



Australian Medical Association (WA)

AMA (WA) Responses to Questions on Notice - Joint Select Committee on End of Life Choices

18 May 2018

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Questions arising from public hearing

1. *Can you provide the recordings of the speeches given by the international guests of the AMA(WA) Symposium as well as the recordings of the Skype interviews held with the Canadian and Dutch experts? Could also confirm whether these recordings will be provided as public evidence? (p 8)*

We have sent the recordings of those speeches and interviews as requested, and confirm they will be provided as public evidence.

2. *In your evidence you spoke of Professor Theo Boer and his indication of an increase in suicide in the Netherlands since euthanasia became accepted as a treatment. Could you please liaise with Professor Boer and provide the source of his statement? (p 9)*

Professor Boer has kindly supplied a copy of his 2017 paper published in the Journal of Ethics in Mental Health, titled *Does Euthanasia Have a Dampening Effect on Suicide Rates? Recent Experiences from the Netherlands*. Within this article are several illustrations of the increasing rates of suicide as the rates of euthanasia have increased, along with appropriate sources.

We have included this article in our response for your reference.

3. *Can you please confirm, to the best of your knowledge, if the same principles of informed consent apply for terminal sedation as with any other medical procedure? (pp 25-26)*

Terminal sedation is sedation designed to relieve extreme distress in a person who is imminently dying, usually the last hours or days of life. Sedation should be appropriately used for the control of specific symptoms once all other alternatives have been considered and found to be ineffective or inapplicable. The most common refractory symptoms requiring sedation are reported as delirium, which is acute confusion often characterized by agitation, and breathlessness.

The principles of informed consent apply to terminal sedation as with any medical intervention. However, given the context in which terminal sedation occurs, patients may not have capacity at the time that sedation is administered. For this reason the doctor-patient relationship, particularly ongoing, open communication with the patient and their family, is vitally important.

We refer you to the submission you received from **Palliative Care Western Australia**, which states:

"Palliative care respects informed patient choice with an emphasis on communication to understand the patient's wishes and values regarding medical treatment, in order to support them with decision making. This requires them to be informed about the potential benefits and side effects of any treatment. Ideally, the loved ones are also aware of these discussions. If the patient lacks capacity to make decisions regarding medical treatment, and no AHD is in place, then the person authorized by WA law would be involved in informed decision making."

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Consent, either implicit or explicit, is obtained before making any treatment changes, such as changing the route of administration of medications (e.g. from tablet to injection), not only those practices specifically mentioned in the questions. In addition, treatment recommendations are generally made by a multidisciplinary team (e.g. nurses, allied health), rather than an individual doctor.

The focus on communication, and respecting the patient's values and wishes, assists in maintaining trust between health professionals and patients."

The European Association for Palliative Care (EAPC) outline a recommended framework for the use of sedation in palliative care¹. With regards to specification of consent requirements, they state:

"In non-critical situations in the management of patients with decisional capacity, the aims, benefits and risks of the proposed sedation should be discussed including reference to the following:

- (1) *The patient's general condition including the cause of the intolerable distress, treatments that have been attempted, limitations of other options of care and, when relevant, limited anticipated survival.*
- (2) *The rationale for the decision that sedation is the only method available for achieving symptom relief within an acceptable time frame.*
- (3) *The aims of sedation.*
- (4) *The method of sedation, including the depth of planned sedation, patient monitoring, possibility of planned weaning (in some circumstances), with an option to discontinue sedation (in some circumstances).*
- (5) *The anticipated effects of sedation including degree of reduction in consciousness levels, estimated effects on mental activities, communication and oral intake.*
- (6) *The potential uncommon risks such as paradoxical agitation, delayed or inadequate relief, and the possibility of complications including hastened death.*
- (7) *Medical treatments and nursing care to be maintained during sedation: treatments and care to maximize patient comfort are continued and the patient's and their family's wishes are respected.*
- (8) *The expected outcomes if sedation is not performed including other treatment options, degree of suffering likely to persist with each option and expected survival with each option.*
- (9) *Commitment to the patient's wellbeing and provision of best possible care irrespective of patient treatment choices.*

With the permission of the patient, it is generally preferable to conduct this discussion with the participation of significant family members. This approach maximizes communication and often facilitates important meaning-related discussions between patients and their families while the opportunity still exists. The content and conclusions from the discussion should be documented in the patient's medical record. If the patient lacks decisional capacity and there is no advanced directive, permission needs to be obtained from a legally recognized proxy. The treating clinicians should emphasize that the role of the proxy or family is not to decide, but rather it is to indicate what the patient would have wanted and the reasoning that leads them to their conclusion. It should be

¹ Cherney NI and Radbruch L. European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care. *Palliative Medicine*. 2009;23(7):581-593.

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emphasized to the family that they are not being asked to make a decision, and that the professional care team takes the responsibility for the medical decision. (This section needs to be consistent with local regulations.)

In the care of terminally ill patients who have no advanced directive and no health-care proxy and who are in severe distress whilst actively dying, provision of comfort measures (including, if necessary, the use of sedation) is the ‘standard of care’ and should be the default strategy for clinician treatment decisions.”



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