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Advising Voluntary Assisted Dying Patients About the Option of Organ Donation: Ethical and Practical Considerations

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ABSTRACT

Voluntary assisted dying (VAD) provides a pathway to organ donation distinct from typical pathways requiring withdrawal of cardiorespiratory support. Patients considering VAD now have the option to be donors and benefit others through donation and transplantation. This is not widely known in the community. In this article, we consider the ethical issues in advising VAD patients about the option of organ donation. We balance patient autonomy against the risks of coercion and conflict of interest. All eligible patients should be advised about the option so they can make an informed decision. However, the timing and source of information are critical in ensuring that patients can make a well-considered, ethically sound choice. We propose a pathway for provision of information about organ donation for patients considering VAD.

JEL Classification: Palliative care, Social determinants of health

1 | Introduction

Historically, people dying from progressive fatal conditions did not die in clinical circumstances that permitted solid organ donation. Voluntary assisted dying (VAD) now enables donation for patients without a medical contraindication, which is about 20% of VAD patients in Australia [1, 2]. Donation after VAD is legal in Australia [3] and more than a dozen such donations have occurred to date.

At the time of writing, VAD is legal in every Australian state and the Australian Capital Territory. While not currently legal in the Northern Territory, VAD legislation is under consideration. As VAD becomes established as an end-of-life option, questions arise about providing information about organ donation to patients pursuing VAD. Options range from only responding to patient-initiated requests to mandating notification of eligible patients [4]. We consider decision making about donation after VAD. Should information be provided and by whom? As a group comprising VAD practitioners, a donation doctor and an ethicist, we recommend ethically sound practices regarding how and when information is provided.

2 | Decision-Making About Donation After VAD

2.1 | Organ Donation as Part of End-of-Life Care

Organ donation is a choice in end-of-life care. For terminal patients in the intensive care unit, organ donation is a routine consideration at end-of-life. Like other considerations (e.g., the arrival of a remote relative), it may influence timing of death.

Similarly, VAD donation affects the circumstances of death. Except in rare cases [5, 6], donation requires death to occur in hospital with intravenous administration of the VAD substance. Patients must understand these implications and weigh the benefits and burdens as with other end-of-life decisions impacting how death occurs.

2.2 | Autonomy

Decisional vulnerability occurs where a person feels internal or societal pressure to die due to a perception that they are a burden [7]. Altruism and perceived social desirability of organ donation may influence the VAD decision [8]. We acknowledge that patients will be influenced by societal norms, but this influence is not necessarily coercive. Society can view donation positively and simultaneously respect the rights of people to not be donors. In the authors' experience, many donation-eligible VAD patients decline organ donation even when aware of it, indicating that it is possible to make distinct decisions about the two processes.

Death is proximate for patients pursuing VAD. Only its manner, not its inevitability, may be altered. Patients can balance the consequences of their decision, and there is no evidence that social norms compromise their decision-making. It would be equally deleterious to autonomy to withhold the option of donation after VAD, thus violating the autonomy of people for whom donation may be a meaningful part of end-of-life care. The ethical task is designing processes to protect the interests of patients seeking VAD while ensuring they are informed of all end-of-life options, including organ donation.

2.3 | Minimising Coercive Influences

Of greatest concern is the risk of entanglement of the VAD decision and the donation decision. A common concern is that donation might be perceived as the reason to seek VAD. However, eligibility criteria for VAD are set by law—most notably, intolerable suffering in the context of an advanced progressive disease—and are entirely independent of the altruistic wish to donate.

Preserving decisional autonomy in the face of these potential internal and external pressures has certain requirements. Patients must understand that their decision to pursue either VAD or donation can be withdrawn at any time. The VAD decision is revisited and reaffirmed throughout the process. Similarly, the donation decision should be revisited, without forcing patients to repeatedly justify their choices.

Patients should understand that donation and transplantation frequently do not proceed after initiation and should not feel that changing their mind would burden staff. Knowing that a specific individual might receive or miss out on a transplant depending on the patient's decision adds a coercive influence, potentially leading a person to progress with VAD (for the purpose of donation) where otherwise they might not. Therefore, directed donation, wherein a specific person or group is identified as the recipient, should not be offered [4, 8]. In directed donation, the proposed recipient may well be a friend or family member of the patient, creating a strong potential for coercive influence.

Providing generic information about which organs are likely to be donated may be important to the individual, although some counsel against this approach [8]. No specifics should be shared about the intended recipients.

3 | Providing Information to VAD Patients About Organ Donation: Ethical Considerations

Ensuring patients are fully informed of their end-of-life options upholds the principle of autonomy. VAD patients make multiple end-of-life choices such as mode and location of substance administration, who will be present and religious rituals. Awareness of the possibility of donation enables the patient to make a similarly informed choice. Providing this information affirms their right to self-determination [9] and fulfils the principle of justice [7]. Some patients will have prior knowledge of donation whereas others will not. A standardised approach ensures equity; to do otherwise ‘only respects the autonomy of those who are well informed’ [9].

Uniquely in donation after VAD, patients are aware of their impending donation and can derive meaning from their passing [10]. First-person donation consent by a VAD patient represents autonomy more than that provided by substitute decision-makers in most other donations, where patients are unresponsive [8]. Importantly, withholding this option risks denying people an opportunity that might align with their values.

Beyond patients, there are considerations relating to families and staff. Families might experience regret or anger if they later become aware that donation was possible [11, 12]. This will likely be intensified if the patient had expressed a wish to donate, such as through a donation registry. Regarding staff, conscientious objectors should not be required to be involved with VAD donors.

4 | Providing Information to VAD Patients About Organ Donation: Practical Considerations

4.1 | How Should Donation Information be Provided to VAD Patients?

Generic information should be available through brochures or online to all patients considering VAD. This could be through information on the relevant jurisdiction's VAD website. Consistent publicly available information supports equitable access and can outline how donation might affect end-of-life. Broad self-screening criteria (age criteria; impending death due to a non-malignant condition or primary brain tumour) will clarify suitability for many.

Individualised information should follow, with timing and methods that avoid conflicts of interest. VAD practitioners and donation coordinators have distinct roles when communicating with patients. VAD practitioners guide the VAD process and should not be expected to discuss organ donation in detail.

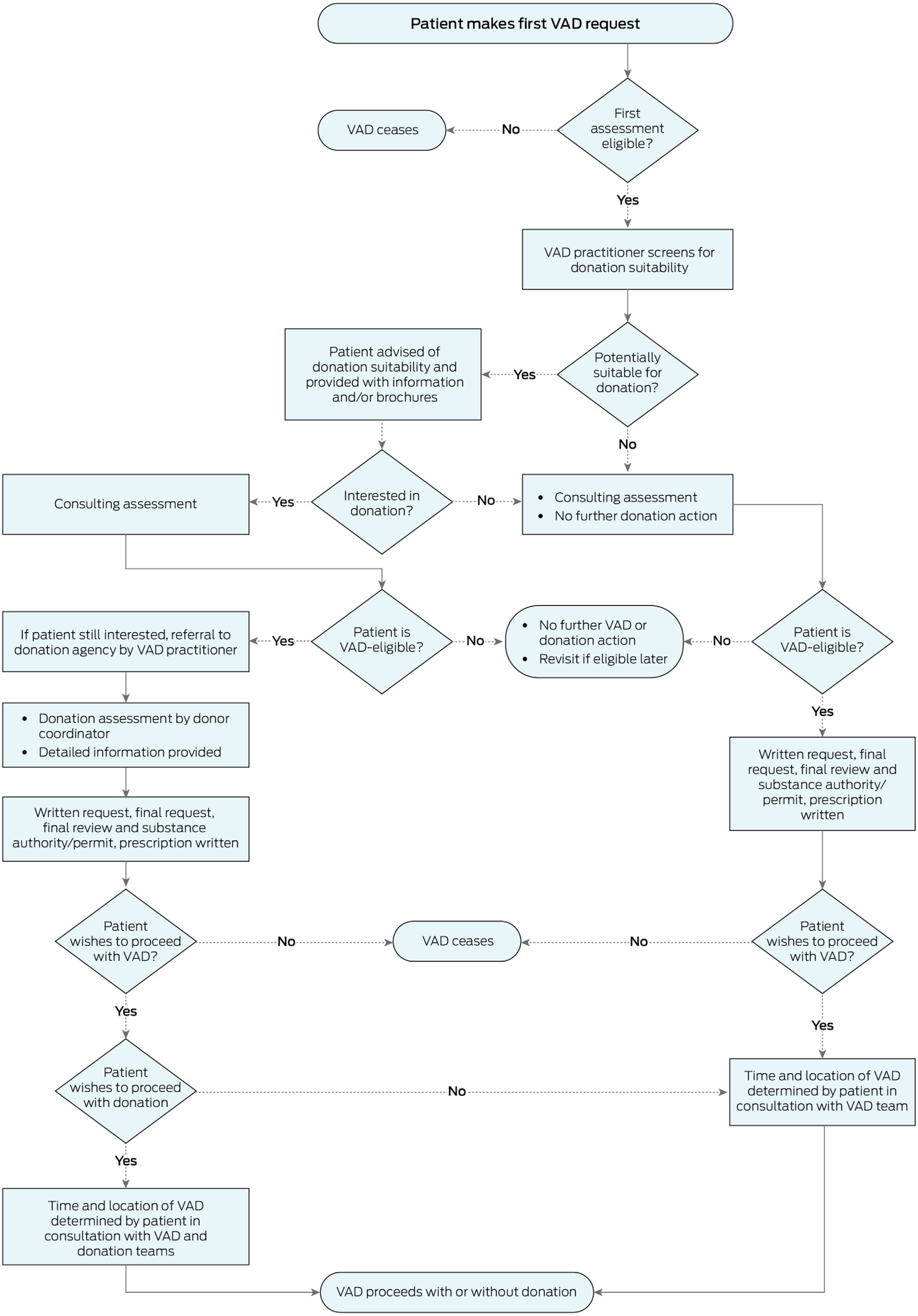

FIGURE 1 | A pathway for ethically sound provision of information for organ donation after voluntary assisted dying (VAD).

However, the VAD practitioner is the first point of contact for the patient and has the ability to perform initial broad medical screening, identify donation as a possibility and refer the patient to the donation agency where appropriate. The VAD practitioner is key in ensuring that the patient makes autonomous decisions about VAD and donation.

Donation coordinators, while skilled in end-of-life care and the technical aspects of donation, might be perceived as having a conflict of interest in the VAD context [13] and should only be involved after eligibility for VAD is confirmed by the consulting assessment [14].

In the currently typical donation scenario for a patient in the intensive care unit (ICU), organ donation is raised by the donor coordinator once the patient is deemed to be on an end-of-life pathway. Before that, the patient's family has no contact with the donation agency. In the VAD context, the analogous moment is the point at which a patient is deemed to be on a VAD pathway; that is, after assessment by a second VAD practitioner. Before that, there should not be any interaction between the patient themselves and the donation agency.

Although donation coordinators should only contact patients after VAD eligibility is confirmed, VAD practitioners should feel free to confidentially discuss individual patient suitability with the donation agency at any stage of the VAD process. This will help avoid unnecessary donation discussions for patients who are unsuitable. Similarly, ICU doctors may discuss potential donors with donation agencies before family discussion to avoid raising donation unnecessarily for patients who are medically unsuitable.

In the interest of justice, regional patients must not be disadvantaged. VAD practitioners and patients are geographically dispersed, but donor coordinators are clustered near larger hospitals. Outreach donation services are required.

4.2 | When Should Information be Provided?

Information should be provided stepwise as patients progress through VAD assessment. VAD practitioners should screen for donation suitability. VAD patients who are dying of cancer, unless it is a primary brain tumour, generally cannot donate. Where a patient is dying of a non-malignant condition or a brain tumour, the VAD practitioner should inform them of the option to consider donation.

VAD practitioners will require some training in raising donation as a discussion topic with patients. An opening statement could be an enquiry about whether a patient is registered on the Australian Organ Donor Register, recognising that many people who support donation are not registered. A negative response should not constitute the end of the donation discussion.

The option of donation is best raised when patients are considering end-of-life choices (e.g., time and location of death), often early in the VAD process. Patients should have the opportunity to discuss donation before making a VAD substance administration decision.

If a patient raises donation spontaneously the VAD practitioner may provide a preliminary view on suitability and how donation would impact the end-of-life process. Further discussion should be deferred until after the patient's eligibility for VAD has been confirmed by the consulting practitioner. Only then should the VAD practitioner refer the patient to the donation agency. A pathway for ethically sound provision of information is presented in Figure 1.

5 | Recommendations

- All patients pursuing VAD should have access to information about the option of organ donation.
- VAD practitioners should raise the possibility of donation with potential donors after preliminary screening to allow patients to consider it in their end-of-life plan. More specific questions other than location of death and method of administration should be deferred until VAD eligibility has been confirmed.
- VAD practitioners require training on the donation process and medical suitability.
- Donation coordinators should only be involved after a patient has been assessed as eligible for VAD by two independent practitioners (e.g., after consulting assessment).
- Patients who have consented to donation should receive reiterated advice that it is their choice to withdraw from VAD or donation at any stage.
- Directed donation and provision of specific recipient details are discouraged.

Author Contributions

All authors contributed to conceptualisation, writing the original draft and writing, reviewing and editing.

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Conflicts of Interest

Leo Nunnink is fractionally employed as the medical director for a state organ donation agency in a position that is partly funded by the federal Organ and Tissue Authority.

Data Availability Statement

This article includes no original data.

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