HRG Meeting Notes
End of Life Policy Reform Salon
12 Feb 2025

# Meeting Summary

This HRG salon explored the policy challenges and opportunities for end-of-life care from two distinct perspectives: The Care of the Frail Elderly; and Voluntary Assisted Dying.

### 1. Care of the Frail, Elderly Terminally Ill

Prof Ken Hillman led a discussion on the “Conveyor Belt” for terminally ill older people. He highlighted the inefficiencies and inhumanities associated with how the Australian healthcare system provides care to the frail elderly, and in particular, those with multiple chronic conditions, often resulting in both too much and/or too little care being offered. The origins of the dysfunction are two-fold: operational pressures interfering with the system’s capacity to properly understand the needs and desires of the frail elderly; and, the structural fragmentation of specialist clinical teams whose clinical scope does not span the clinical complexity of multi-morbid patients. Administrative responses to these issues (e.g. advanced care directives) fall short of what is required, and are usually ignored. It was proposed that community-based, independently governed care navigators for the frail elderly be established, modelled off the respected and effective breast cancer nurse system. Their role would focus on first properly understanding the needs of their frail elderly patients, and then helping to advocate within the system to have these needs met. The intended benefit would include a significant reduction in unwanted, and low value care.

### 2. Voluntary Assisted Dying (VAD)

Dr Linda Swan led the discussion on the evolution and challenges of VAD laws across Australia. As the first jurisdiction to introduce VAD, Victoria was also the jurisdiction with the most restrictive safeguards, whereas the VAD laws recently passed in the ACT reflect the most liberal legislation nationally. Another major issue is that VAD practitioners canoot access MBS payments due to the lack of dedicated VAD-specific MBS item numbers and other MBS rules. Impediments to change include conservative elements within the medical profession and the strong political influence of faith-based organisations that also deliver much of Australia’s end of life care. The peak body Voluntary Assisted Dying ANZ has been established to represent practitioners and advocate for policy reform.

**Follow Up Actions**

HRG to consider adopting the following policy positions:

**Care of the Frail Elderly**

* Advocate for earlier and more robust identification and disclosure of terminal illness and more informed conversations regarding individual end-of-life preferences.
* Explore the feasibility of introducing a dedicated "navigators" role to assist patients and families with end-of-life planning and system navigation.

**Voluntary Assisted Dying**

* Harmonise VAD laws nationally;
* Remove restrictions on VAD practitioners accessing MBS;
* Introduce VAD-specific MBS item numbers;
* Enable the delivery of care via a carriage service e.g. phones, fax;
* Streamline the administrative and clinical processes supporting access to VAD; and
* Improve VAD clinical training and support for interested clinicians.

# Meeting Notes

### 1. Care of the Frail, Elderly Terminally Ill

#### Current State

* The default process for an elderly person living in the community who falls sick is hospitalisation. This is problematic given that many of these people are in the last 12 months of their lives i.e. terminally ill. This process can be described as a conveyor belt – mechanical, thoughtless, and excluding people from being involved in their own health care goals.
* Prior to someone falling acutely ill, there is little discussion or negotiation regarding the patient’s desire to go to hospital, despite there being multiple opportunities for various healthcare touchpoints to do so - GPs, community workers and ambulance drivers.
* Invariably, frail older patients arrive in the perennially pressured Emergency Department, which is not an ideal place for lengthy, nuanced and complex discussions.
* If a patient is admitted, they are then dispatched under the care of a specialist - great if you are younger, with a single acute disease, but not so good if you are older with multiple chronic conditions.
* Once admitted, it is common for frail older patients in hospital to deteriorate due to: Extended bed rest causing deconditioning. Noisy wards interrupting sleep. Poor nutrition.
* One of the saddest calls an intensive care doctor can take from a ward doctor goes something like “The patient is deteriorating. I’ve spoken to the family. They want everything done.” because it suggests that the wrong questions have been asked, often to avoid more complex, difficult but necessary discussions.
* Intensive care clinicians are very interested in the conveyor belt because they stand at the end of it, and are the ones who ultimately need to have these challenging discussions.
* Intensive care currently costs $5000 per patient per day and often involves the treatment of terminally ill patients. This is a poor allocation of resources, not only on economic efficiency grounds, but morally and ethically, because it is entirely likely that these people do not want this treatment.

#### Defining Terminal Illness

* The concept of “terminal illness” is central to this - it is routine to describe patients with a defined disease like cancer or a neuromuscular condition as terminally ill. It is a much harder description to use when the person is older and frail with multiple chronic conditions, despite the evidence-based prognosis being similar.
	+ The [Crystal Tool](https://spcare.bmj.com/content/5/1/78) has been developed to help define when someone is terminally ill. But it is very complex to administer and not practical for the real world.
	+ The [Rockwood Frailty Scale](https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2022/02/rockwood-frailty-scale_.pdf) is the most commonly used tool to track frailty.
	+ Major research efforts to use these tools to trigger conversations about terminal illness in teaching hospitals, ED and general practice have all failed.
	+ There are also ‘flags’ to increase awareness of terminal illness in the elderly eg multiple admissions to ED and hospitals; decrease in three or more Acivities of Daily Living (ADLs); and weight loss.

#### Impact of Frailty on Risk of Death

* In a prevalence study of patients over the age of 70 presenting to RNS ED, of the 15% classified as frail, there was a 5 fold increase in 3 month mortality, and a 14 fold increase in 6 month mortality.
* Being frail or not made no difference to treatment, nor to the outcomes of the initial hospital admission.
* The biggest challenge at present is establishing the uniform measurement of frailty on entry to ED.
* Highlights the need to inform frail elderly patients of their frailty and consequences this may bring for them once back in the community.

#### Role of Palliative Care?

* Palliative Care as a specialty emerged from Oncology, and this origin has influenced the kind of patients they continue to focus on. Frail, elderly, multi-morbid patients are rarely cared for by Palliative Care doctors.
* The top 10 priorities of frail older people are rarely medical. They are social, things like loneliness, self care, shopping and housekeeping… not living longer. This is difficult for doctors to integrate.

#### Medical Culture and End of Life Care

* Doctors are drawn to treating reversible conditions irrespective of the broader clinical context as it pertains to frailty.
* Diagnosis and treatment are core elements of being a doctor that are reinforced and promoted from the very start of medical school.
* Reversing this reflexive response to patient need may prove difficult.

#### Economics and Resource Allocation

* ~25% of healthcare spending occurs in the last year of life.
* ~80% of patients do not wish to die in hospital.
* Public hospital systems nationally are under operational and financial duress.
* Most of healthcare (including public hospitals) is remunerated based on activity, suggesting that they may be conflicted out of encouraging high value end of life care care based in the community.

#### Current Policy Posture

* Current policy making structures seem uninterested in acknowledging terminal illness in the multi-morbid frail elderly.
* Discussions seem centred on maximising lifespan and healthspan while willfully ignoring the inevitability of death.

#### The Evolution of Birthing - An Inspiration

* The changes that birthing has enjoyed over the last century provides hope and inspiration. In the mid-20th century, it was a very regimented, clinically dominant process that prevented partners from being present at the birth, and separated the newborn from the mother. Modern day birthing is mother/baby centred and inclusive.
* What was the impetus for this change? Not the obstetricians. It was the women.

#### Solution: Shared Decision Making

* Involve society. Involve the elderly. Involve their families.
* Shift the clinical focus from just “what’s the matter with you” to “what matters to you”.
* Be honest with the terminally ill frail elderly - they may not want “everything done”.
* Be honest about the limitations and dysfunctions of the current system.
* Engage in genuine, earnest, shared decision making (vs. tick box advance care directives) - once you know a person and their context properly, it is easier to contemplate what they want medically.
* Not necessarily a doctor’s job. Nurse? A new role?

#### Solution: Care Navigator

* Shared decision making is necessary but not sufficient, because during an emergency (fall, acute deterioration), such discussions can be sidelined.
* A dedicated Care Navigator, based on the care model established for Breast Cancer Care, needs to be expanded.
* A navigator will know the person, and be able to refer to their documented wishes.

#### See also:

* [The Conveyor Belt for Terminally Ill Older People](https://johnmenadue.com/the-conveyor-belt-for-terminally-ill-older-people-very-good-an-author-of-years-ago-jm/) (Pearls & Irritations)
* [The Common Signs Your Loved One Is Dying](https://www.theguardian.com/society/2025/feb/16/it-can-be-really-frightening-knowing-the-common-signs-that-a-loved-one-is-dying-can-help-in-their-final-days?CMP=share_btn_url) (The Guardian)
* [BMJ 2024 ;387 Facing Death Differently](https://www.healthreformgroup.au/wp-admin/post.php?post=384&action=edit)

### 2. Voluntary Assisted Dying (VAD)

VAD is principally about the relief of extreme suffering at the end of life when other approaches aren’t working.

#### Current VAD Context

* End of life care is a fraught policy area in need of much reform
* Stigma, religious beliefs and politics only intensify the discourse
* Demographics and resourcing are drawing more attention to the space
* A lot of low value end-of-life care will continue to be delivered until we hit a crisis
* One of the most wantonly wasteful situations occurs when someone is approaching the end of their life, they have a miserable day-to-day quality of life, and they’ve made a decision that they no longer want to live, but are forced to continue receiving treatment. This is where we were before VAD laws were introduced.
* So called “Terminal Sedation” was permitted, but this was an option selected by the clinician rather than the patient.
* A key driver behind the introduction of VAD was about giving power back to the individual to make a choice about how they ended their life.
* VAD is about the subset of people who are interested in the option being able to access the choice. It is absolutely respectful of the fact that not everyone approaching the end of their life will be interested in such an option e.g. due to religious/spiritual beliefs.
* Significant positive feedback from families of those who have accessed VAD.
* Significant positive feedback from clinicians who suggest it to be some of the most positive and rewarding work they’ve ever done.

#### VAD Legislative Evolution

* VAD laws are running in all states in Australia, expected shortly in the NT.
* They have become more patient centric with each state’s passing of VAD laws. Victoria was the first and most restrictive. ACT was the most recent and is the most flexible, while maintaining strong safeguards for all involved.
* Clear reporting and governance is a mainstay nationally i.e. good clinical governance:
	+ every VAD case is reviewed by a review board
	+ mandatory reporting is in place
* To date, there have been no instances of coercion over the last five years.
* This positive history and thorough collection of data makes this an excellent time to reflect on progress and improve how things are done, but there is currently zero political interest.

#### VAD and Dementia

* Many people wanting to access VAD are especially motivated by the concern they may develop dementia.
* Assisted dying in this context is no longer “voluntary” at the time of administration of VAD drugs as patients are *non compos mentis*.
* Even in jurisdictions where VAD is permitted with dementia (Netherlands, Scandinavia) one of the biggest obstacles are the VAD clinicians being uncomfortable administering VAD drugs to patients they may not know, who have previously indicated their intentions, but at the time of drug administration are contradicting their previous directive by strongly objecting to the drugs being administered.

#### And finally, in the countries where VAD is permitted in the context of dementia, VAD is accessed very infrequently if ever, most likely due to clinician hesitancy.

#### VAD Challenges

* Professional stigma.
* Little or no remuneration.
* Current administrative processes take between 3 weeks and 3 months to navigate, which can consume significant family resources at a time when loved ones would prefer to be spending quiet time with the patient.
* A 50:50 split exists amongst palliative care doctors as to whether VAD is a part of what they do, with palliative care leadership leaning to VAD being excluded.
* There is no specific area within the federal DoHAC bureaucracy relating to VAD, only palliative care who do not see VAD as within their scope.
* No current political will to advance changes due to controversy.
* Estimating time until death is a highly uncertain practice at the individual level.
* Basing access to VAD on estimated time to death is misplaced - it should instead be based on the capacity of the patient to tolerate their circumstances.
* Unlike with organ donation, relatives are not able to block a loved one from accessing VAD, but have been known to disrupt the process, sometimes requiring police intervention.
* Orally administered VAD medications are intentionally flavoured with very bitter additives to avoid accidental administration. This has the unpleasant side effect of making the last beverage a VAD patient consumes disgusting.
* Faith based healthcare organisations currently provide much end of life care and carry significant political influence. Some religions believe that suffering represents the path to God, thus fuelling their objections to VAD.

#### VAD Reform Opportunities

* **Prohibition on Open Conversations:** Healthcare practitioners cannot currently have open conversations about VAD i.e. clinicians are prohibited from raising VAD in a clinical conversation with a patient in any circumstances in Victoria and South Australia; the patient must raise the topic.
* **Carriage Service Ban:** Under the Federal Criminal Code, health practitioners are forbidden from using a “carriage service” to incite or promote suicide, without there being any definition of what suicide is, impacting severely on access to VAD for rural communities.
* **Workforce, Training, Support and Remuneration:** Lack of workforce is another major consideration with very few clinicians currently wanting to support VAD due in part to lack of training and professional support for what is a challenging and controversial area of practice. MBS items can not be used in VAD due to MBS rules prohibiting payment for anything associated with “suicide”). Consequently, most practitioners who currently provide VAD services do so out of a sense of professional duty and desire to help patients. There is also a recognised professional stigma against those clinicians who do support VAD.
* **Raising Awareness:** Even amongst practitioners, there is low awareness of the legal changes with current community estimates suggesting 20% know about it.
* **Harmonising Definition of Terminally Ill:** Different conditions enjoy different periods of remaining life where VAD can be accessed. Harmonising the estimated period of remaining life to 12 months would reduce confusion.
* **Development of Nationally Harmonised Laws:** There is an acknowledgement that the differing laws across jurisdictions is confusing for patients and clinicians. As experience of the legislation supports the worth of the various protections, a fundamental Australian model, common across all states, is emerging where patients must:
	+ have a terminal illness
	+ be suffering intolerably
	+ have capacity to decide
	+ be close to the end of their lives (6 or 12 months depending on the condition)
	+ have two independent healthcare practitioners confirm the above and be convinced that there is no coercion present.

#### VAD and the bereaved

* While the discussion focused mainly on more abstract policy matters, it was important to acknowledge the importance of human relationships, exposed and at play during the end of a person’s life, and how they contribute in subtle, complex and powerful ways, positive and negative, to the nature of the experience of the conclusion of any person’s life.
* The death of a loved one impacts powerfully on all those connected, usually for the remainder of the loved ones’ lives, with feelings of partial or complete resolution, and/or ongoing distress, trauma, guilt, anger, and the full array of human emotion, often buried but turbulent.
* There is little if any meaningful community-based psycho-spiritual response to enable healing, especially in the modern techno-medical model.
* There can be no doubt that VAD brings benefits, but these may be inadequate in isolation, and potentially inflammatory, if specific-VAD burdens are not addressed.
* It is known that families who help their loved ones act on their wishes are able to grieve more effectively, supporting the need for early, thoughtful conversations about end of life wishes.

#### VAD suggestions and next steps

* Find politicians with lived experience of relevant end of life circumstances and build an alignment around that group.
* Some believe VAD to be a reflection of failed palliative care, and amongst the medical profession, many have a strong philosophical reluctance to support VAD… crossing the chasm between palliative care and VAD will be an important enabler of VAD’s future alignment with the profession.
* Patient advocacy is the most effective way to get political attention in a healthcare context and was the main driver behind the existing VAD legislation.
* Voluntary Assisted Dying Australia and New Zealand is being established as the peak body to represent all clinicians working in VAD and improve training and support for clinicians.

#### See also:

* [2024 State of Voluntary Assisted Dying Report](https://www.healthreformgroup.au/wp-admin/post.php?post=377&action=edit)
* [2024 Voluntary Assisted Dying Convention Report](https://www.healthreformgroup.au/2024-voluntary-assisted-dying-convention-report/)
* [Voluntary Assisted Dying Practitioners of Australia and New Zealand](https://www.vadanz.com.au/)
* [Go Gentle Australia](https://www.gogentleaustralia.org.au/)