

- Points I think I omitted

Amahl, my partner was 36 when he died. We were living in Randwick at the time where Amahl was treated by staff at Prince of Wales Hospital and Sacred Heart Hospice.

Amahl did not ask to be euthanised, to my great relief, but he was passionate about it being his right.

After our excellent nurse had strongly advocated with the head of palliative care for us to receive immediate treatment for breathlessness for Amahl, she was taken off our case because she was “too upset” about it. It was demoralising.

- Elder Abuse?

I wanted to back up the statement made by Dr David Leaf in response to the question about the possibility of coercion and elderly abuse.

If I was malicious and wanted to end my Amahl’s life myself, I agree that there would be no need what-so-ever to undergo the process of coercing him into applying for VAD and then to coerce him to undertake it. That is, a VAD would have no impact at all on this possibility.

Amahl was so vulnerable because he could not speak or eat himself, he could only twitch his index finger. He was 100% dependent on his ventilator and on me to survive. I did have sedatives in the house, but all I really would have had to do is neglect him. Just not hold up his head or leave him lying down on the bed rather than sitting up, or even put the slightest pressure on his chest. I spent every minute working to make sure none of these things happened so that he didn’t die accidentally.

However, The Royal Commission into Aged Care Quality and Safety has demonstrated that over 30% of elderly in residential aged care facilities are neglected (including Christian organisations) thereby having their life shortened. Not least, “chemical restraint” as a practice is used frequently in such facilities and is currently legal. I can’t see any way that the introduction of the VAD bill would impact this neglect.

- An impossible law to navigate

I don’t think I should have been put in a situation where I was, in order to care for the person I loved, expected to navigate a law that is impossible to understand, where the stakes of getting it wrong were possibly my partner undergoing a horrible death, or me going to jail. I don’t think I should have been thinking about possible guardianship for my daughter when I should have been able to just do what Amahl wanted and then grieve for him.

- Dealing with terminal illness

I believe that people usually don’t know what their level of tolerance of suffering is until they are faced with it. It quite possibly is more than they thought. From my experiences with Amahl, I think the best way of navigating terminal illness would be to just “see how it goes”. The problem with that, is the current law doesn’t give the person any confidence that this strategy won’t leave them powerless and vulnerable and wanting to die. I believe that VAD would help people to live longer with terminal illness and I’m confident that the data will show this in the future. Then the people who advocated against VAD will have to reconcile with their conscience with the fact that they were advocating for the shortening life and not the preservation of it.