euthanasia means killing on request and is defined as a doctor intentionally killing a person by the administration of drugs, at that person's voluntary and competent request. In euthanasia the *intention* is to kill the patient, the *procedure* is to administer a lethal drug and the successful *outcome* is immediate death³.

Assistance in suicide means knowingly and intentionally providing a person with the knowledge or means or both required to commit suicide, including counseling about lethal doses of drugs, prescribing such lethal doses or supplying the drugs.

Physician Assisted Suicide is defined as a doctor intentionally helping a person to commit suicide by providing drugs for self-administration, at that person's voluntary and competent request.

Most commentators make no formal ethical distinction between euthanasia and assisted suicide since in both cases the person performing the euthanasia or assisting the suicide deliberately facilitates the person's death. There is disagreement about whether euthanasia and assisted suicide should rightly be considered "medical" procedures.

Background

When a person's medical diagnosis precludes the hope of health being restored or maintained and the death of the patient is inevitable, the physician, the care team, the patient and the family are often faced with a complex set of decisions regarding medical interventions.

The duty of doctors is to heal, where possible, to relieve suffering always and to provide care that benefits the patient without causing harm. There shall be no exception to this principle even in the case of incurable disease. The primary responsibilities of the doctor and care team in end-of-life care are to assist the patient in maintaining an optimal quality of life through controlling symptoms and addressing psychosocial and spiritual needs, and to enable the patient to die with dignity and in comfort.

Health care practitioners must ensure decisions are properly documented including clinical findings, discussions with the patient or others involved in decision making and details of treatment. Records of these discussions and decisions reached should be legible, clear, accurate, unambiguous and accessible to team members.

WHPCA notes with interest the evolution of language relating to euthanasia and how there is a similarity in language between the palliative care discourse and the euthanasia discourse. Palliative care includes the care and support of people at the end of their life to assist their dying in comfort and dignity as far as possible and describes this as a 'good death'. Chochinov observes that "the more that healthcare providers are able to affirm the patient's value—that is, seeing the person they are or were, rather than just the illness they have—the more likely that the patient's sense of dignity will be upheld."⁴

None of the following should be seen as euthanasia²

- . withholding futile treatment;
- . withdrawing futile treatment;
- . palliative sedation

Withholding or withdrawing treatment is a sound clinical decision when reached in discussion with the patient (if competent), the family and the care team. It is important to identify when active treatment will improve quality of life and prolong life and when active treatment is futile without likelihood of improving the condition and merely prolonging the dying process.⁵

Palliative sedation is defined as the use of sedative medication to relieve intolerable suffering in palliative care. In palliative sedation the *intention* is to relieve intolerable suffering, the *procedure* is to use a sedating drug for symptom control and the successful *outcome* is the alleviation of distress². The level of sedation is guided by the level of patient distress and the aim is to calm the patient without causing unconsciousness so that the patient is able to interact with the family. Occasionally, deep sedation is required to relieve severe distress but this should be a temporary measure. Clinicians may find the European Association for Palliative Care framework for palliative sedation⁶ a helpful guide in caring for patients with refractory symptoms.

Advance Care Planning⁷ and Advance Directives

The WHPCA support and encourage advance care planning as an important aspect of palliative care. Advance care planning is the process of discussing and documenting a person's wishes for care in the event of their not being able to communicate this in the future.

Documents describing advance care planning may be referred to by different names in different countries such as an Advance Directive or a Living Will. The value of these documents is to guide medical and healthcare decisions. In many parts of the world, they are not legally binding documents. The importance of the Advance Directive or Living Will is that the person drawing up this document in discussion with family and healthcare providers indicates their preferences for care while they are able to discuss these preferences. This will assist families and health care professionals to make decisions relating to a person's care.

The Canadian Hospice Palliative Care Association *Speak Up* campaign encourages Canadians to Start the Conversation and state that "Most of us hope to die peacefully, able to communicate with others until the very end. Death does not always occur this way. It's not easy to think about the care you'd like to receive at the end of life - but it's important. Making your wishes known ensures that you - and those who care about you - can make the right decisions if you can't speak for yourself."⁸ There is information on how to make an Advance Care Plan for individuals and to assist health care professionals to have this conversation with patients and family members.

The **National Hospice Palliative Care Organisation** in the United States provides the following information:

"A living will allows you to document your wishes concerning medical treatments at the end of life.

Before your living will can guide medical decision-making two physicians must certify:

- You are unable to make medical decisions,
- You are in the medical condition specified in the state's living will law (such as "terminal illness" or "permanent unconsciousness"),
- Other requirements also may apply, depending upon the state.

A medical power of attorney (or healthcare proxy) allows you to appoint a person you trust as your healthcare agent (or surrogate decision maker), who is authorized to make medical decisions on your behalf.⁹

Position statement

The WHPCA recognises the importance of the societal discussion on euthanasia and assisted suicide and understands that some countries have legalized or decriminalized assisted dying. The philosophy of palliative care includes holistic assessment and management of a person's needs, paying attention to the multidimensional aspects of the whole person. The expressed desire for euthanasia needs to be explored holistically as an expression of existential suffering. This is done by engaging the person in dialogue with active listening and empathy, and exploring the following themes:

1. Reality of the disease progression
2. Exploring and understanding the person's goals for care
3. Perceptions of their suffering and sense of burden to others
4. Anticipation of the dying trajectory
5. To explore the timing of desired death (this is often seen as sometime in the future – not yet)
6. The desire for good quality end-of-life care
7. The care and support that is or can be offered by good health care and supportive significant others
8. Clinical depression as co-morbidity

This dialogue requires clinicians to be skilled in sensitive communication, to have knowledge and skills in clinical care and in addressing bioethical issues.

The WHPCA upholds the right for people to be involved in the decision-making process concerning their treatment or non-treatment and that a request by a person for euthanasia is identified as part of this process. Understanding and respect for this alternate view point is not the same as ethical acceptance thereof. Hudson et al describe that "A 'desire to die' statement may be about a request for hastened death, a sign of psychosocial distress, or a comment that is not intended to be heard literally as a death wish".¹⁰ It requires a compassionate and caring response which addresses the person's distress effectively. The obligation of a health care professional in the palliative care setting is to try, as far as possible, to offer care that will ease the dying, but not deliberately bring about death. WHPCA promotes the effective relief of symptoms for

people with life-threatening and life-limiting illness. Euthanasia and physician assisted suicide are not part of palliative care practice.

Recommendations for all governments:

- 1) To integrate palliative care into their country's health care system
This will enhance the accessibility and affordability of palliative care to those people in need of this service. The essential steps to integration of palliative care into the formal health care sector include:
 - i) the development of a palliative care country strategy, documenting policies, procedures and standards for delivery of palliative care and recognition of palliative care specialization;
 - ii) education of healthcare workers in palliative care and support of these workers to transfer learned palliative care skills into their work settings;
 - iii) a review of the Essential Medicines List to ensure the availability and affordability of essential palliative care medication.
- 2) To ensure training of health care providers in communication skills, bioethics and palliative care.
- 3) To encourage advance care planning and discussion of preferences for end-of-life care

Conclusion

Quality palliative care intends neither to hasten death nor to postpone death but to improve the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

¹ Sepulveda C, Marlin A, Yoshida T, Ullrich A. Palliative Care – the World Health Organisation's Global Perspective. *Journal of Pain and Symptom Management* 2002; 24 (2): 91-96.

² <http://www.palliativecare.org.au/Portals/46/PCA%20position%20statement%20-%20Euthanasia%20and%20Physician%20Assisted%20Suicide.pdf> (accessed 6 May 2012)

³ Materstvedt L. J., Clark D., Ellershaw J., Førde R., Boeck Gravgaard A-M., Müller-Busch H C., Porti Sales J., Rapin C-H. Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force. *Palliative Medicine* 2003; 17: 97-101

⁴ Chochinov H. Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care. *BMJ* 2007; 335: 1840-187

⁵ Gwyther L. Withholding and Withdrawing Treatment: practical applications of ethical principles in end-of-life care. *South African Journal of Bioethics and Law*. June 2008 1 (1) 24-26

⁶ Juth et al. *BMC Palliative Care* 2010, 9:20 <http://www.biomedcentral.com/1472-684X/9/20> (accessed 5 May 2012)

⁷ http://www.endoflifecareforadults.nhs.uk/assets/downloads/pubs_Advance_Care_Planning_guide.pdf (accessed 31 July 2011)

⁸ <http://www.advancecareplanning.ca/> (accessed 31 July 2011)

⁹ <http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3285> (accessed 31 July 2011)

¹⁰ Hudson PL et al Responding to desire to die statements from patients with advanced disease: recommendations for health professionals. *Palliative Medicine* 2006: 20 : 703-710