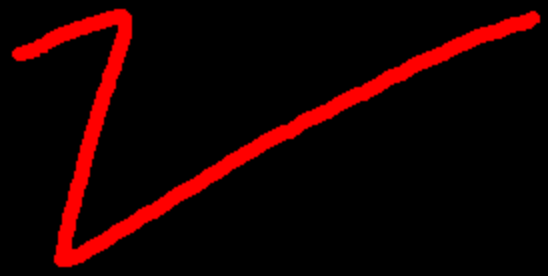
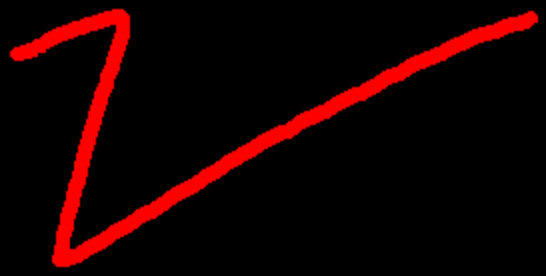


Personal reflections of a VAD academic turned VAD practitioner

Dr Charles Douglas PhD JD FRACS

Clinical Director of Voluntary Assisted Dying, HNE LHD

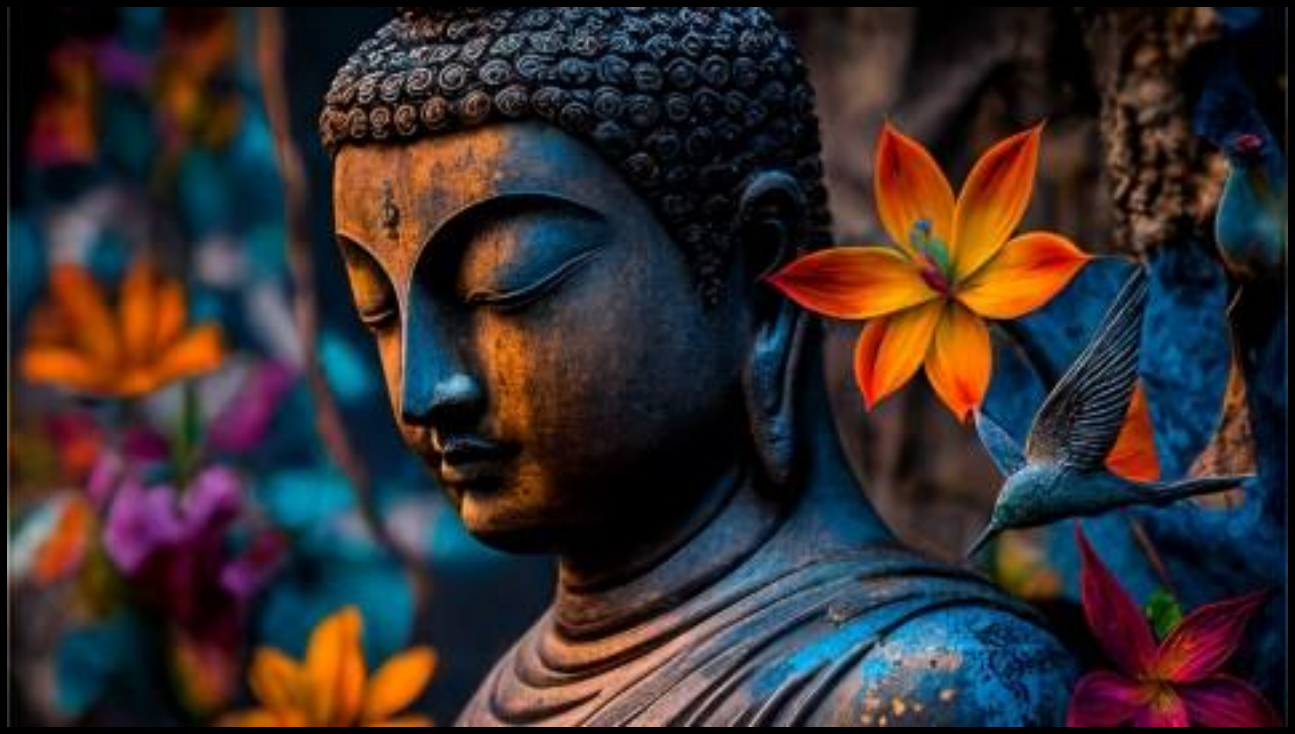
Cancer surgeon, ‘ethicist’, ‘lawyer’

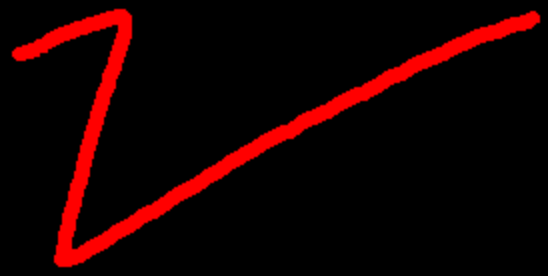


My PhD (1997-2012)

- *End Of Life Decision-Making And Moral Psychology: Intending, Foreseeing, Killing And Letting Die*

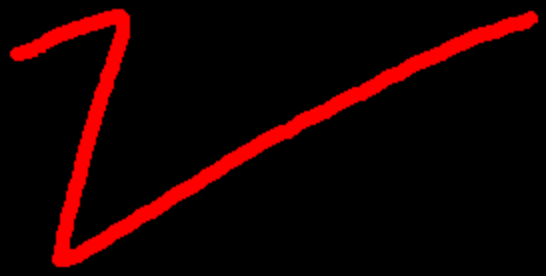
My position up to 2023





What happened?

- With NSW legislation about to come into force in 6 weeks, I saw a position as Clinical Director of VAD advertised for our Local Health District…and (on paper) I was ridiculously well-qualified
  - Clinician involved with end-of-life care
  - PhD on VAD
  - Newly acquired law degree…
- (Would I have to kill people myself? Yes…)
- So…not a zealot



"Fresh insights…

- *…on challenges old and new"*

- A caveat – my research was qualitative and quantitative, and as far as possible rigorous. These 'fresh insights' on VAD are mostly anecdotal
- They are also NSW-centric

Is (legal) VAD a good thing?

- Yes
- The benefits FAR outweigh the harms IMHO
  - At least, under the current legislative regime
  - As far as we can know at this point

Some common themes of the pre-permissive era

- "Sustained desire for euthanasia is rare"
  - NSW: over 1% of all deaths occur by VAD
  - Roughly twice as many get substance approval
  - Lots more ineligible or don't get through the process
  - So….maybe a sustained desire for euthanasia used to be rare because we kept saying no…

Some common themes of the pre-permissive era

- "Desire for euthanasia is generally a cry for help"
  - Definitely true in some cases – more attention, more love, better analgesia is sometimes what a person wants when they start talking about VAD
  - But for most (at least in the referred population, at least by the time they see me) a desire for euthanasia is a desire for euthanasia and it is patronizing to suggest otherwise

Some common themes of the pre-permissive era

- "Legislation will make euthanasia a bureaucratic nightmare"
  - I thought this – and reading the Victorian legislation in about 2016 did not make me feel reassured
  - But kudos to NSW where the median time from first request to substance authorization is 12 days AND
    - Patients only have to sign one or two forms
    - Doctors do most of the 'paperwork' online and are well remunerated for it

NSW Voluntary Assisted Dying Clinical Practice Handbook

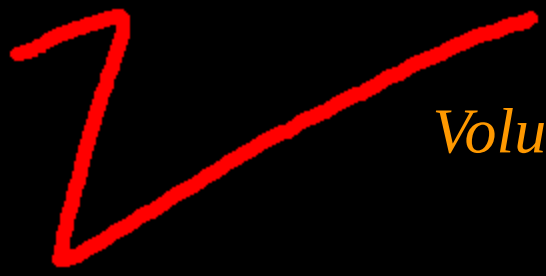
Version 2.0

Some common themes of the pre-permissive era

- (From opponents) “We need to encourage patients to enjoy the time they have left with their families rather than [bail out or whatever]”
  - Well…hold that thought

Some common themes of the pre-permissive era

- People want VAD because
  - "They have intolerable pain and suffering that generally [can or can't] be relieved by palliative care"
  - "They want 'control'"
- Both explanations are too simple, but legislators have certainly leaned into the pain and suffering:



Voluntary Assisted Dying Act 2022 No 17 (NSW)

16 Eligibility criteria

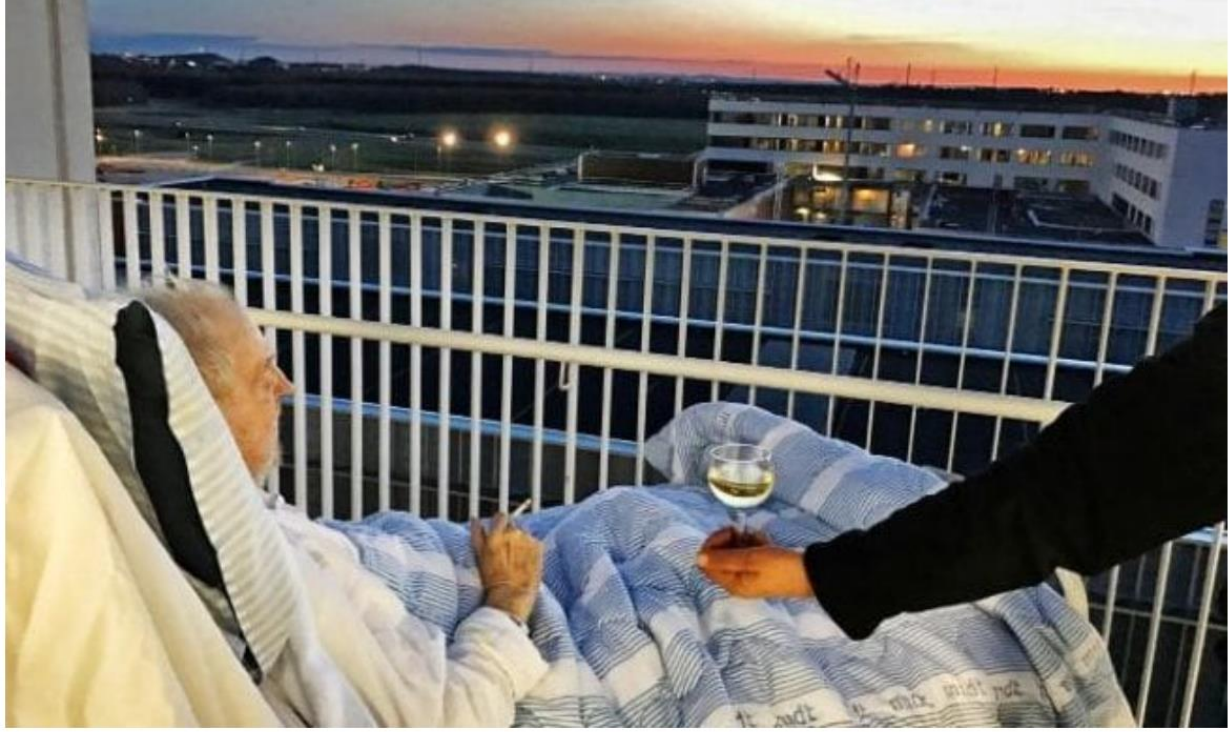
d) the person is diagnosed with at least 1 disease, illness or medical condition that—

(iii) is causing suffering to the person that cannot be relieved in a way the person considers tolerable

- A lawyer in the audience:
  - "Is section 16 d) (iii) a subjective or an objective test?"
- Me:
  - "Section 16 d) (iii) is bullshit"
  - I will never ask a person to justify their choice of VAD on the basis of "intolerable suffering" because I don't believe that that is what VAD is about for all - or even the majority of patients

How effective is palliative care?

- I developed a great deal of respect for palliative care professionals during my research years
  - They do a lot more than treat pain and shortness of breath and run morphine / midazolam infusions
- However, I think those in the palliative care world would almost unanimously accept that there are horrible deaths where their power to ameliorate is limited
- And now…I can see routinely the evidence that [in the words of one of my palliative care respondents]: “there aren’t a lot of great ways to die”



Carsten Flemming Hansen enjoys a final glass of wine and a cigarette while viewing the sunset. CREDIT: AARHUS UNIVERSITY HOSPITAL

By Adam Boult

10 APRIL 2017 • 2:53PM

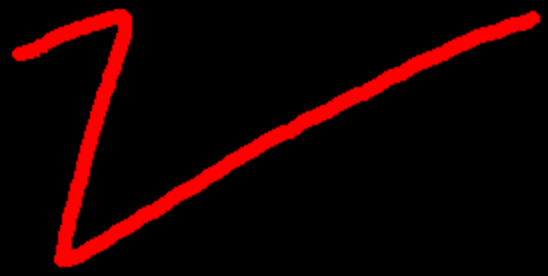
A hospital in Denmark has released a photograph of a patient fulfilling his dying wish - enjoying a cigarette and a glass of white wine while viewing the sunset from a hospital balcony.

Carsten Flemming Hansen, 75, was admitted to Aarhus University Hospital last week suffering from a ruptured aortic aneurysm.

Learning that he was too ill to undergo surgery, and would die within days, if not hours, from internal bleeding, Mr Hansen told his nurse Rikke Kvist of his wish.

So why DO people choose VAD?

1. There is a group of people who are in so much discomfort that they literally cannot wait to die – they will drink the VAD substance before the pharmacists have got back to their car – those who truly have intolerable suffering.
2. There are those who are miserable, elderly, infirm, who have chronic pain, depression, personality disorders. Most of these are ineligible (and at least some, as I said before, are crying out for more love and attention).
3. This leaves what I think is the largest group: Those with a terminal illness who are not yet suffering intolerably, but who want to die a dignified death BEFORE they vomit blood or faecies, or choke or suffocate, or become incontinent or lose capacity.



The living wake

- A proper goodbye
- Often a party
- A lot of laughter (more often than not!)
- MORE quality time with loved ones than a ‘natural’ death can provide

Does ‘slow euthanasia’ happen (in the guise of palliative sedation)?

- When I was a researcher my answer to this was “it’s complicated”
- There is absolutely no doubt in my mind that this was a ‘grey’ area before VAD was legalized
- *It remains a grey area* because patients who ‘leave it late’ to request VAD often lose capacity during the assessment and approval process, and then cannot legally proceed with VAD under the legislative framework
- Most of these patients end up on a ‘SCIP’ (subcutaneous infusion pump) of morphine and midazolam
- Is there more incentive than ever to run these infusions at a ‘generous’ rate (now that the prohibition against euthanasia has been lifted)?
- At least one doctor told me (when I asked him for a prognosis assessment) that he would have preferred to euthanize the patient slowly

Is there a "morally relevant difference" …

- …between killing and letting die…?
- …or between intending and foreseeing death (as envisaged by the principle of double effect in some cases of terminal sedation)?
- I (still) believe so, although I am a consequentialist. Agency matters.

- *End-of-life decisions and moral psychology: Killing, letting die, intention and foresight*
  - *Journal of Bioethical Inquiry 6 (3):337-347 (2009)*

It is a grave responsibility to give an injection that takes a life

- We use the euphemism ‘administration’…
- But…

It is a grave responsibility to give an injection that takes a life

- When I assess patients for VAD, it *usually* (but not always) strikes me that these are patients who are *dying*.
- They really are choosing VAD because they are running out of good options, and as such…
- I *feel* that VAD (under the current legislative framework) reasonably sits within end-of-life care, and is reasonably an extension of what I do otherwise as a doctor
- Who will do the killing of
  - Demented patients who don't want to be killed, but whose advance directive (from their pre-demented self) demands that they must?
  - The mentally ill?
  - The chronically ill?
  - Anyone who wants to be killed?