Voluntary Assisted Dying and Palliative Care
How can they co-exist?

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Palliative care and voluntary assisted dying – many similarities and shared concerns

- patient-centred care
- voluntariness
- competence in practice
- empathy and compassion
- relief of suffering
- addressing medical futility
- avoiding unnecessary prolongation of dying
Some differences and controversies

• means of relieving suffering – e.g. VAD vs palliative sedation

• “VAD is counter to the philosophy of palliative care”
  - **WHO definition of PC** ("intends neither to hasten nor postpone death")
  - “**Saunderism**” – Dame Cicely Saunders – St Christopher's Hospice, London (1960’s)
    - pioneered the modern hospice/ PC movement “to prevent euthanasia being necessary”
    - “suffering is only intolerable when nobody cares.”
Some differences and controversies

- concept of “palliative futility”
  - PC unable to relieve all suffering
  - pt choice to either not engage or to disengage with PC
  - prolonged dying with PC unacceptable to some suffering pts

- perceived differences in the dominant ethical values
  
  autonomy + beneficence (VAD) vs beneficence + non-maleficence (PC)
What do palliative care organisations say?

ANZSPM (2017)

ANZSPM does not support the legalisation of euthanasia and physician assisted suicide, but recognises that ultimately these are matters for government to decide having regard to the will of the community and, critically, informed by appropriate research and consultation with the medical community, including palliative medicine practitioners.

If these practices are legalised in the Australasian context, ANZSPM endorses international guidelines reaffirming that they are not part of best practice palliative care.

PCNA (2017 - under review)

Palliative care does not include the practice of euthanasia or assisted suicide; and that the intent of palliative care is to neither hasten or postpone death
EAPC (2015)

• The EAPC position paper states that the provision of **euthanasia and PAS should not** be included into the practice of palliative care.

• Within Europe, several approaches to euthanasia and PAS are emerging, and **open and respectful debate surrounding this** is to be encouraged.
CSPCP (2015)

- A survey of our members in **January 2015** (74% response rate) indicated that the majority of our members are opposed to legalization of euthanasia (73%) or assisted suicide (69%). **The majority of our members (74%) believe that euthanasia and physician assisted suicide, if legalized, should not be provided by palliative care services or palliative care physicians.**

APM (of GB & Ireland) (2019)

- The APM **opposes any change in the law** to license doctors to supply or administer lethal drugs to a patient to enable them to take their own lives.

- Actively assisting a patient to take his or her life **undermines the fundamental principles of the doctor-patient relationship** irrevocably and harmfully.
What do palliative care organisations say?

**AAHPM (2016)**

- AAHPM takes a position of **studied neutrality** on the subject of whether PAD should be legally permitted or prohibited.

- AAHPM acknowledges that morally conscientious individuals adhere to a **broad range of positions on this issue**.

**BUT**

- Such a change [to assisted dying] **risks unintended long-range consequences** that may not yet be discernible, including effects on the relationship between medicine and society, the patient and physician, and the perceived or actual integrity of the medical profession.
What do palliative care organisations say?

Asia Pacific Hospice and Palliative Care Network

We do not support the deliberate ending of life and we view with concern moves in certain jurisdictions in the region to legalise physician-administered euthanasia and physician-assisted suicide.

For those of us trying to improve end-of-life care, licensing doctors to provide or administer lethal drugs to patients poses serious risks of sabotaging efforts around the globe to convince governments that pain relief and good end-of-life care are basic human rights.

The APHPCN appeals to you therefore to recognise your responsibilities on the world stage when considering any proposed legislation before you.
Palliative Care Australia (2016) – currently under review

The practice of palliative care does not include euthanasia or physician assisted suicide.

Palliative care does not intend to hasten or postpone death.

BUT

‘aspex consulting’ for PALLIATIVE CARE AUSTRALIA

- Experience internationally of the legalisation of assisted dying on the palliative care sector: FINAL REPORT 28 October 2018

- An assessment of the palliative care sectors following the introduction of assisted dying for each of the in-scope jurisdictions provided no evidence to suggest that the palliative care sectors were adversely impacted by the introduction of the legislation. If anything, in jurisdictions where assisted dying is available, the palliative care sector has further advanced.
Euthanasia: statement of consensus of the three palliative care federations (Brussels, Flemish and Walloon palliative care federations)

- Far from being contradictory or divergent, these two practices respond to the suffering of incurable patients in a concern for humanising the end of their life and with the desire to fulfil their expectations.

- The federations wish to respect the right of patients to autonomy and self-determination. Some will let death come to them, having been supported to the end of their lives. Others, exhausted by suffering that has become intolerable, will request euthanasia despite the palliative support initiated. Still others, anxious to save themselves from the physical or psychological decline that they foresee, will decide to advance their deaths and will request euthanasia at once.

- It is important that the federations respect the choice of patients who want euthanasia and put them at the centre of the procedure.
Some thoughts on co-existence - clues from the Belgian experience (FPCF)

- ‘euthanasia accompaniment’ and ‘integral palliative care’
- PC considers VAD is one possible form of “a good death” (in minority of pts)
- continuity of care is vital – not wanting to refer pts to external/unfamiliar practitioners
- PC not harmed by legalisation of VAD – PC forced to develop further/ more funding
- legalisation has stimulated more thorough E of L discussions/conversations
- VAD acceptable to many PC physicians in same way as a pt voluntarily deciding to cease life-prolonging treatment (e.g MND pt ceasing NIV voluntarily)
- process before VAD is intensive (informative & deliberative)
- “..to help a patient die is deeply moving and has a life-intensifying and sacred dimension.” (Dr Arsène Mullie, Pall Care Physician, FPCF)
VAD - challenges for palliative care

- Responding to a request by current patient for VAD assessment
- Accepting new referral of patient known to be considering VAD (or already found eligible for VAD)
- Information, referral, ‘accompaniment’/non-abandonment
- ? transfer of pt out of familiar care environment (e.g. Catholic hospital or RACF)
- Where will it occur? - home, hospital, pall care unit, RACF
- Who will be there? – will pall care nurse be present (if requested)?
VAD - challenges for palliative care

• Conscientious objectors vs ‘conscientious providers’
• ‘Non-providers’ vs conscientious objectors
• Not only be empathetic (to feel for & with pt) but also compassionate (the motivation/desire to do something about the suffering & request for VAD)
• Improved skills/broader repertoire in symptom management/assessment of suffering
Responding to a desire to die or hasten death – core task for palliative care clinicians

Respond with:

• empathy AND compassion
• professionalism - regardless of your stance on voluntary assisted dying
• awareness of own beliefs, fears, prejudices, moral/ethical stance about death, dying and assisted dying

• extensive exploration of person’s suffering is vital
  - can often, but not always, avoid voluntary assisted dying
Reasons – that patients see as causing them to have a wish to die

- Physical
  - acute/chronic pain
  - severe breathlessness
  - chronic nausea
  - incontinence
  - smelly/ disfiguring wounds/ulcerated/fungating lesions
  - severe lethargy/drowsiness

Palliative care generally good at relieving these symptoms
Reasons

• Psychological
  - anxiety/depression
  - pervasive sadness
  - loss of hope
  - fear of loss of cognitive function/inability to make decisions
  - fear of dependency/ being ‘hooked up to machines’

Requires multidisciplinary approach
Reasons

• Social
  - loneliness/ social isolation
  - loss of social role
  - financial difficulties
  - lack of adequate caring network
  - family conflict
  - fear of being a burden
  - fear of (or actual) abandonment (by partners/family friends/doctors)

Lots of extra resources required to help
Reasons

• Existential or spiritual
  - loss of sense of self/loss of dignity
  - ‘trapped in a disabled body’
  - the hopelessness of their terminal condition
  - uncertainty/fear of the dying process (timelines, ‘quality of death’)
  - profound lack of sense of life
  - relationship with ‘god’ (“time to meet my maker”)

Can be more resistant to palliative care interventions
Meanings – a wish to die can be a wish to:

- allow a **life-ending process to take its course** (not to impede the process of dying)
- let death put an **end to suffering** (death seen as lesser of 2 evils therefore desirable)
- put an end to an unbearable demand/personal burden (**reached the limit of tolerance of suffering**)
- spare others from the **burden** (to family/healthcare providers/society)
- preserve self-determination at the end of life (**control** over the timing & manner of death)
Meanings – a wish to die can be a wish to:

- end a life that is perceived to be **without value** (loss of personal relationships, ability to enjoy usual meaningful activities/interests)
- not have to wait around until death arrives (**avoid a drawn out dying process**)
- be an **example** to others (of how dying is done well)
- move on to another reality (**afterlife**/‘another level of existence’)

Possible functions of wish to die statements

• ‘Cry for help’
  - triggers dialogue with others about suffering including fears/shame/burden/frustrations, poorly-controlled symptoms

• Re-establishing control
  - winning back some personal control when it seems to be under threat
  - self-reassurance that “I can get out of it at any time”

• Manipulation
  - attention-seeking (carers/family/healthcare providers)
  - provocative ploy – to test the reactions
Challenges for ‘conscientious providers’ of VAD in palliative care (e.g. me!)

- knowing/accepting that PC has done all it can to relieve suffering & that for some people it is no longer tolerable to live on
- clear boundaries between different facets of clinical work
- explanation/clarification to pts, families clinicians re intention of therapeutic interventions
- continual emphasis on the ‘voluntariness’ of VAD (no VAD ‘by stealth’)

Challenges for ‘conscientious providers’ of VAD in palliative care (e.g. me!)

• vigilance re one’s practice/ feedback from team/colleagues/families/carers

• acceptance of closer scrutiny/ critique of clinical practice

• collegial support/personal care in face of possible hostility from within PC sector (and general medical profession in general)

• ? being seen as “Dr Death” - the “go to doctor” for most cases in my area
Palliative care, VAD and the future – personal hunches & hopes

• increased comfort with VAD as another legitimate option in E of L care
  (more states in Australia will legalise VAD)

• stimulus for PC doctors to undertake deeper reflection and study of the ethics of VAD

• more PC (& other) physicians will become assessors and providers of VAD
Palliative care, VAD and the future – personal hunches & hopes

• closer scrutiny of palliative sedation practices (for whose benefit – pt or Dr?)

• Peak PC bodies and Associations will adopt a more neutral stance on VAD within PC practice

• Palliative Care and Aged Care will always be the main players in E of L care
“Ultimately, helping eligible patients who wanted choice over the manner and timing of their deaths is consistent with what I have always done: relieve suffering.”

“…in my experience, the availability of MAID has only increased trust in doctor-patient and doctor-family relationships, as I have explored suffering and offered a legal and ethical end-of-life option in a compassionate and sensitive way.”

“Why I decided to provide assisted dying: it is truly patient centred care”

Dr Sandy Buchman - PC physician (Toronto)
- President of CMA

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