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Dr Jeannine Purdy  
Principal Research Officer  
Joint Select Committee on  
End of Life Choices  
Parliament of Western Australia  
Parliament House  
PERTH WA 6000  
eolcc@parliament.wa.gov.au



Level 1, Suite 375,  
241 Adelaide Street  
Brisbane  
Qld 4000

T: 07 5429 8480  
admin@pcna.org.au  
www.pcna.org.au

Dear Dr Purdy,

Please find following responses to the questions that were taken on notice by Mrs Grace Buchanan at the Public Hearing on End of Life Choices, 14 December 2017. Mrs Buchanan is a committee member on the Palliative Care Nurses Australia (PCNA) national board.

PCNA is a national member based organisation for nurses working with people who are living with and dying from a progressive life limiting illnesses and their families. The vision of PCNA is to promote excellence in palliative care nursing for our community, through leadership, representation and professional support. The World Health Organization (2002) definition of palliative care underpins our work.

PCNA has been following the current societal, academic and parliamentary debate in Australia on the topic of legalisation of euthanasia and assisted suicide for people living with a life limiting illness who are experiencing suffering. Euthanasia and physician assisted suicide are currently illegal in all Australian states and territories.

PCNA appreciate the opportunity to provide this information to the Select Committee on this important issue.

Should you wish to discuss our views further, please feel free to contact our office on to arrange a suitable time.

Yours sincerely

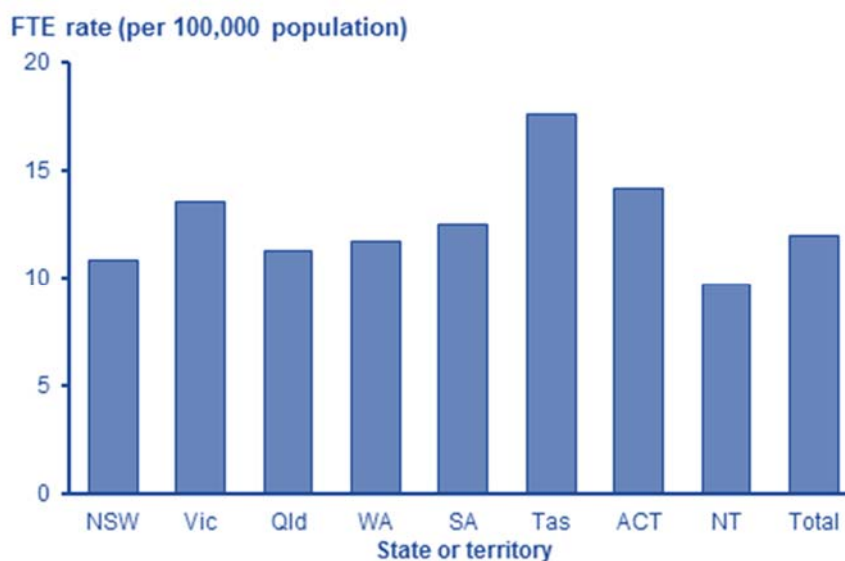
Jane Phillips PhD RN  
**PRESIDENT**

## Palliative care nursing workforce

Whilst we do not have access to Western Australian specific palliative care workforce data, recent national data indicates that palliative care nurses made up around 1 in every 90 (1.1%) employed nurses in Australia, with over 3,300 working in Australia in 2015 <sup>(1)</sup>.

Nationally, there were 12.0 FTE palliative care nurses per 100,000 in 2015. The rate of FTE palliative care nurses across the states and territories ranged from 9.7 in the Northern Territory to 17.6 in Tasmania (Figure 1). The average hours worked varied across jurisdictions, ranging from 30.9 hours per week for Western Australia and South Australia to 36.3 hours per week for the Australian Capital Territory <sup>(1)</sup>.

**Figure 1: Employed palliative care nurses, FTE per 100,000 population, states and territories, 2015 (1)**



Source: National Health Workforce Data Set 2015.

Source data [Palliative care workforce Table Wk.9 \(514KB XLS\)](#).<sup>(1)</sup>

Approximately three quarters (73.5%) of FTE palliative care nurses worked mainly in major cities during 2015, with a further 18.4% working in Inner regional areas. Taking into account differences in population sizes for each remoteness area, the FTE palliative care nurses per 100,000 population was highest for Major cities (12.7 FTE), followed by Inner regional (12.4 FTE) areas, but this drops to 2.3 FTE in remote and very remote areas.

More than 9 in 10 employed palliative care nurses were clinicians (94.5%). About half (51.2%) of all employed palliative care nurses were employed in a hospital setting, followed by community healthcare services (22.7%) and hospices (15.9%).

## Management of hydration and nutrition at the end of life

It is common and natural for palliative care patients to have reduced food and fluid intake during their illness, especially in the final weeks and days of life. Management of reduced oral food and fluid includes discussion with the patient, family and staff involved and may include the provision of nutrition and hydration with medical assistance. Yet, a recent Cochrane Review did not show a significant benefit in the use of medically assisted hydration in palliative care patients <sup>(2)</sup>; and another updated review found insufficient good-quality trials to make any recommendations regarding the use of medically assisted nutrition in palliative care patients <sup>(3)</sup>.

As palliative care nurses, we recommend the use of an ongoing decision-making process that examines the benefits and burdens of medically assisted nutrition and hydration in accordance with the patient's current clinical condition, individual goals and values. There are rare occasions when medically assisted nutrition and/or hydration may be trialled by palliative patients for a limited time to achieve a specific goal. However, before commencing this type of intervention, there will be an agreement between health team and patient that the medically assisted nutrition and/or hydration will be discontinued if the goal is not met.

There are also occasions when a patient who is not actively dying may wish to forgo treatment/s that may maintain and/or extend their life. At times, this may include the desire to cease or forgo medically assisted nutrition or hydration. This situation is a more complex scenario, as the patient is not actively dying, so it raises a range of legal and ethical issues. A fundamental principle of all health care is that every person with decision-making capacity has the right to request and/or agree to any medical therapy that offers reasonable probability of benefit and to refuse and/or withdraw from any medical therapy. As palliative care nurses, we have a responsibility to support informed decision-making and advocate for care that is consistent with the stated wishes of the patient or, if they lack capacity, their substitute decision makers.

In the same respect that a patient's values are honoured, so too should be the nurse's values. If the nurse is uncomfortable with commencing or continuing, withholding or withdrawing treatments, they ought to openly communicate their concerns during team discussions about a patient's care plan. In some instances, it may be ethically and professionally necessary for the nurse to remove himself or herself from this person's care after finding a replacement nurse.

## Sedation at the end of life

Sedation that is administered during the last days to hours of a person's life with the intention to relieve intractable symptoms i.e. intensely distressing symptoms that are not relieved by all other appropriate therapeutic means, is correctly termed 'palliative sedation'<sup>(4)</sup>. Palliative sedation is not required by all dying people, but is reserved for rare and sometimes crisis situations of intractable pain, breathlessness and/or delirium. The most common class of medication used for palliative sedation is benzodiazepines.

Research evidence is consistent that

- i. palliative sedation does not hasten death; and
- ii. it's overall effectiveness in relieving symptoms and distress has not been fully established<sup>(5)</sup>.

The evidence therefore supports the ethical and safe nature of palliative sedation in situations of intractable symptoms and distress in the last days and hours of life, yet also informs us of the continued need to establish what are the most effective ways to provide comfort to dying persons through rigorous research.

International guidelines for the use of palliative sedation recommends the following clinical actions:

- expert palliative care evaluation of the patient's situation;
- fully informed consent of the patient or their substitute decision maker;
- sedation levels and duration that are proportionate to the specific needs of the person at each point in time;
- consideration of and attention to the patient's whole needs e.g. nutrition and hydration;
- care and information for the family; and
- care for the health care professionals involved<sup>(4)</sup>.

Nurses who care for patients receiving palliative sedation therefore have a professional and ethical responsibility to collaboratively communicate and work with others in the patient's interdisciplinary team (which always includes the patient and family) to ensure that these recommendations are met.

## Principle of Double Effect

The principle of double effect is a long-established bioethical and legal concept that provides moral justification for an action that has two foreseen effects: one good and one bad. The key factor is the intent of the person performing the act. If the intent is good (e.g., relief of pain and suffering) then the act is morally justifiable even if it causes a foreseeable but unintended result (e.g., hastening of death).

To qualify the principle of double effect in everyday clinical practice, palliative care interventions based on evidence-based clinical practice guidelines and the individual characteristics of the patient and made by clinicians with appropriate qualifications and skills are highly unlikely to result in death. The most common foreseen but unintended effects of palliative care interventions are non-life threatening medication side effects, such as nausea, which is likely when a person first begins taking opioids for pain relief.

The principle of double-effect is consistent with Section 259 of the Western Australian Criminal Code, which offers nurses the protection they require to care for terminally ill people in Western Australia.

*Section 259: "Surgical and medical treatment A person is not criminally responsible for administering, in good faith and with reasonable care and skill, surgical or medical treatment — (a) to another person for that other person's benefit; or (b) to an unborn child for the preservation of the mother's life, if the administration of the treatment is reasonable, having regard to the patient's state at the time and to all the circumstances of the case. [Section 259 inserted by No. 15 of 1998 s. 5.]*

## Responding to requests for physician assisted suicide

As detailed in our position statement (Appendix 1).

## Terminology

Many of the terms used in the question route submitted to PCNA are not universally recognised or accepted medical terms. To ensure that there is a universally understanding of all of the palliative and end-of-life care terms used, PCNA recommends that the committee adopts terms that are widely understood with accepted definition. If this approach is adopted, then:

- 'Palliative starvation' would not be used, as it denotes withholding or refusal of food and fluids with the deliberate intention to cause a person's death. The clinically correct term and concept that is universally understood and accepted as ethical medical care is 'forgoing medically assisted nutrition or hydration'.
- 'Terminal sedation' would also not be used, as it denotes, either inadvertently or deliberately, that sedation is being used with the intent to hasten the patient's death. For these reasons, PCNA does not use or support the use of the term 'terminal sedation'. Sedation that is given in doses and duration that are disproportionate to the symptoms of the dying person with the intention to hasten death is unethical, unlawful and not part of palliative care. This term currently is having a resurgence in jurisdictions where euthanasia is legal, or by proponents of hastened death<sup>(6)</sup>.

- 'Palliative sedation' would be used, as it has long been recommended by clinical and ethical experts as the preferred and more accurate term to describe the practice of using sedation with the intention to relieve (i.e. palliate) intractable symptoms and distress during dying <sup>(6)</sup>.

Additional advice on the best end-of-life and/or palliative care terminology to use can be found on the Care Search website funded by the Australian Government (<https://www.caresearch.com.au/Caresearch/Default.aspx>). Alternatively PCNA would be happy to advise the Committee on universally recognised terms.

## References

1. Australian Institute Health and Welfare. Palliative Care Services in Australia. Canberra: AIHW,; 2017.
2. Good P, Richard R, Syrmis W, Jenkins-Marsh S, Stephens J. Medically assisted hydration for adult palliative care patients. Cochrane Database Syst Rev. 2014(4).
3. Good P, Richard R, Syrmis W, Jenkins-Marsh S, Stephens J. Medically assisted nutrition for adult palliative care patients. Cochrane Database Syst Rev. 2014(4).
4. Cherny NI, Radbruch L. European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care. Palliat Med. 2009;23(7):581-93.
5. Beller EM, van Driel ML, McGregor L, Truong S, Mitchell G. Palliative pharmacological sedation for terminally ill adults. Cochrane Database Syst Rev. 2015(1).
6. Cohen-Almagor R, Ely EW. Euthanasia and palliative sedation in Belgium. BMJ Supportive and Palliative Care. 2018.

## Appendix 1

### Position Statement: Euthanasia and Physician Assisted Suicide

#### Preamble

There is current societal, academic and parliamentary debate in Australia on the topic of legalisation of euthanasia and assisted suicide for people living with a life limiting illness who are experiencing unbearable suffering. Euthanasia and physician assisted suicide are currently illegal in all Australian states and territories.

#### Background

Palliative Care Nurses Australia Inc. (PCNA) is a national member based organisation for nurses working with people who are living and dying from progressive illnesses and their families. The vision of PCNA is to promote excellence in palliative care nursing for our community, through leadership, representation and professional support. The World Health Organization (2002) definition of palliative care underpins our work.

Palliative Care Nurses Australia believes that:

- Palliative care does not include the practice of euthanasia or assisted suicide; and that the intent of palliative care is to neither hasten or postpone death;
- Nurses play a key role in minimising the patient's suffering and maximising their function and access to support and comfort. Optimal palliative care nursing involves:
- advocating for and ensuring all patients have access to palliative care in accordance with their needs;
- impeccable assessment and management of the physical, psychological, socio-cultural and spiritual needs of the person and their family in accordance with the best available evidence;
- discussing and supporting a patient's choices to withhold or withdraw treatments where the potential harm outweighs possible benefit or is against their expressed wishes;
- considering the complex and multi-dimensional nature of suffering and acting to prevent and alleviate it where possible by seeking and utilising the best available evidence and interdisciplinary advice;
- respectfully and compassionately acknowledging a person's desire to die statements or requests to hasten death in the context of a life limiting illness, and seek to understand the origins of the request; whilst acknowledging that for a small proportion of people pain, distress and/or suffering can persist despite the provision of best palliative care;
- responding to a person's request to hasten death in accordance with: the law, professional codes of conduct, ethical health care principles, best available evidence, and the unique needs of the person and their family; and
- fostering informed and respectful communication with patients, their families, other health care professionals and the wider community about death, dying and end of life care, including the topic of euthanasia and physician assisted suicide.

## Definitions

**Palliative Care** as defined by the World Health Organization (2002) 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.

Palliative care provides relief from pain and other distressing symptoms, and:

- affirms life and regards dying as a normal process;
- intends neither to hasten nor 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 patient's 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.

**Euthanasia** is a physician (or other person) intentionally killing a person by the administration of drugs, at that person's voluntary and competent request (EAPC, 2015).

**Physician assisted suicide** is a physician intentionally helping a person to terminate their life by providing drugs for self-administration, at that person's voluntary and competent request (EAPC 2015).

## References:

ANZSPM 2013 position statement euthanasia and assisted suicide

<http://www.anzspm.org.au/c/anzspm?a=da&did=1005077>

PCA position statement (last updated August 2016) voluntary euthanasia and assisted suicide

[http://palliativecare.org.au/wp-content/uploads/dlm\\_uploads/2015/08/20160823-Euthanasia-and-Physician-Assisted-Suicide-Final.pdf](http://palliativecare.org.au/wp-content/uploads/dlm_uploads/2015/08/20160823-Euthanasia-and-Physician-Assisted-Suicide-Final.pdf)

Krikorian, A. et al., (2012). Suffering and distress at the end-of-life. *Psycho-Oncology* 21 (8): 799-808.

Radbruch, L., et al., Euthanasia and physician-assisted suicide: A white paper from the European Association for Palliative Care. *Palliative Medicine*, 2015,

<http://www.eapcnet.eu/LinkClick.aspx?fileticket=28Vb6Oln9SQ%3D>

WHO 2002. Palliative Care Definition. World Health Organisation, Geneva. Viewed online 2/2/16

<http://www.who.int/cancer/palliative/definition/en/>