ACN

Legal and Constitutional Affairs Legislation Committee
The Australian Senate
PO Box 6100
Parliament House
CANBERRA ACT 2600

Euthanasia.sen@aph.gov.au

To whom it may concern

Medical Services (Dying with Dignity) Exposure Draft Bill 2014

Australian College of Nursing (ACN) is pleased to submit comment on the Medical Services (Dying with Dignity) Bill 2014 Exposure Draft. ACN is a national professional organisation for nurses with members in all states and territories, health care settings and nursing specialties. ACN's membership includes many nurses in roles of influence, including senior nurses, organisational leaders, academics and researchers. ACN is also the Australian member of the International Council of Nurses headquartered in Geneva.

ACN consulted with its members about the proposed Bill. This consultation elicited many responses and ACN hopes that this submission provides valuable feedback to inform the review of the Bill.

Please do not hesitate to contact me for further discussion of ACN's submission. We look forward to the outcomes of this inquiry.

Yours sincerely

Adjunct Professor Debra Thoms FACN (DLF)
Chief Executive Officer

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Canberra
PO Box 219, Deakin West ACT 2600
freecall 1800 061 660 (*charges apply to mobile phones*)
t 02 6283 3400 | f 02 6282 3565

Sydney
Locked Bag 3030, Burwood NSW 1805
freecall 1800 265 534 (*charges apply to mobile phones*)
t 02 9745 7500 | f 02 9745 7501

www.acn.edu.au
Australian College of Nursing Ltd
ABN 48 154 924 642

ACN

Submission to the Senate Inquiry into the Medical Services (Dying with Dignity) Exposure Draft Bill 2014

Australian College of Nursing (ACN) is pleased to provide comment on the Medical Services (Dying with Dignity) Exposure Draft Bill 2014 (the proposed Bill). ACN consulted its members on the proposed Bill. Notwithstanding the divergent views on whether dying with dignity medical services should be made available or not, a number of issues for further consideration in the drafting of this Bill are raised below.

General Comments

Given that an object of the proposed Bill is "to recognise the right of a mentally competent adult who is suffering intolerably from a terminal illness to request a medical practitioner to provide medical services that allow the person to end his or her life peacefully, humanely and with dignity" (Section 3 (a)), ACN recommends that the proposed Bill provide greater detail and clearer definitions in a number of areas.

Whilst the proposed Bill relates to 'terminal illness' and provides a definition of such, adequate distinction is not made from a 'chronic condition' which may meet the definition of 'terminal illness' as provided in the draft Bill. The term 'extraordinary measures' included in the definition of 'terminal illness' also requires further clarification.

The proposed Bill does not make clear what constitutes a dying with dignity medical service and what services may be provided. Section 5 (1) defines dying with dignity medical services as "a medical service provided by a medical practitioner to a person to enable the person to end his or her life in a humane manner". The meaning of this definition is broad and may include a range of services. Further, the meaning of 'humane' is not defined and is open to subjective interpretation, as are the means by which the service is delivered. The proposed Bill further needs to clarify the context and environment in which the service is provided. For example, many people choose the setting in which they will die and these include residential aged care facilities, at home, acute or palliative care settings. The proposed Bill omits any reference to the setting or environment where dying with dignity medical services may be delivered and the requirements for dying with dignity medical services which may be specific to particular settings. Without precise definitions and clear boundaries on the type of service and measures of service quality, potential for great variability in services and quality exists.

Further, the proposed Bill relates only to medical practitioners yet health services are generally provided by multidisciplinary teams. The role of all health practitioners in the delivery of dying with dignity medical services should be considered in the drafting of a Dying with Dignity Bill.

Much work has been undertaken to develop and implement advance care directives for end-of-life care. The proposed Bill should be reviewed in the light of practices relating to advance care directives. Such a review should also explore the articulation between advance care directives and dying with dignity medical services.

Role of nurses

The proposed Bill stipulates the roles of three medical practitioners. ACN proposes that the Bill's requirements for a person to receive dying with dignity medical services should also include a role for nurses with expertise in palliative care or other relevant nursing specialties. Nurses bring a nursing perspective to peoples' experience of terminal illness that includes a deep familiarity with the phenomena of pain, discomfort, physical, mental and/or spiritual distress as well as indignity. Thus a nursing perspective contributes to a more comprehensive assessment of the pre-conditions the requesting person must meet to become eligible to receive dying with dignity medical services.

Section 12 (2) of the proposed Bill requires that in the case of the *first medical practitioner* not having special qualifications in the field of palliative care, the information on the availability of palliative care options to be provided to the person must be given by another medical practitioner who has such special qualifications. ACN proposes that a nurse practitioner with qualifications and experience in palliative care nursing is able to take on this specific role.

Many nurses experience caring for a terminally ill person as a special privilege, partially because the human bond forged between a dying patient and his/her nurse can be very strong. Thus any discussions by medical practitioners about a patient considering requesting dying with dignity medical services should also include the views of those nurses who are significantly involved in the terminally ill patient's care.

The care of terminally ill patients is usually delivered by multidisciplinary health care teams. Nurses are significant members of these teams providing 24 hour care. When caring for a terminally ill patient, it is a nurse's role to explore with the patient and his/her significant others the patient's wishes for end-of-life care and to provide information and counselling about options. ACN suggests that this role has not been given due consideration in the drafting of the Bill.

Further, any documentation verifying a person's decision to receive dying with dignity medical services should be accessible to nurses and indeed to all health care professionals involved in the care of the patient. Even though no legal obligation arises for nurses under the Exposure Draft Bill, nurses have a professional and moral obligation to protect their patients from harm. To this end, nurses will require assurance that a patient freely participated in a decision making process sufficient to come to the well-grounded conclusion that the patient wants to receive dying with dignity medical services. Access to verifying documentation will enable nurses to satisfy themselves that all pre-conditions under the proposed Bill have been met.

Access to services

Section 12 of the proposed Bill assumes that access to palliative care services is available throughout Australia. However, some rural and remote (as well as regional) communities do not have access to palliative care services. The proposed Bill assigns to the medical officers the role of education to terminally ill patients about palliative care options that may be unavailable to some communities.

In many geographical areas the medical workforce required to support the bill may be unavailable. The pre-conditions to providing dying with dignity medical services as set out in Section 12 require that the requesting patient be assessed by three medical practitioners. One of these doctors is required to have special expertise in palliative care, another must be a psychiatrist. The supply shortage of medical practitioners in rural and remote Australia may prevent persons in rural and remote areas from accessing dying with dignity medical services. However, relative to medical practitioners, nurses are often in better supply in rural and remote areas. ACN suggests that palliative care nurse practitioners may improve access to dying with dignity services by taking on the roles as suggested under the heading *Role of nurses*.

Further, palliative care medical specialists and psychiatrists are often employed by health services covering large geographical areas. Whilst the stipulation that the three medical officers must not be employed by the same employer aims to safeguard against institutionally driven dying with dignity medical services, this safeguard may also reduce access for people with a terminal illness. This situation may arise where health services cover large geographical regions or metropolitan areas with a high population density.

The proposed Bill requires a medical practitioner to keep "a note of any oral request of the person for such services" as stipulated in section 19 (a). This requirement restricts access for those patients who do not have capacity to make an oral request. For example, patients suffering from motor neurone disease may be unable to communicate an oral request to their medical practitioner to receive dying with dignity medical services as required under Section 19 (a). Further, the proposed Bill should identify how and how often the person's request for dying with dignity medical services should be verified and updated.

Conscientious objection

Section 11 (2) makes provision for the medical practitioner to "refuse to provide dying with dignity medical services to the person for any reason and at any time". ACN strongly believes that the proposed Bill should also protect nurses' right to conscientious objection if nurses do not want to be involved in any way in the delivery of care associated with dying with dignity medical services.

Conscientious objection by medical officers and other members of a person's multidisciplinary health care team may result in a person being denied access to dying with dignity medical services. The proposed Bill should make provisions for alternative access to dying with dignity medical services for patients whose health care professionals deny this access by refusing to participate.

Infrastructure supports

Enactment of the proposed Bill requires institutional level supports to ensure that health care professionals are confident in their roles and obligations under the proposed Bill. Such supports would need to target the educational needs of health care professionals and the general public. Education for health care professionals should address the specific information needs of multidisciplinary team members in the provision of dying with dignity medical services.

Strong clinical governance structures and processes and clinical leadership will also be required to support implementation of such a Bill.

Further, in ACN's view it will be necessary for health care services to have structures in place that ensure staff can discuss and receive advice on any clinical, legal, moral or religious concerns about the proposed Bill's implementation and continued enactment.

Protection of vulnerable groups

ACN does not believe that the proposed Bill includes adequate protection for groups vulnerable to involuntary receipt of dying with dignity medical services. For example, some frail aged people or people with severe physical disabilities who are terminally ill may be vulnerable to being bullied into and/or being persuaded to receive dying with dignity medical services they do not want. Such a situation may arise, for example, if such an individual aligns his/her wishes with that of a powerful family member. The three assessing doctors may find it difficult to identify that the terminally ill patient's wish for dying with dignity medical services arises out of the patient aligning his/her wish with that of another person.

Concluding comments 16105

ACN recommends that a review of the Exposure Draft Bill gives much greater consideration to the details contained within the Bill as well as the Bill's implications for health care professionals and for the community. In ACN's view the Draft Exposure Bill would benefit from further, extensive consultation with health care professionals and the community.