VOLUNTARY ASSISTED DYING: REFLECTIONS FROM FIVE YEARS ON

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HLEN Seminar October 8, 2024

Professor Ben White
ARC Future Fellowship
Enhancing End-of-Life Decision-Making: Optimal Regulation of Voluntary Assisted Dying

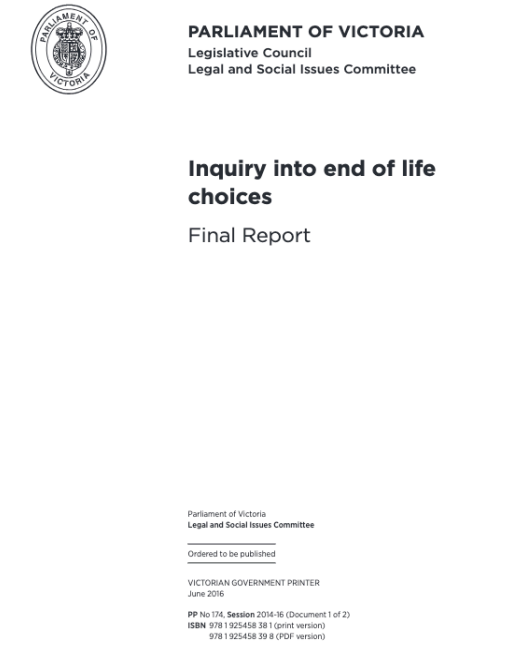
https://research.qut.edu.au/voluntary-assisted-dying-regulation/

Overview

- History of Victorian VAD laws
- **Summary** of Victorian Framework and who is accessing it
- **Overview** of some evidence and recent developments

Timeline

1. Parliamentary Committee Inquiry into End of Life Choices, which recommended, *inter alia*, that Victoria introduce VAD legislation
2. Ministerial Advisory Panel was appointed to provide advice to the government about an appropriate legislative framework
3. A VAD bill was introduced into parliament
4. Bill passed on 29th November 2017
5. Act took effect on the 19th June 2019


PARLIAMENT OF VICTORIA
Legislative Council
Legal and Social Issues Committee

Inquiry into end of life choices

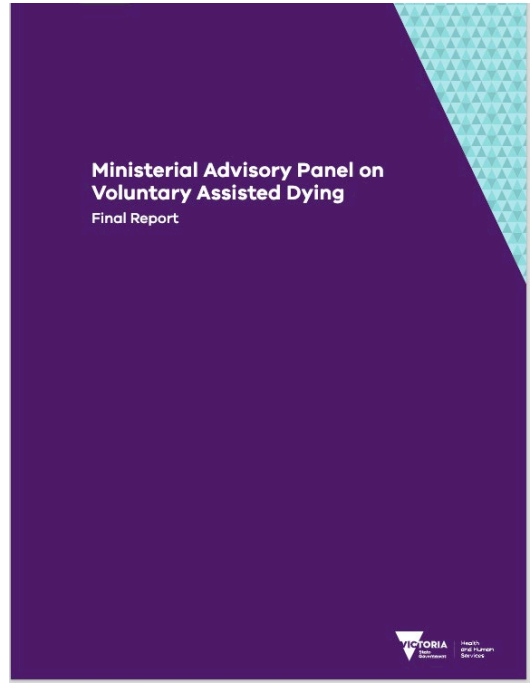
Final Report

Parliament of Victoria
Legal and Social Issues Committee

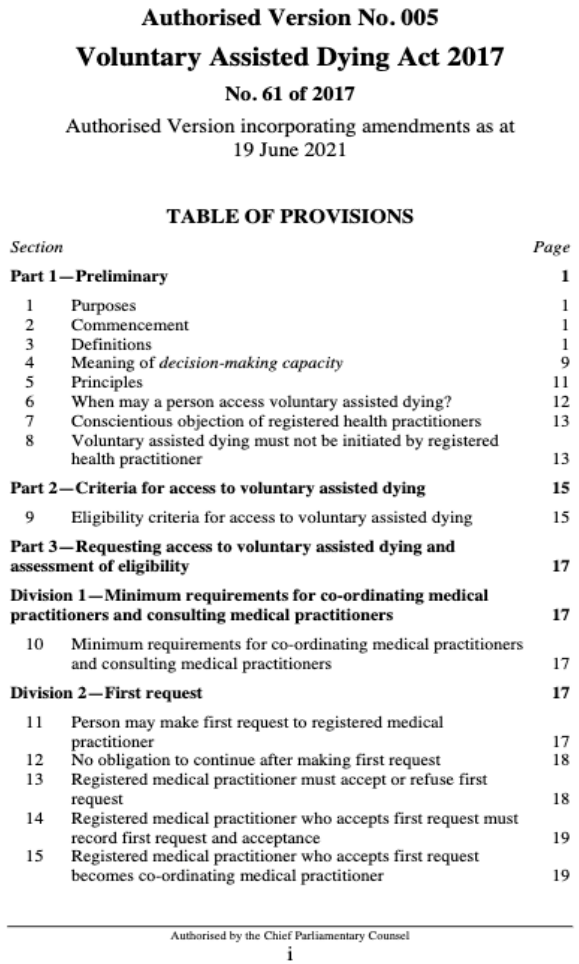
Ordered to be published

VICTORIAN GOVERNMENT PRINTER
June 2016

PP No 174, Session 2014-16 (Document 1 of 2)
ISBN 978 1 925458 38 1 (print version)
978 1 925458 39 8 (PDF version)



Voluntary Assisted Dying Act 2017 (Vic)



Authorised Version No. 005

Voluntary Assisted Dying Act 2017

No. 61 of 2017

Authorised Version incorporating amendments as at 19 June 2021

TABLE OF PROVISIONS

Authorised by the Chief Parliamentary Counsel

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- 1st Australian state to introduce VAD laws*
- 68 safeguards
- Implementation period of 18 months

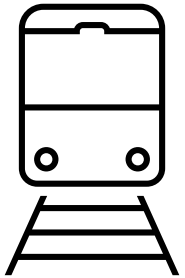
*This will be the **safest scheme** in the world, with the most rigorous checks and balances.*

*This is about **compassion and choice** and giving Victorians the support and care they deserve in their final moments.*

Daniel Andrews (Former Premier of Victoria)

* *Rights of the Terminally Ill Act* (NT) was briefly in effect, before being nullified by the *Euthanasia Act 1997* (Cth) [subsequently repealed by the *Restoring Territory Rights Act 2022* (Cth)]

Victoria was the trailblazer and others followed



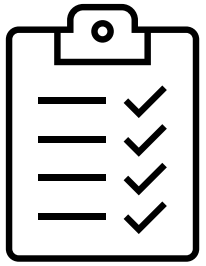
Jurisdiction	Year passed	Date came into effect (or expected to)
Western Australia	2019	July 2021
Tasmania	2021	October 2022
Queensland	2021	January 2023
South Australia	2021	January 2023
New South Wales	2022	November 2023
Australian Capital Territory	2024	November 2025
Northern Territory	Independent Expert Advisory Panel in the Northern Territory handed down its Report in 2024	

Victoria was first and we've avoided a few pitfall that they've had.

We benefitted so much from Victoria being so open and so willing to share their experience and their advice and their resources

(Haining et al., 2023, JLM)

Eligibility criteria



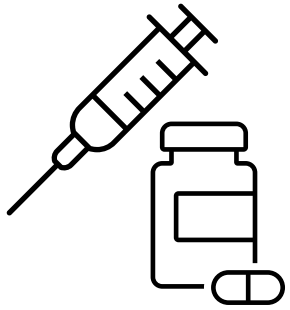
To be eligible the person must:

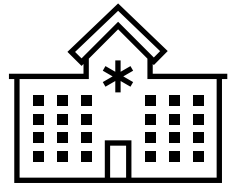
- be an adult
- be an Australian citizen or permanent resident
- at the time of making a first request have been ordinarily resident in Victoria for 12 months
- have decision-making capacity in relation to VAD
- be diagnosed with a disease, illness or medical condition that is:
  - incurable
  - advanced, progressive and will cause death within 6 months (or 12 months if neurodegenerative)
  - causing suffering that cannot be relieved in a manner that the person considers tolerable.

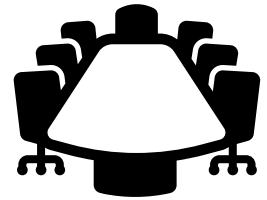
The person must also be acting voluntarily and without coercion and must have an enduring request.

The person must be assessed by at least **two suitably qualified medical practitioners**, one of whom must have "have relevant expertise and experience in the disease, illness or medical condition": **s 10(3).**

- Default of self-administration, unless the person is physically incapable of self-administration or digestion of the substance
- VAD permit must be issued by the **Secretary**
- One centralized pharmacy **Statewide Pharmacy Service**
- Supported by a **Statewide Care Navigator Service**
    - Metropolitan service and regional navigators
    - Institutional equivalents
- Monitoring provided by **Voluntary Assisted Dying Review Board**, supported by a **Secretariat** that manages the VAD-IMS
- **Community of practice**







Overview of the process

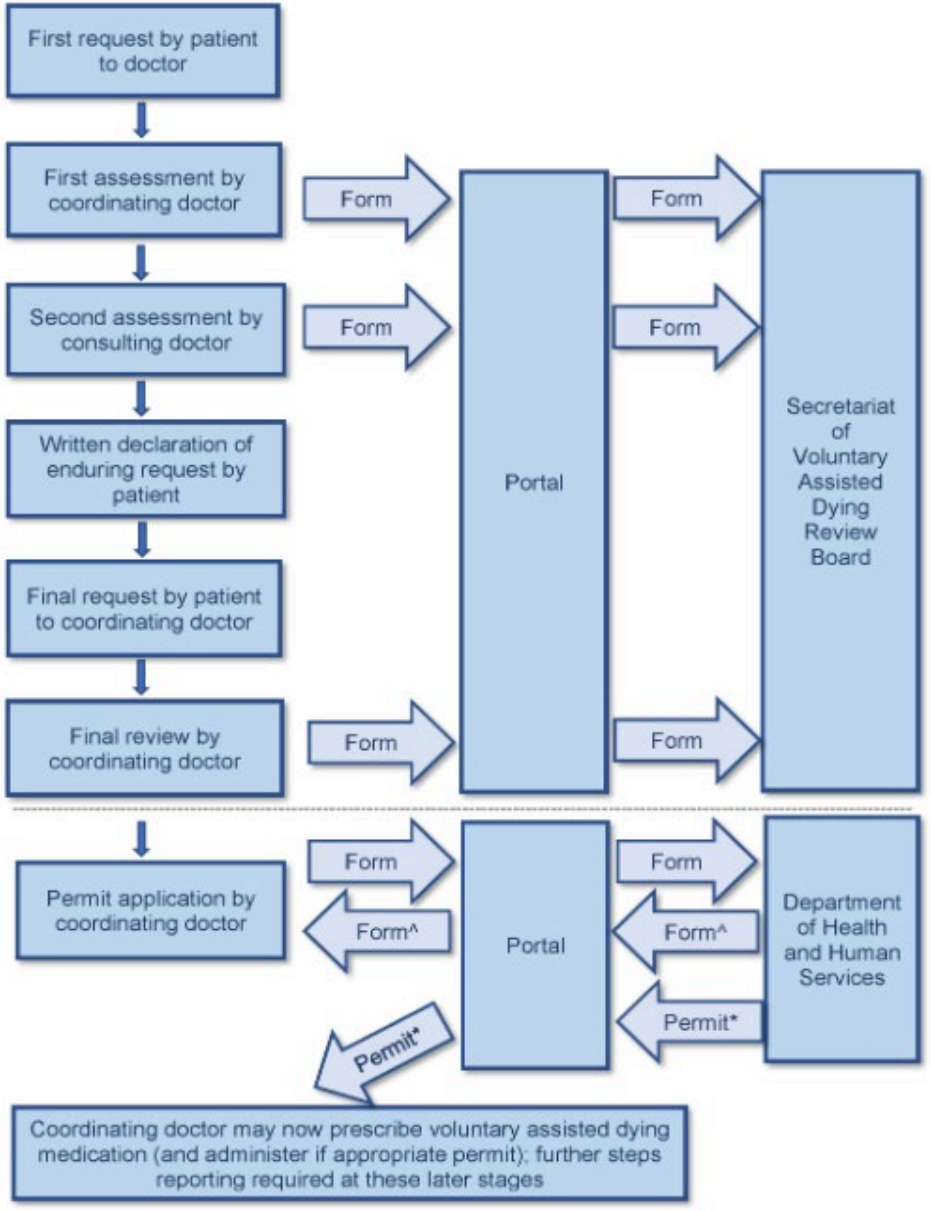


Figure 1 Overview of Victorian prospective oversight and approval process. ^ The nature of an application for a permit contemplates that it may not be approved or may be returned to a doctor for clarification or further information before resubmission. *If satisfied with the application form, a permit will be issued. A permit may authorise only one type of AD, namely self-administration or practitioner administration. AD, assisted dying.

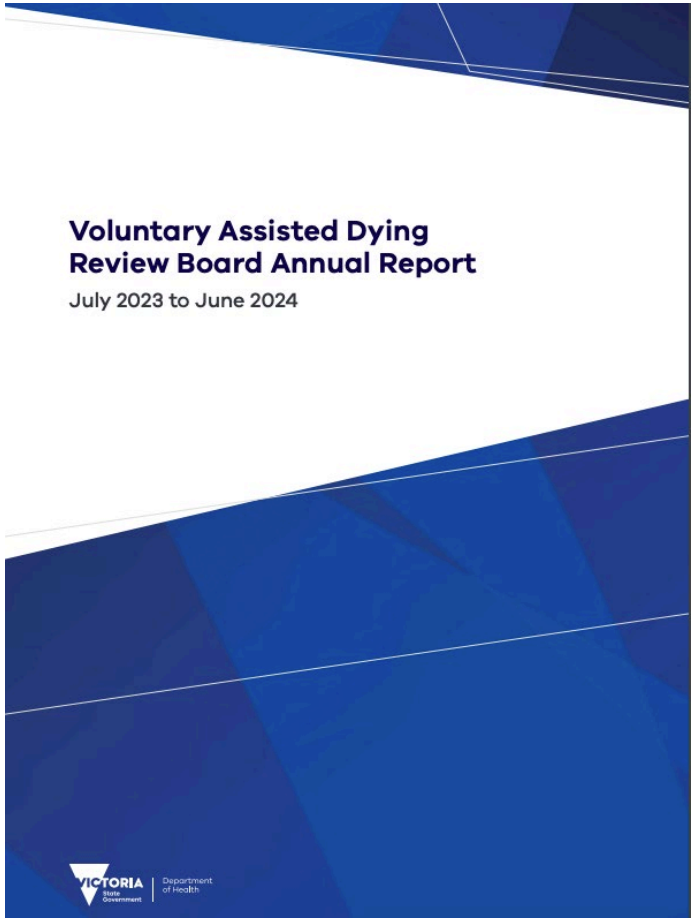
(White et al. 2021) BMJ Supportive and Palliative Care

Other features

- Doctors must complete legislatively mandated training
- No health practitioner is able to raise VAD with a patient
- Individual conscientious objection is protected
- Legislation is silent on institutional participation
- Provision is limited to medical practitioners

Who is accessing VAD?

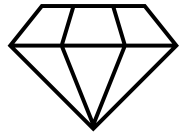
- 1,282 VAD deaths (since 2019), 371 deaths in 2023-2024
  - 80% of applicants applying for VAD have access or are currently being cared for by a palliative care service.
- Since inception 318 practitioners have been involved in at least one case as either the coordinating or consulting practitioner.
  - Mostly general practitioners, followed by oncology
  - 59% metro; 41% regional



Reflecting on the evidence from 5 years on

Based on the experience of the first five years, the Board is satisfied that the objective of safety has been achieved through the Voluntary Assisted Dying Act 2017 **(VADRB 2023-2024, Foreword)**

Key strengths are the people



Statewide pharmacy

*The two pharmacists that came down were just **beautiful humans**. They were friendly, they were kind, they were – went through everything, any questions that anyone had answered freely. They were amazing, I have nothing but absolute praise for them*

Medical practitioners

*I think once Mum raised it with the oncologist, the doctor that we dealt with was amazing. He made then the next steps just all come together. He was the coordinator and he was very **compassionate** and available*

Care Navigators (and institutional equivalents)

*Then obviously the care navigator, which is the first port of call, they were fantastic … I keep going on about that word **compassion and care** … They made a very difficult situation more manageable*

(White et al., 2023, MJA)

Dearth of providers

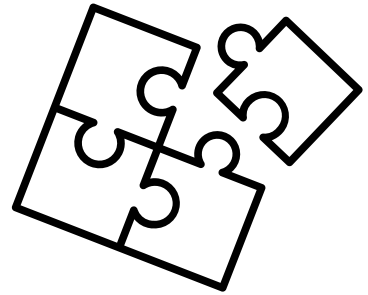
- Concerns have been raised about the ability for current workforce to meet demands
- Limited specialist providers makes provision difficult, particularly for those living regionally

We are concerned about the ongoing sustainability of the program given that the data shows there are only seven medical practitioners trained to provide voluntary assisted dying per 100,000 adults in Victoria. **(VADRB 2023-2024, p. 6)**

Ten doctors with the highest case load over this period either co-ordinated or consulted on 55% of all cases in this 12-month period. Four of these practitioners have been involved in over 50 applications each (of a total 768 applications started) this reporting year. **(VADRB 2023-2024, p. 6)**

Exacerbating matters is the workload involved and lack of support and remuneration: **(Haining et al. 2022, MJA)**

Connecting with the system



- Community awareness about VAD remains patchy
- Finding a point of access to the VAD system is challenging
- Raising VAD is challenging

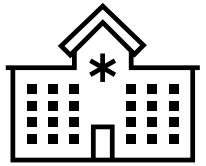
... for someone as educated as her it was ... a bit difficult to navigate. So we reflected on how difficult it must be for people who don't have PhDs and don't have first language as English is challenging

... we couldn't work out how to find the actual specific information, who was the person that you needed to talk to, to get the specifics of what you had to do or how you had to go about it ... it's hard to find the information. ... it probably took two to three months of research to get this document [government VAD brochure] ...

I remember him being nervous ... it was a big thing for him to bring that up with his doctor. Like that's not an easy conversation to have. And he had a really good relationship with his doctor who was ... easy to chat with, but ... he still found that stressful

(White et al., 2023, Health Expectations)

Institutional objection



- Claimed on religious and secular grounds
- Not all institutions are transparent about their position **(Close et al., 2023, JBI).**

Impacts include:

- Delays, transfers and forced choices between progressing an assisted death application and receiving palliative or other care.
- Adverse emotional experiences and distrust

It will always be a great sadness for me that the last few precious hours on Mum's last day were mostly filled with stress and distress, having to scurry around moving her out of her so-called "home".

They said "Well, actually we can't do it on hospital grounds." So Dad [said], "Well, okay, push me out to the carpark and I'll do it there." **(White et al., 2023, BMC Medical Ethics).**

Objection is not binary

CO in the context of VAD has been found to exist across a spectrum **(Haining & Keogh 2021, BMC Med Ethics)**

> *I'd like to change the word "conscientious objector" in the next legislation because I think it's quite a negative word. When I say people are conscientious objectors, I'm cringing inside because they're still sympathetic to the whole process*. **(Haining et al., JBI, Accepted 2024)**

Similar observations can be made in the context of IO

> *It's very enculturated at [Institution X] that you hold the patient at the centre. And that's different to some of the other [institutions] who've struggled a bit and got themselves into a bit of argy-bargy*. **(Haining et al., JBI, Accepted 2024)**

Approaches to objection

Institutional participation

- Qld, ACT, NSW, SA have all introduced provisions pertaining to institutional participation.
  - Example: Queensland : *Voluntary Assisted Dying Act 2021* (Qld) Pt 6, division 2
    - No entity (or their staff) are obliged to participate in the VAD request, assessment or administration process, but obligations exist.
      - Disclose whether they provide VAD services and permit information provision
      - Further obligations exist but vary depending on whether in a non-residential or residential setting (also permanent resident cf. non-permanent resident)

Conscientious objection

- Provide some form of information about VAD (e.g. prescribed information, details about Navigation Service/Commission)

Prohibition of Telehealth

- *Commonwealth Criminal Code Act 1995: ss* 474.29A and 474.29B
  - Using a carriage service for suicide related material.
  - Possessing, controlling, producing, supplying or obtaining suicide related material for use through a carriage service.

"All discussions, consultations and assessments with patients, family and carers regarding [VAD] must occur face-to-face"

(DoH Guidance for Health Practitioners, p.74).

For doctrinal analysis see: **(Del Villar et al., 2022, Monash LR)**

Impacts of the Commonwealth Criminal Code

If I was able to use telehealth, I could get this done in 40 minutes, but instead, I've got to drive two hours, see the patient, drive two hours back.

[My patient] was in a wheelchair coming in her jammies and her dressing gown because she was too sore and too tired to get dressed, but had to come in person to have another consultation.

By the time I managed to get a meeting with the pharmacist … [my patient] was now on a syringe driver and semi-comatose and no longer eligible.

(Willmott et al., 2022, MJA, Supplementary Material)

Federal Court Decision and Response

FEDERAL COURT OF AUSTRALIA

Carr v Attorney-General (Cth) [2023] FCA 1500

File number(s):	VID 428 of 2022
Judgment of:	**ABRAHAM J**
Date of judgment:	30 November 2023

The term "suicide", as used in ss 474.29A and 474.29B of the *Criminal Code Act 1995* (Cth), **does apply** to the ending of a person's life in accordance with, and by the means authorised by, the *Voluntary Assisted Dying Act 2017* (Vic) and *Voluntary Assisted Dying Regulations 2018* (Vic).

MP Kate Chaney launches bid to overturn ban on accessing assisted dying appointments via telehealth

Exclusive: Teal MP to introduce bill exempting voluntary assisted dying appointments from criminal code

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- Get our morning and afternoon news emails, free app or daily news podcast

Criminal Code Amendment (Telecommunications Offences for Suicide Related Material—Exception for Lawful Voluntary Assisted Dying) Bill 2024

Type	Private
Sponsor(s)	CHANEY, Kate, MP
Originating house	House of Representatives
Status	Not Proceeding
Parliament no	47

Evidence of non-compliance

Medical Board of Australia v Carr (Review and Regulation) [2023] VCAT 945 (14 August 2023)

Last Updated: 15 August 2023

VICTORIAN CIVIL AND ADMINISTRATIVE TRIBUNAL

ADMINISTRATIVE DIVISION

REVIEW AND REGULATION LIST VCAT REFERENCE NO. Z232/2022

Facts:

Patient failed to sign the written declaration

Dr got the patient to sign the document in absence of witnesses and backdated the document.

Finding:

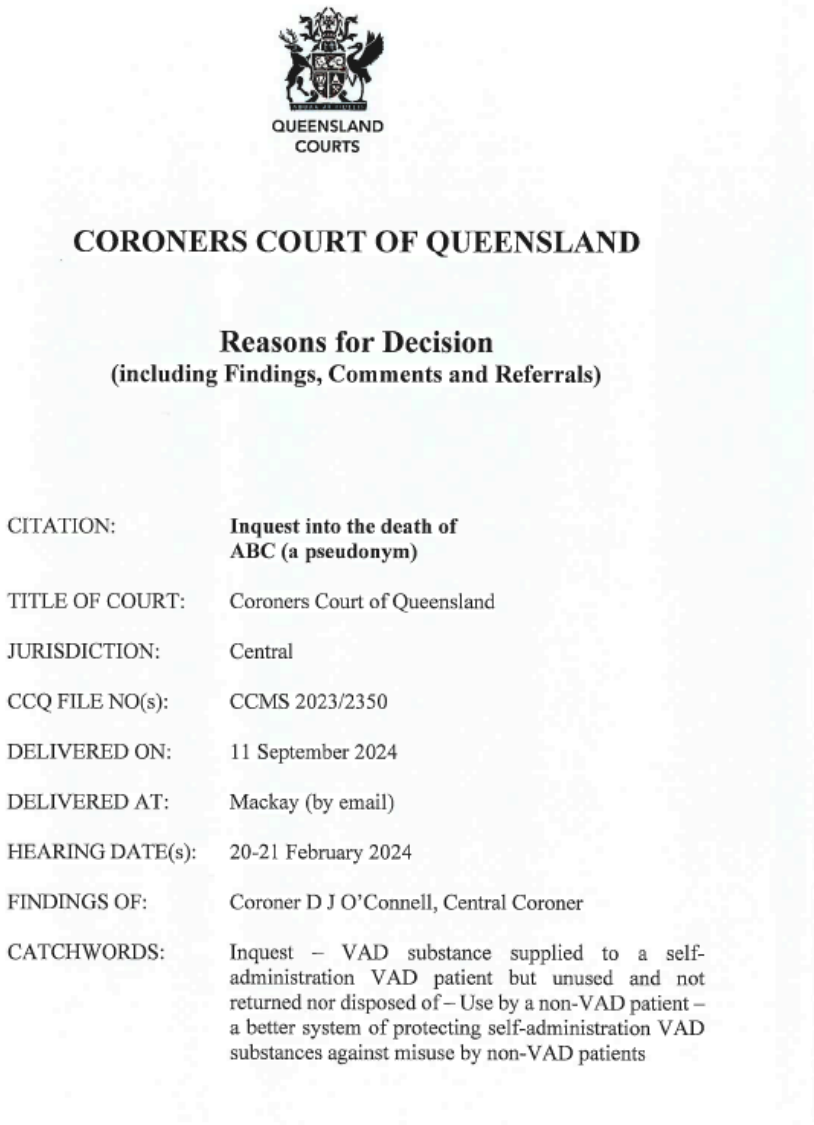
Professional misconduct; $12,000 fine

Compliance with all these requirements is vital, not only to protect the rights of patients, but also **to ensure that public confidence in the VAD process is not eroded** [24]

The task of completing documentation for a VAD process carries the **highest level of professional responsibility** [26]

In making determinations the tribunal emphasised both **general and specific deterrence** are to be considered [41].

Evidence of misuse



QUEENSLAND COURTS

CORONERS COURT OF QUEENSLAND

Reasons for Decision
(including Findings, Comments and Referrals)

CITATION:	**Inquest into the death of ABC (a pseudonym)**
TITLE OF COURT:	Coroners Court of Queensland
JURISDICTION:	Central
CCQ FILE NO(s):	CCMS 2023/2350
DELIVERED ON:	11 September 2024
DELIVERED AT:	Mackay (by email)
HEARING DATE(s):	20-21 February 2024
FINDINGS OF:	Coroner D J O'Connell, Central Coroner
CATCHWORDS:	Inquest – VAD substance supplied to a self-administration VAD patient but unused and not returned nor disposed of – Use by a non-VAD patient – a better system of protecting self-administration VAD substances against misuse by non-VAD patients

The implemented VAD oral self-administration laws unfortunately overwhelmingly favoured **patient autonomy** and this has led to an outcome which has caused very significant distress to the family and a life has been unnecessarily lost, which loss was, in my respectful opinion, avoidable if appropriate considerations for lethal medication safety had been implemented. [57]

Review of the Victorian VAD Act

The Minister must cause a *review of the operation of [the] Act* to be conducted: **s 116(1)**

Media Release

The Hon Mary-Anne Thomas MP
Leader of the House
Minister for Health
Minister for Health Infrastructure
Minister for Medical Research

VICTORIA State Government

Monday, 31 July 2023

VOLUNTARY ASSISTED DYING REVIEW BEGINS

The legally required review of the first four years of the nation's first voluntary assisted dying law has now begun, with a final report due by the end of 2024.

The review will not consider any changes to the legislation.

It will instead evaluate the systems, processes and practices which underpin the operation of the *Voluntary Assisted Dying Act* including safeguards and protections, equity of access, the Voluntary Assisted Dying Review Board's role and functions and the Department of Health-commissioned Statewide Pharmacy and Care Navigator services.

Those engaged in voluntary assisted dying, including doctors and families, will take part in a consultation process to gauge how voluntary assisted dying is operating since its introduction.

The review will be conducted by the Centre for Evaluation and Research Evidence and will apply recognised methods, practices and ethical guidelines throughout the evaluation process.

Since its introduction in June 2019, the voluntary assisted dying law has given eligible Victorians a dignified and compassionate choice at the end of their life, giving them the support and care they deserve in their final moments.

Victoria has led the way on voluntary assisted dying laws, with the *Voluntary Assisted Dying Act* coming into effect in 2019. In the years since, all other states have followed our lead.

Only Victorian adults who have an incurable, advanced and progressive medical condition and who have decision-making capacity can access voluntary assisted dying.

Once the review concludes in 2024, the final report will be tabled in both Houses of Parliament.

For more information on voluntary assisted dying visit health.vic.gov.au/patient-care/voluntary-assisted-dying

Quotes attributable to Minister for Minister for Health Mary-Anne Thomas

"We've led the way in voluntary assisted dying access in Australia, and our voluntary assisted dying law continues to give Victorians a compassionate option at the end of their life."

"By speaking with those involved in voluntary assisted dying, this operational review will allow us to look at how the law has been implemented and consider ways to make the existing system work even better for those who need it."

Thank you and questions