



# Voluntary assisted dying can be hard to access but system supports can help



## What is this research about?

Victoria was the first Australian state to permit voluntary assisted dying (VAD). The law sets out a detailed and rigorous process that people must go through to seek VAD. This ensures only people who meet the eligibility criteria can access VAD, but it can also make the system complex. In this Australian-first study, we explored patient experiences of seeking VAD.



## What did we do?

We interviewed 32 family caregivers and one patient about the experience of 28 patients seeking VAD in Victoria. We investigated the factors that helped patients when seeking access and factors that made it harder.



## What did we find?

**Five factors made the process of accessing VAD hard**

1. Patients and families found it difficult to find doctors who were willing and qualified to assess a person's eligibility for VAD.

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**[The referring doctor] must have written to several dozen neurologists over several weeks ... Many never answered, others responded to say that they were objectors and others just said they were unavailable.**

2. The steps in the VAD application process can take a long time and sometimes there were delays. This was especially hard for very sick patients whose illness meant they had very little time left.

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**[T]he whole process, every day just seemed like a month and every other appointment just seemed like another hurdle to jump over and another hoop to go through and another boulder to climb to get to the top of the mountain.**

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**The GP noted that it would probably be a race to see which came first: approval for and implementation of VAD, or an unassisted death alone.**

3. Telehealth cannot be used for VAD consultations. This caused pain, distress and hardship for some patients who had to travel to appointments, sometimes over great distances.
4. Some hospitals, aged care facilities, and other healthcare institutions objected to VAD. Often, patients could not be assessed for VAD in these facilities, nor receive or take the VAD medication there.
5. Doctors are not legally allowed to raise the topic of VAD. Patients needed to know that they had to ask about VAD first.

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**For a whole raft of reasons, including health literacy and communication ... it's a real problem with the Victorian legislation.**

These barriers meant that patients were sometimes unsure about how to seek VAD and where to go for more information. These barriers also caused suffering for patients and families, and led to delays in accessing VAD. Access was more difficult for people in regional areas or with neurodegenerative conditions.

**Four factors helped patients access their choice of VAD**

1. The Statewide VAD Care Navigators (health professionals funded by the government to help patients navigate the VAD system) were invaluable, as were VAD coordinators in hospitals or health services. Their guidance was especially helpful when patients were starting the VAD process and were not sure of the required steps.

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**They were fantastic ... I keep going on about that word compassion and care ... They made a very difficult situation more manageable.**

**The jewel in the crown.**

2. Finding a supportive doctor willing and qualified to assess eligibility for VAD was often a turning point for patients. But sometimes finding this doctor depended on luck.

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**[If] we hadn't had a doctor of that commitment ... and skill I'm not sure what would have happened.**

3. The Statewide Pharmacy Service's education and support, when providing the VAD medication, was very reassuring for patients and families.

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**Just beautiful humans. They went through everything, any questions that anyone had answered freely. They were amazing, I have nothing but absolute praise for them.**

4. Aside from some logistical challenges in the VAD system's early days, once patients made contact with the system – through a willing doctor or a VAD Care Navigator – they felt well supported through the process.

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### **It was like a coordinated team working together ... We could just sit back and it happened all around us.**

These factors helped patients and families to navigate a complex and rigorous VAD assessment process and to feel more supported and confident when doing so. Interview participants repeatedly commended the commitment and compassion of the doctors, navigators, and pharmacists involved in the VAD system.



### **What should happen next?**

- 1. Improve access to VAD:** Although the system has improved over time, continued work is needed to support access to VAD for those who want this choice. This includes better information being more widely available to enable patients to make earlier initial contact with the VAD system, e.g. via VAD Care Navigators. Improving access for people in regional areas and with neurodegenerative conditions should be a priority.
- 2. Increase pool of doctors:** Measures are needed to increase the pool of doctors willing and qualified to be involved in VAD, and retain those doctors already participating. This includes support to undertake the required VAD training and adequate remuneration.
- 3. Doctors must refer on:** To address the problem of not being able to find a doctor, the Victorian VAD law should require doctors who will not provide VAD to refer patients to a willing doctor, or provide the VAD Care Navigators' contact details.
- 4. Remove specific barriers:** Law reform is needed to allow doctors to raise VAD when appropriate and use telehealth. Law should also ensure patient access to VAD is not blocked by objecting institutions (government policy can help with this too).
- 5. Adequately resource system supports:** Because system functionality depends on VAD Care Navigators and the Statewide Pharmacy Service, sufficient resourcing and support for these roles is critical.

### **For more information**

This research briefing is based on Ben P White, Ruthie Jeanneret, Eliana Close and Lindy Willmott, "Access to voluntary assisted dying in Victoria: a qualitative study of family caregivers' perceptions of barriers and facilitators" *Medical Journal of Australia* 2023; 219: 211-217. More information about study limitations, research ethics and disclosures are available in the article: <https://doi.org/10.5694/mja2.52004>.

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