

Navigating the complexities of voluntary assisted dying in palliative care

Voluntary assisted dying is not part of palliative care

The *Voluntary Assisted Dying Act 2017 (Vic)*¹ came into effect in Victoria on 19 June 2019. We present the case of an inpatient death under the voluntary assisted dying Act in our health service and describe a short case history followed by a discussion examining two relevant topics related to voluntary assisted dying and palliative care: conscientious objection and the complexity of palliative care involvement.

Case report

The patient was diagnosed with metastatic (axillary nodes) breast cancer in 2016 at the age of 53 years and declined completion staging and all conventional treatment options. She was referred to community palliative care services in 2019 with clinically progressive locoregional disease, manifesting as fungating malignant disease of the chest wall and axilla. She experienced symptoms of pain, nausea, anorexia, and weight loss. Pharmacological treatment options for her symptoms were refused due to her sensitivities to many medications. The patient lived alone but had support from friends and siblings. She had a history of chronic fatigue syndrome and mood disorder. She did not subscribe to a religion, but believed in the soul and an afterlife. She had been caring for her mother, who died from advanced breast cancer. Her mother's suffering at the end of her life was a significant reason for the patient's decision to pursue voluntary assisted dying. She commenced the voluntary assisted dying process in July 2019.

Her initial intention was to self-administer the voluntary assisted dying substances at her home on her birthday (early December). However, she was admitted to the palliative care unit (PCU) in late November for symptom management. During her admission, it became clear to the patient and her carer (who was also her voluntary assisted dying support person) that her deterioration would preclude her from returning home. She made a request to self-administer the voluntary assisted dying substances in the PCU. The organisational voluntary assisted dying clinical practice guidelines stated that voluntary assisted dying could not occur in the PCU, in line with the Royal Australasian College of Physicians (RACP) statement on voluntary assisted dying, which recommended that "voluntary assisted dying must not be seen as part of palliative care".² The patient was informed of the organisational approach and the need to minimise misperceptions about the PCU. Both the patient and her support person understood and accepted our stance, and we commenced the search for another site within the service that could accommodate her wishes.



Staff in the first venue of care option conscientiously objected to the admission. Despite her condition continuing to deteriorate and the imminence of her preferred date of administration, she remained understanding. Another venue of care within the service was found and she was transferred there 2 days before her birthday. She self-administered the voluntary assisted dying substance on her birthday as originally intended.

Conscientious objection

Although not defined in the Act, conscientious objection has been outlined by the Victorian Department of Health and Human Services (DHHS) as an outcome of a conflict in beliefs or values.³ A similar conflict was recently discussed in relation to a growing concern about moral injury in health care, where moral injury was defined as "perpetrating, failing to prevent, bearing witness to, or learning about acts that transgress deeply held moral beliefs and expectations".⁴ Health care professionals are subject to moral injury as a result of "being unable to provide high-quality care and healing in the context of health care".⁵ In this context, conscientious objection becomes integral to the psychological safety of the health care workforce as voluntary assisted dying is introduced into mainstream medicine.

The DHHS in Victoria permitted each health service within its jurisdiction to decide on their extent of involvement in voluntary assisted dying.⁴ This was determined by "whether participation aligns with the values of the health service".⁶ The Catholic Health and Aged Care Services, which are responsible for several health services across Victoria, were clear that they would not provide or facilitate voluntary assisted dying.⁷ Such health services are under no obligation to refer a patient who has requested voluntary assisted dying. However, there is a requirement to inform the patient as soon as practicable that they will not

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assist them and the services cannot actively inhibit the patient's access to treatment.³ All health services were obliged to nominate their level of participation, irrespective of the actual number of health care professionals in the organisation willing to be involved with voluntary assisted dying.³ These choices were:

- pathway A — single service (it has the necessary suite of services and staff with sufficient expertise to provide voluntary assisted dying within their existing health service);
- pathway B — partnership service (these services would require the assistance of other services to provide the full requirement of voluntary assisted dying); and
- pathway C — information and support service (it includes services electing not to provide voluntary assisted dying).

The dilemma of this approach for health care services is the contentious nature of voluntary assisted dying. Organisations consist of people some of whose individual values and beliefs are unlikely to align neatly under the organisational approach when it comes to voluntary assisted dying.

The Voluntary Assisted Dying Act (Part 1, Section 7) outlines scenarios where registered health care practitioners may conscientiously object to participation in the voluntary assisted dying process.¹ It provides for health care staff to refuse to participate in, or be present for, the administration of the voluntary assisted dying substance. The DHHS has provided clear guidelines for individual health care practitioners with regards to conscientious objection.³ A health practitioner "has the right to refuse to assist or support the patient when the assistance is associated with voluntary assisted dying". Health practitioners are expected to "provide routine and other care unrelated to a request for voluntary assisted dying".³ Health practitioners also need to balance their own moral and ethical beliefs while respecting differences and ensuring the rights of the patient are upheld. Therefore, health services face the challenge of navigating between the principle of justice and equity in access to health care and the responsibilities to their employees. Health practitioners cannot conscientiously object to the routine care of a patient who has elected to undertake voluntary assisted dying.

Palliative care

The specialty of palliative care is in its infancy, having only received recognition in Australasia as a specialty in 1998. It aims to improve the quality of life of patients and caregivers, faced with life-limiting illness, by addressing physical, psychosocial and spiritual challenges. There is mounting evidence that it is indeed effective in doing so.⁸ Nevertheless, population-based studies demonstrate a public misperception associating palliative care with euthanasia.⁹ The International Association for

Hospice and Palliative Care has stated that assisted dying in all its forms corrodes the work done by the specialty and risks patients refusing palliative care for fear that health practitioners may hasten their death.¹⁰ There is a continuing need to increase public awareness of palliative care and clarify misperceptions. Therefore, palliative care services need to maintain their differentiation from voluntary assisted dying. The RACP emphasises that voluntary assisted dying "must not be seen as part of palliative care" and that they need to be seen as "distinct practices".² Peak palliative care organisations, such as Palliative Care Australia and the Australia and New Zealand Society of Palliative Medicine, similarly emphasise that voluntary assisted dying is not part of palliative care practice.^{11,12} The International Association for Hospice and Palliative Care has recommended that assisted dying practices not take place in PCUs.¹⁰ The risk otherwise is further blurring of the public perception and an erosion of trust.

The RACP has recommended that all patients seeking voluntary assisted dying should be made aware of palliative care and that a referral to palliative care is strongly recommended.² The Victorian DHHS, in its voluntary assisted dying documentation, has also outlined a key role for palliative care. This includes "managing complex communication interactions with patients and families, and responding to complicated, multifaceted psychosocial and/or spiritual distress".³ Furthermore, they describe the most "valuable [role] palliative care specialists play is supporting other healthcare teams and professionals through consultation, advice and support to provide end-of-life care for their patients".³

The challenges for palliative care services are therefore clearly visible: how to maintain its distinction and separation from voluntary assisted dying and yet provide a necessary and expected service for patients at the end of life who have elected voluntary assisted dying. The RACP and the DHHS guidelines will necessitate palliative care involvement, not only for our patients and their families but also in support of medical practitioners. Palliative care services risk becoming the gatekeepers for voluntary assisted dying because of our expertise in managing complex communication and discussions around death and dying. In addition, there is the risk of further burdening already stretched palliative care services, with education, counselling and support of fellow health service staff, in matters relating to voluntary assisted dying. It is important to note that the voluntary assisted dying legislation does not provide extra resources to services to support their health care staff.

Nevertheless, specialist palliative care services can help patients who elect voluntary assisted dying, as they are well placed to provide specialist support within clear boundaries of engagement. This can include optimal symptom management as well as psychosocial and spiritual support. The RACP, the Australia and New Zealand Society of Palliative Medicine and Palliative Care Australia have all

emphasised the need for greater access and resourcing for specialist palliative care. Our concern echoes that of the Catholic Health and Aged Care Services that we cannot, at this time, be distracted by the diversion of limited palliative care resources to voluntary assisted dying and lose focus on the need to ensure adequate and timely access to palliative care across Victoria and Australia.⁷ The perception of specialist palliative care services in cases where voluntary assisted dying has been requested will remain problematic. Collaboration with families and treating teams is essential and should involve the recognition of specialist palliative care involvement separate from voluntary assisted dying. The challenge remains to

educate the public and health care professionals about palliative care and how it differs from voluntary assisted dying, amidst a new background of mixed messages. Regardless of the end-of-life choice made, holistic care and good communication skills are not solely related to our specialty, these are skills that can be, and need to be, routine for all areas of medicine.

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