

## DEFINING WHAT MATTERS MOST: DELPHI-BASED DEVELOPMENT OF A CORE OUTCOME SET FOR PALLIATIVE SEDATION

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**Introduction.** Despite its frequent use in end-of-life care, quality evaluation of palliative sedation (i.e. use of sedating drugs to induce decreased consciousness until death) is hindered by the absence of a robust set of outcomes for evaluating palliative sedation.

**Research question.** What outcomes should be included in a standardised core outcome set (COS) to evaluate palliative sedation quality in research and practice?

**Methods.** A three-round Delphi study was conducted with healthcare professionals, academic research experts, bereaved relatives, and patients. An exhaustive list of outcomes—derived from literature and empirical research—was rated for consensus using predefined criteria in two online survey rounds. The third round comprised an in-person consensus meeting to finalise the COS and address stakeholder differences.

**Results.** In round one, 114 participants responded, round two achieved a 90% response rate (103/114). Across 206 listed outcomes, consensus was reached on 12: patient's suffering is controlled and comfort ensured, no contradictory communication by healthcare providers (HCP), pain monitoring, continuation of basic care and beneficial analgesics, empathetic HCP attitude, attention to patient anxiety, avoidance of unnecessary interventions, opportunity to say goodbye, complication management, and close cooperation with relatives in home-settings. At the consensus meeting (n=18), seven items were added: stand-by experts, HCPs' communication, timely communication with patient and relatives, HCPs' experience, relatives/patients understanding the difference with euthanasia, and informed relatives. Outcomes on existential needs and alignment with patient wishes achieved only moderate consensus.

**Conclusions & recommendations.** By integrating all relevant perspectives, including patients, this study delivers the first consensus-based COS for evaluating palliative sedation. It illustrates the practice's complexity, highlighting the need to contextualise the COS, while defining minimal requirements for good practice. The COS supports targeted quality improvement, informs legal, clinical, and ethical reflections, and informs the development of a core measurement instrument to evaluate palliative sedation.

## Voluntary Assisted Dying in Western Australia 2021–2024: Uptake, Practitioner Involvement, and Service Delivery

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### Background:

Since July 2021, Voluntary Assisted Dying (VAD) legislation in Western Australia has provided eligible terminally ill adults with a legally safeguarded choice at the end of life. Monitoring service uptake, patient characteristics, and practitioner involvement from 2021 to 2024 provides important insights into utilisation, workforce trends, and service delivery, informing strategies for sustainable, equitable care.

### Aims:

This study aimed to examine VAD service utilisation and workforce capacity in Western Australia from 2021 to 2024. To inform recommendations for VAD equity and quality of care across WA.

### Methods:

A descriptive analysis of Western Australia VAD Board annual reports (2021–2024) was conducted to identify trends in uptake, workforce engagement, and delivery settings.

### Results:

Between July 2021 and June 2024, 737 patients died following VAD: 190 (2021–2022), 255 (2022–2023), and 292 (2023–2024). Most patients had cancer, and approximately 85% were receiving palliative care. Workforce training declined over time: 70 medical practitioners trained in 2021–2022, 27 (20 medical, 7 nurse practitioners) in 2022–2023, and 17 (13 medical, 4 nurse practitioners) in 2023–2024. Only 79 medical practitioners and 3 nurse practitioners actively participated as Coordinating, Consulting, or Administering Practitioners since 2021. Practitioner-administered VAD accounted for most deaths: 147 (77.4%) in 2021–2022, 210 (82.4%) in 2022–2023, and 277 (94.9%) in 2023–2024, with administration at patients' homes in 53.7%, 45.7%, and 49.5% of cases, respectively. Among active practitioners, 71.1% practiced in Perth metropolitan areas and 28.9% in regional areas.

### Conclusion:

VAD uptake in Western Australia has steadily increased. Despite rising demand, workforce participation is limited, training numbers are declining, and practitioner distribution is concentrated in metropolitan areas. These findings underscore the need for targeted workforce planning, inclusive VAD education and support within the tertiary sector, including Nurse Practitioner Education.

Enhanced regional support, and policy measures to ensure sustainable and equitable VAD service delivery.

## An international exploration of best practice for patient decision-making on assisted dying methods and administration

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This presentation shares findings from a 2025 Churchill Trust Fellowship project that investigated best practices in assisted dying administration, with a focus on practitioner and patient decision-making on assisted dying methods and protocols on the day of death. Conducted across Canada, The Netherlands, and New Zealand—jurisdictions where both self-administration and medical practitioner-assisted administration are legal—the project examined how methods of administration are discussed, chosen, and implemented in practice.

The research explored how patients and assisted dying practitioners navigate the choice between self-administration and practitioner-assisted dying, balancing and considering the clinical, ethical, and emotional dimensions of each approach. Central to this is the process of informed consent—how information is presented, what questions patients ask, and how decisions are supported to ensure autonomy and dignity at the end of life.

In-depth interviews and site visits revealed several common themes across all three countries. The presentation highlights practical frameworks used by clinicians to guide these sensitive conversations, manage uncertainty, and maintain ethical integrity.

The project also examined the procedural and ethical standards followed on the day of death, including how the environment, timing, and communication between support people are managed to ensure safety and respect. Attention was also given to how assisted dying practitioners can avoid and manage risks and complications, better support the patient and families and themselves on the day.

By synthesising insights from multiple international systems, the presentation offers practical recommendations for jurisdictions considering or refining assisted dying practitioner guidance and training. It aims to support safe, ethical, and patient-centred assisted dying practices, grounded in respect for patient autonomy and clinical responsibility.

## How do assisted dying regulatory models shape practice? A Belgian case study

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**Background:** While there is a trend to permit assisted dying (AD) internationally, different jurisdictions are adopting different regulatory models to do so. Little research explores how these different regulatory models are influencing how AD is provided in each jurisdiction. Belgium has permitted AD since 2002. Well-known features of its regulatory model include that its AD legislation is relatively short, has relatively broad eligibility criteria, and provides for retrospective oversight. This study took Belgium as a case study for examining how AD regulatory models shape practice. It aimed to identify the contextual considerations shaping the regulatory model, the structures and processes which comprise the regulatory model, and the influence of the regulatory model on health professionals' AD practice.

**Methods:** This study used regulatory theory as the conceptual lens through which to explore Belgium's AD regulatory model. Reflexive thematic analysis was used to analyse three data sources: a scoping review of the literature, semi-structured interviews with Belgian health professionals and organisational regulators, and scholarly and grey literature searches. The findings reported in this presentation focus on how the regulatory model influences practitioners' AD practice.

**Results:** This regulatory model gives practitioners considerable scope to exercise clinical discretion, places a high degree of trust in practitioners and norms, and enables practitioners to tailor their AD practice to their personal and professional views. This model also gives providers limited legal certainty, fosters non-uniform AD provision, and can make it difficult for practitioners to discern best-practice AD provision.

**Conclusion:** The Belgian AD regulatory model has a large bearing on practice. These findings are useful for Belgian policymakers who may consider reform to address any unintended or unknown impacts of the regulatory model. International jurisdictions should also be aware of the relative strengths and limitations of Belgium's model when developing or reviewing their own AD regulatory models.

## Victorian experience in providing Voluntary Assisted Dying Coordinator services in public and private healthcare systems

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<sup>1</sup>Eastern Health, <sup>2</sup>Epworth Healthcare

Eastern Health is a large Victorian healthcare network covering an extended geographical area.

Epworth Healthcare is Victoria's largest private not-for-profit hospital group.

In Victoria, Voluntary Assisted Dying legislation passed in 2017 and commenced on 19th June 2019.

I commenced my role as the inaugural Voluntary Assisted Dying Coordinator at Epworth Healthcare

in 2019 to implement the Voluntary Assisted Dying service. Approximately 3 years later I began

employment at Eastern Health as the first Voluntary Assisted Dying coordinator. I provide

information and support to patients and their loved ones as well as education and support to staff

(directly or indirectly involved with VAD provision). I provide services in both the inpatient and outpatient setting.

There have been several differences in the handling of VAD implementation between public and private healthcare services, including differences in access and uptake.

This unique perspective has provided numerous learnings and has adapted over time, which may be of benefit to others working in newer VAD services.

## The Vanishing Voice: Loss of Capacity Mid-Process in Voluntary Assisted Dying -A Case Series

Dr Richard Arnold<sup>1</sup>

<sup>1</sup>NSW Health

### Background:

Australian Voluntary Assisted Dying (VAD) frameworks require decision-making capacity at each step of the process, as do most international jurisdictions. For many patients, especially those with advanced illness, this capacity is precarious. Acute or subacute decline can abruptly terminate eligibility despite prior intent.

### Case Series:

Three illustrative cases will be discussed:

- Case 1: A 79-year-old with metastatic lung cancer who developed septic delirium during the statutory waiting period. Although capacity later improved, uncertainty delayed progress and created distress.
- Case 2: An 84-year-old with frailty and cerebrovascular disease who suffered a large ischaemic stroke after initial assessment, leading to permanent incapacity.
- Case 3: A 72-year-old with pancreatic cancer whose escalating opioid and benzodiazepine use, compounded by hypercalcaemia of malignancy, precipitated fluctuating cognition and repeated concerns about validity of consent.

### Discussion:

Loss of capacity mid-process is not rare. Common medical precipitants include:

- Delirium (infection, metabolic derangements, medications).
- Neurological events (stroke, seizures, subdural haematoma).
- Progressive decline (rapid dementia progression, terminal agitation).
- Medication effects and metabolic complications (opioids, benzodiazepines, hypercalcaemia).

Proactive strategies include early identification of high-risk patients, aggressive delirium prevention (hydration, medication review, infection vigilance), correction of reversible contributors, and judicious timing of requests. Clinicians should also prepare families for the possibility of sudden ineligibility.

### Conclusion:

Capacity loss during VAD is primarily a clinical phenomenon rather than a legal technicality.

Awareness of common causes and early mitigation strategies can reduce risk and preserve patient autonomy.

## VAD's impact on grief and bereavement: insights from families' and carers' lived experiences

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Listening to the VAD bereaved is an important mechanism for improving the VAD journey for families. How is practitioner administration experienced by families? Is self-administration better for the grieving process? What was helpful on the day? What was unhelpful? Was stigma experienced directly, or perceived?

We are able to amplify the carer's voices - closing the vital feedback loop that will support service delivery and legislative improvements.

We will share the stories of end-of-life choices made by families. We will also reflect on potential future directions for VAD-specific grief and bereavement support in Australia.

Since 2023, Griefline and Dying With Dignity Victoria (DWDV) have been running VAD-specific support groups for the family members, friends and carers of people who choose VAD. These groups provide a safe space for people to connect and share with others who can relate to the uniqueness of loss and grief associated with VAD. Group participants are able to discuss at length over 6-week period the legal, ethical and emotional challenges they have faced. Themes of stigma are regularly cited and feeling judged and silenced, as well as the grief related to the VAD death experience and the uniqueness of it.

We aim to present learnings from the post-VAD 6-week group program, and our monthly pre-VAD drop-in group. The stories from the carers of people choosing VAD and those left behind can inform best practice in end-of-life care.

## Why Administration Of Lethal Drugs Should Not Be The Role Of The Doctor

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The suitability of doctors as agents of assisting dying remains debated, although it is common in many jurisdictions, and forms part of the proposed assisted dying legislation for England and Wales.

We examine the established philosophical and legal role of doctors in England and Wales, and compare it to the active role required of doctors under proposed assisted dying legislation. For clarity, we refer to the latter role as 'assisted dying practitioner' (ADP). We interrogate two common claims: that a) the role of doctors and ADPs hold normative conceptual analogy by virtue of shared goals to uphold autonomy and reduce suffering, and b) the practical skills required of ADPs are specific and exclusive to a doctor's training. Examination reveals that neither claim is justified and, despite both roles prioritizing patient welfare, identifies significant conflict between their primary goals. The role of an ADP is philosophically and legally singular. To add a duty to the role of the doctor which is antithetical to their overall goal of cure and disease prevention disrupts the defining characteristic of being a doctor: this may have repercussions on who applies to medicine, how doctors are trained, interact with patients, and are regulated. We do not advocate for or against assisted dying but propose that if it is to be taken forward in England and Wales, society would be more appropriately served by considering the role of an ADP as a novel profession whose goals, competencies, research base and regulation can be established independently.

## When MAiD is refused: findings of a descriptive-interpretive qualitative study

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<sup>1</sup>University Of Ottawa, <sup>2</sup>University Of Montreal

### Background

Despite access to palliative care, some individuals continue to experience suffering that leads them to request medical assistance in dying (MAiD). In jurisdictions where MAiD is legal, refusals can deepen suffering and leave individuals with limited support. Literature highlights the absence of systematic approaches to address the needs of those affected. A deeper understanding of these experiences is required to inform practice and policy.

### Aim

To describe and interpret how individuals and healthcare professionals experience MAiD refusals.

### Methods

Grounded in relational ethics, this study employs a descriptive-interpretive qualitative design. Participants include: (1) individuals whose MAiD requests were refused, (2) relatives of deceased individuals whose requests were refused, and (3) healthcare professionals with refusal experience. Recruitment was conducted through purposive and snowball sampling. Semi-structured interviews were transcribed and analyzed using Thorne's interpretive description methodology, an inductive thematic analysis aimed at generating clinically relevant interpretations.

### Results

Emerging results reveal tensions in how refusals are understood and experienced. Professionals often frame refusal as a legal obligation, while patients perceive it as denial of suffering or moral injustice. Both groups report emotional consequences, including distress, ethical burden, and isolation. Communication strongly shapes these impacts showing that clear and empathetic explanations may reduce distress, whereas poor communication fuels mistrust and feeling of abandonment. Across participants, the absence of structured follow-up after refusals is seen as a critical gap, with repercussions for both patient well-being and professional resilience.

### Conclusion

MAiD refusals are not merely legal or clinical acts but also deeply human and ethical experiences. Divergent perceptions generate emotional and moral strain for all parties. Addressing the lack of structured follow-up is essential to reduce harm and promote ethical continuity of care. This study provides new insights that can directly inform policies, professional training and practices.

## Factors of MAiD outcomes: An Empirical Study Based in Spain

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The annual reports on euthanasia issued by the Spanish Ministry of Health since the legalization of MAiD in 2021 provide a unique opportunity to examine, for the first time, the profiles of applicants and the outcomes of their requests. These reports make it possible to analyze not only who applies for the procedure, but also which factors are associated with three main outcomes: approval and provision, denial, and death prior to provision.

This study focuses on exploring how variables such as age, sex, underlying pathology, region, the presence of advance directives, and reduction in the time between the first and second requests are related to the final resolution. The aim is not only to quantify associations but also to identify patterns that may remain hidden under more traditional approaches.

To achieve this, the research adopts a mixed perspective that combines statistical analyses with interpretable machine learning models. This design allows for the estimation of measurable effects—such as the increased probability of dying before resolution among patients with certain conditions—while also enabling the detection of more complex interactions that may better reflect the dynamics of the decision-making process.

Preliminary observations suggest, among other findings, that oncological patients present a higher likelihood of dying during the procedure, and that the type of underlying pathology is a key element. Beyond the clinical dimension, the study aims to contribute empirical evidence that clarifies how applicant characteristics are linked to different outcomes of MAiD requests in Spain. This evidence can serve as a foundation for subsequent discussions in areas such as healthcare policy, bioethics, and end-of-life decision-making.

## Hospice and Palliative Care Social Workers' Perspectives on Minimal Comfort Feeding in Advanced Dementia

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Hope Wechkin and colleagues published the first paper on Minimal Comfort Feeding (MCF) in February of 2025. The MCF approach is designed as an option for people in the advanced stages of dementia who have previously expressed the desire to not have their dying prolonged in the end stages of disease. Comfort Feeding Only (CFO) is the standard palliative practice towards nutrition and hydration in advanced dementia; it provides scheduled handfeeding as long as the person with dementia is receptive to eating. MCF is being proposed as a compromise between VSED and CFO; patients receiving an MCF approach do not have scheduled mealtimes but continue to receive limited food and hydration to avoid discomfort if they appear distressed. An MCF approach to end-of-life care shortens dying from months or years to weeks. The purpose of this study was to find out from practicing social workers their thoughts and perspectives related to this new end-of-life option. Online (RedCap) survey data were collected after a presentation about MCF at the 2025 conference of the Social Work Hospice and Palliative Care Network (SWHPN) in Minneapolis, Minnesota (USA). Respondents include 76 licensed Masters prepared social workers (MSW), over half of whom reported being credentialed in palliative care. Survey items included demographic information, work setting, social work experience with people with dementia and people who had requested the withholding of food and drink, perspectives on comfort levels discussing MCF with patients and families, opinions about family openness to MCF as well as whether the respondent would elect MCF for themselves, if diagnosed with dementia. Results indicate openness to the concept of MCF, concerns about implementation feasibility and family acceptability, although the majority indicated they would elect MCF for themselves, should they find themselves in the situation.

## "To stop the war inside of me": insights from assisted suicide decision making

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**Introduction:** As more countries enact legislation permitting assisted dying, individuals gain access to this end-of-life option. In Switzerland, this practice is known as assisted suicide and many people report considering it as a potential choice. While prior research has examined the contemplation of assisted suicide, little have investigated the experiences of individuals actively making the decision to request it. Qualitative research is essential to deepen our understanding of how such individuals experience, and justify this decision.

**Aim:** This study aims to explore and describe the experiences of individuals at the point of requesting assisted suicide. We focus on how they make sense of their decision and identify the motivations articulated when explaining their choice.

**Methodology:** We conducted 48 semi-structured interviews with individuals involved in the assisted suicide request process across Switzerland. Participants were invited to reflect on their decision and identify key factors that contributed to its consolidation. Data were thematically analyzed, with particular attention to how these factors shaped assisted suicide as a preferred end-of-life option.

**Results:** from participants accounts', six interrelated themes emerged each representing a core motivational driver in the decision-making process. Each themes report one driver identified as having had considerable influence in their decision-making, namely: a) reaching the unbearable, b) framing one's own death, c) maximizing the benefits of the Swiss model, d) finding common grounds, e) ensuring self-determination, f) recognizing a narrowing window of opportunity. These themes interact and reinforce each other in consolidating the decision for assisted suicide.

**Conclusions:** Findings suggest that the decision to request assisted suicide is not solely driven by illness or the experience of unbearable suffering. Rather, participants framed their decision through a range of interconnected drivers. These insights reveal a complex, multidimensional decision-making process in which assisted suicide is perceived as a meaningful, legitimate, and preferred end-of-life option.

## Academy of Aid-in-Dying Medicine: Modeling a Professional Organization Dedicated to Improving Care in Assisted Deaths

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**BACKGROUND:** Medical aid in dying (MAID) encompasses care for terminally ill patients considering hastening their deaths, by allowing clinicians to prescribe medication aimed at ending life. MAID became legal in 12 U.S. states and the District of Columbia between 1994 and 2025. All U.S. legislation requires the individual be >18 years, have a terminal illness with life expectancy <6 months, self-administer the medication, and possess decision-making capacity. However, there are considerable differences in U.S.-based assisted death versus the practice in Canada, Europe, Australia, and Latin America. In the U.S., national professional associations have historically offered little to no clinical guidance to clinicians offering MAID, and provider training has been isolated, fragmented, and anecdotal.

**INTERCESSION:** In February 2020, a national group of clinicians formed an organization subsequently renamed the Academy of Aid-in-Dying Medicine. The Academy helped establish evidence-based best-practice MAID standards involving drug selection and administration, and developed an active listserv through which clinicians throughout the U.S. share patient-based experience, seek practical advice on clinical issues, and network with other providers. The Academy also offers ethics consults, educational materials, practice guidelines, and a patient referral service. The last several iterations of drug regimens nearly universally used across the U.S. have been developed and refined through Academy research.

**CONCLUSIONS:** The Academy of Aid-in-Dying Medicine has emerged as the leading authority in supporting the clinical, ethical, and practical applications of MAID in the U.S. By consolidating provider experiences, developing drug protocols, and offering accessible education and ethics consultation, the Academy has filled a critical gap left by national professional organizations and teaching institutions. As other nations consider implementing or expanding aid-in-dying frameworks, the Academy offers a proven, scalable model for building a robust and humane assisted-dying care system—one that prioritizes patient dignity, clinician education and support, and continuous quality improvement.

## Self-directed dying by voluntary stopping eating and drinking: an interview study with confidants

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Voluntary stopping eating and drinking (VSED) is a way to hasten one's own death without the help of a doctor. In the Netherlands, an estimated 0.5% to 2.1% of all annual deaths are the result of VSED. Little is known about the decision-making process that results in VSED, the involvement of others in the preparation and implementation of VSED, and how the quality of dying is experienced. We conducted a qualitative interview study among confidants of people who died by VSED. After completing an online questionnaire (Jan-March 2024), confidants were purposefully selected to ensure variety in the relationship to the deceased, gender and age of the deceased and the place of residence of the confidant. Interviews were conducted by three researchers using a topic list. Interviews were audio recorded and transcribed verbatim. Data were analyzed thematically using NVivo.

Sixteen interviews were conducted between June and December 2024. According to confidants, reasons for choosing VSED were: psychological and/or physical suffering, a rejected request for euthanasia, confidence in the method, or not wanting to put the responsibility on others (e.g. a doctor). The decision to choose for VSED was usually made independently and then communicated to loved ones. In some cases, the option was suggested by a healthcare provider. Experiences with the dying trajectory and the quality of dying varied. Confidants sometimes indicated that the process took longer than expected and that it was an undignified way to die. Others indicated that the self-directed dying trajectory went according to plan and that it was a 'good death' for the deceased. The decision to hastening death by VSED seems to be made autonomously in most cases and stems from psychological or physical suffering in combination with other factors. Confidants' experiences with the process are sometimes positive and sometimes negative.

## Operating a VAD-responsive program as part of palliative care in a faith-based organisation.

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St Vincent's Hospital Melbourne operationalised a tiered clinical governance response to patients raising VAD to ensure a holistic, sensitive and compassionate response as a commitment to provide our usual suite of palliative care services to patients who are pursuing a parallel VAD pathway.

Supported by the ethical, philosophical and organisational underpinnings of a St Vincent's health service, since the enactment of the legislation, this structure and the team supporting it have responded to all cases in which a patient has been cared for at St Vincent's. This response has seen us care for patients who are engaged with the VAD system at all stages – from expressing interest to prescription or possession of the VAD substance.

In our workshop, we will use case studies to discuss and demonstrate the underpinnings, framing and structure of our response, as well as demonstrate from our data, that even with a trending uptick in VAD related activity, that regardless of a person's level of participation, our particular response to VAD has proven relevant for all our health and aged care services, that incorporates VAD as part of our palliative care service.

We will conclude with cases that exemplify the framework in action that continues to respond well to maintain a person centred approach to patients, residents, their carers and families, and staff responding to palliative care and VAD needs.

## Challenges of drafting an advance request for MAiD in Quebec: A multi-perspective qualitative descriptive study

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**Background:** Since October 2024 in Quebec, the Quebec Act Respecting End-of-Life Care allows a person to write an advance request (AR) for medical assistance in dying (MAiD) after having been diagnosed with a serious and incurable illness leading to incapacity (e.g. major neurocognitive disorder). The law requires that AR-MAiD be drafted with the assistance of a physician or specialized nurse practitioner. The person requesting MAiD may also, if they wish, identify a trusted third party whose role is to ensure that the wishes expressed in the AR are known and respected. Globally, only the Netherlands has a similar practice. No research in Quebec has yet documented the formulation of an AR-MAiD in anticipation of a loss of decision-making capacity.

**Objective:** To examine the process of drafting an AR-MAiD, with the aim of gaining insight into stakeholders' perspectives (patients, trusted third parties and professionals) and identifying the challenges associated with this procedure.

**Method:** A qualitative descriptive study involving up to 10 triads (target of N = 30 participants) composed of (1) a person diagnosed with a major neurocognitive disorder who drafted an AR; (2) their trusted third-party; and (3) the professional who accompanied this person in formulating their AR. Interview transcripts will be analyzed thematically.

**Results and Conclusion:** Our study is still in the recruitment phase, but preliminary findings highlight the unique experience of professionals confronted with the administration of MAiD to individuals having lost decision-making capacity. Challenges related to the administrative procedures surrounding ARs have also been emphasized. Clinical concerns have emerged, particularly regarding how to translate patients' expressed wishes into observable clinical criteria. Though preliminary, these results raise questions about whether administrative and clinical barriers could ultimately compromise the implementation of AR-MAiD.

## Relatives' needs in terms of bereavement care throughout euthanasia processes: A qualitative study

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**Background:** A death-related loss is a profound experience that typically affects five to nine relatives and may have lasting implications for their health and well-being. While most individuals are able to cope with bereavement, a small minority experience persistent and debilitating grief that significantly impairs daily functioning. Tailored bereavement care can reduce the risk of such complications. However, in the context of assisted dying, it remains unclear how best to provide care that is responsive to the specific needs of bereaved relatives.

**Aim:** This study aims to explore the bereavement care needs of relatives involved in euthanasia processes, examine how healthcare providers respond to these needs, and assess the degree of alignment between relatives' and providers' perspectives.

**Methods:** A phenomenological approach was used, employing reflexive thematic analysis of interviews with relatives (N = 19) and healthcare providers (N = 47).

**Results:** Five main themes and several subthemes emerged, reflecting relatives' needs throughout the euthanasia process. Both groups (relatives and healthcare providers) reported similar patterns. Although relatives infrequently communicated their needs explicitly to healthcare providers, they appreciated it when staff proactively met their needs. Healthcare providers aimed to assist with the relatives' grief process by tending to their specific needs. However, aftercare was not consistently offered, but relatives did not have high expectations for professional follow-up care.

**Conclusions:** This study highlights key strategies for healthcare professionals to provide needs-based bereavement care during euthanasia processes. It also emphasises the importance of recognising the unique needs of relatives and proactively addressing them in the period before the loss to positively contribute to relatives' grief process.

## What about the family? Content analysis of international legislative frameworks and guidelines on assisted dying

Dr. Charlotte Boven<sup>1</sup>, Dr. Gilla K. Shapiro<sup>2,3,4</sup>, Dr. Liesbeth Van Humbeeck<sup>1</sup>, Dr. Let Dillen<sup>5</sup>, Prof. Dr. Nele Van Den Noortgate<sup>1</sup>, Prof. Dr. Gary Rodin<sup>2,3,4</sup>

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**Background:** Assisted deaths have a significant impact on families. Legislation and professional guidelines help regulate and standardize care, supporting high-quality healthcare delivery. Bereavement care plays a key role in helping relatives prepare for death and may reduce the risk of prolonged grief.

**Aim:** This study aimed to examine whether and how current legislation and guidelines on assisted dying address family members and their bereavement care needs. It explored the frequency of the term “family” and its synonyms and the professional bereavement care services described for family members.

**Methods:** A content analysis was conducted on assisted dying legislation and guidelines from countries permitting physician-administered lethal medication. Documents were identified between August 2022 and June 2023. Quantitative and qualitative analyses were used to assess references to family members and to identify descriptions of bereavement care services.

**Results:** In total, 22 legislative frameworks and 38 guidelines from nine countries were analysed. Legislative documents contained fewer references to family (N=147) compared to guidelines (N=1,213). The average frequency of family-related terms varied across countries, with guidelines showing a broader range (2–83 mentions) than legislation (0–18 mentions). Eight themes related to bereavement care were identified, though many lacked specific guidance for practice.

**Conclusions:** To improve care quality, it is important to strengthen the inclusion of family members in assisted dying guidelines by integrating clear best practices for professional bereavement care based on the eight identified themes. Further research should explore bereavement care needs from the perspectives of family members involved in assisted dying.

## Voluntary Assisted Dying in Western Australia – administration data from the first four years

Mrs Tanya Burgess<sup>1</sup>, Ms Tanya Burgess<sup>1</sup>, Ms Helen James<sup>1</sup>

<sup>1</sup>WA Voluntary Assisted Dying Statewide Pharmacy Service

**Background:** There is limited information available for the enteral Voluntary Assisted Dying (VAD) protocols used in Western Australia (WA). The expected time to death (TTD) can vary greatly and the range and incidence of adverse effects is poorly documented. As such, the information that is currently given to VAD practitioners, patients and families regarding enteral protocols is often broad and generic, based on anecdotal reports.

**Objective:** Aiming to establish a baseline, we analysed patient factor and experience data collected by the WA Statewide Pharmacy Service (SWPS) between July 2021 to July 2025.

**Method:** Survey responses were collected via reply-paid postage of paper-based feedback forms by family, friends and practitioners to SWPS, and via REDCap platform survey instruments submitted by practitioners. Data were exported to Microsoft Excel for analysis. Quantitative survey items were coded numerically and analysed. Descriptive statistics were calculated to summarise response distributions. Qualitative free-text responses were analysed using thematic content analysis, involving coding, categorisation, and identification of recurring themes.

**Evaluation:** Considerable opportunities for further data collection and analysis were identified. Given the relatively small number of enteral VAD administrations in WA, the importance of robust, standardised and routine data collection for each administration was highlighted as a priority. Data sharing and collaboration with other Australian States and Territories was identified as a way to accelerate development of stronger evidence-based information and advice.

**Implications:** A stronger evidence base would enable practitioners and pharmacists to more confidently provide specific and tailored information to patients and families, resulting in improved expectation setting and better-informed decisions for patients.

## Exploring Assisted Dying service experiences of Nurse Practitioners and Medical Practitioners in Aotearoa New Zealand

Mrs Heather Bustin<sup>1,2</sup>, Dr Kate Reid<sup>1</sup>, Dr Cathy Andrew<sup>1</sup>

<sup>1</sup>University Of Canterbury, <sup>2</sup>Health New Zealand

**Background:** The End of Life Choice Act allows eligible adults to end their lives lawfully, however, for this service to be functional, sustainable, equitable and accessible, there needs to be a well-established network of health practitioners (HPs) willing to provide this service. In Aotearoa New Zealand, one hospice permits assisted dying services on the premises, the others across the country do not (Hospice, n.d.). Health care accessibility is broad and complex; according to Levesque et al.'s (2013) accessibility framework, there are five key dimensions which determine overall accessibility. These are: approachability, acceptability, availability and accommodation, affordability and lastly, appropriateness. For HPs with a scope of practice which permits AD service provision, this end-of-life care option can be challenging. The AD experiences of HPs help to shape their attitudes, contributing to their approachability and acceptability of the AD service; thus, HPs have a vital role in the accessibility of AD services.

**Aim:** To explore the experiences of health practitioners with a scope of practice which permits assisted dying service provision.

**Design:** Hermeneutic phenomenology has been used to explore the common shared experiences of health practitioners working within an assisted dying jurisdiction. Nurse practitioners and medical practitioners have been recruited using purposive and snowball sampling. Semi-structured interviews have been conducted using a participatory based approach.

**Results:** Themes will be identified and discussed

**NB:** The findings are provisional, reflecting initial analyses from a study in progress. Comprehensive data analysis is ongoing and is planned to be completed prior to the presentation.

## Should Minors be Able to Access Voluntary Assisted Dying?

Mr Tobias Cantoni<sup>1</sup>, Dr Katrine del Villar<sup>1</sup>

<sup>1</sup>QUT

Whether children should be permitted to access voluntary assisted dying (VAD) is a topical issue in Australia and worldwide. While it is uncontroversial that young people, as well as adults, may be suffering intolerably from an incurable terminal illness, permitting young people to choose to end their lives remains controversial.

Currently, children of varying ages may access euthanasia or VAD in only three countries: Belgium, the Netherlands and Colombia. Canada has been considering extending its existing law to include 'mature minors' for several years. The 2024 Scottish VAD Bill initially applied to all persons aged 16 or over, but this is now likely to be amended to 18 if the Bill passes. In 2024, the inclusion of minors with a terminal illness and decision-making capacity was explicitly considered by the Australian Capital Territory (ACT) when enacting the Voluntary Assisted Dying Act 2024 (ACT).

In the ACT, this issue of access for mature minors must be revisited in 2028, when the ACT's VAD law undergoes its first mandatory review. The Victorian Greens have also introduced draft legislation which (among other amendments) proposes that expanding access to mature minors be considered when the Victorian VAD law is next reviewed. These legislative steps indicate that the conversation about access for minors is topical in Australia (and other countries).

This presentation considers the ethics of permitting minors to access VAD. It focusses on three main areas of debate in the literature – equality and non-discrimination; autonomy, in particular children's developing autonomy and how that intersects with the legal concept of capacity; and parental authority and responsibility. It aims to provide a conceptually coherent foundation to inform the debate on the eligibility of children to access VAD.

## Understanding and Managing Grief Associated with Assisted Dying in Regional Areas.

Associate Professor Melissa Carey<sup>1</sup>

<sup>1</sup>Edith Cowan University

Voluntary Assisted Dying (VAD) has been legally available in Western Australia (WA) since the implementation of the Voluntary Assisted Dying Act 2019, which came into effect in July 2021. Our research of early experiences of VAD in Aotearoa New Zealand has identified that the grief associated with VAD is different from grief experienced when people do not use VAD. In Australia early research findings suggest that there is emotional complexity and ambiguity, limited access to culturally appropriate support, health professional distress, ongoing barriers to open access and communication. This presentation explores support models for people experiencing grief associated with the use of assisted dying, to identify tools and resources for the management of the unique feelings and emotions that develop because of this grief. We explore specific needs within the regional, rural and remote contexts to identify barriers to grief support and access to tailored services for VAD in regional communities. This insight will enable a better understanding of policy and practice, contribute to evidence for best practice in non-traditional grief management, enhance equity and establish place-based approaches to grief support in regional communities.

## Tiredness of life in older persons: a conceptual description through a multidisciplinary lens

Professor Kenneth Chambaere<sup>1</sup>, dr Judith Appel, dr Sam Carr, Prof Liesbeth De Donder, dr Chao Fang, dr Ralf Jox, dr Jana Rek, dr Marjolein Matthys, dr Anne Nobels, Prof John Troyer, dr Lisa Van Hove, Prof Els van Wijngaarden, Prof Nele Van Den Noortgate

<sup>1</sup>End-of-Life Care Research Group, Ghent University & Vrije Universiteit Brussel (VUB)

In recent years, 'tiredness of life' has been introduced as a novel concept, particularly in the context of societal and political debate on assisted dying in Europe. Through an accumulation of vulnerabilities, the older person is confronted with the feeling that life is no longer worth living. Our international multidisciplinary research network 'Understanding Tiredness of Life in Older Persons' (UnTiL) set out to develop a consensus description of tiredness in life in older persons, through a structured consensus-building process. The resulting conceptualization comprises four distinct 'modules': the description of the experience itself; the base antecedent category underlying the experience; the dynamic nature of the experience; the various forms of manifestation. Core considerations were: tiredness of life invariably constitutes some form of suffering; identification of 'multidimensional loss' as central antecedent, to which other antecedents are retraceable; the significant influence of the culture narrative and a person's social ecology in fostering or inhibiting the experience; tiredness of life presents in a myriad of ways, ranging from a general resignation to actively seeking death. As such, the conceptualisation helps distinguish the phenomenon from terms such as depression, completed life and the wish to hasten death. The necessity and merits of the developed consensus description are discussed. Open questions ensuing from the group work relate to: the universality of tiredness of life; the relationship with other existing concepts; normalization vs. medicalization. In terms of research, there is a need to further refine, validate and operationalize the concept, which will be instrumental to a more robust debate and to ways to address the phenomenon in healthcare and in society.

## Completed Life: Dying as a Transformative Experience

Professor Stephen Clarke<sup>1</sup>, Dr Tessa Holzman<sup>1</sup>

<sup>1</sup>Charles Sturt University

In 2014 L. A. Paul published the hugely influential book *Transformative Experience*. Paul (2014) argued that many of life's most important choices are typically not made rationally. This is because such choices are both epistemically and personally transformative. They allow us to access to forms of knowledge and insight we previously lacked, and they can lead to lasting changes to our preferences, desires, and values. Because we are unable to anticipate how we will be epistemically and personally changed by a transformative experience such choices cannot be made on the basis of rational calculation. Examples of transformative experiences are becoming a parent for the first time and joining an army.

Here we consider two conceptual problems that are raised by transformative experiences for people who would like to access assisted dying services because they are convinced that their lives have become permanently meaningless – that their lives have been 'completed'. One problem is that, given the impossibility of predicting how a transformative experience will affect a person's outlook, one cannot rule out that she may undergo an experience that will prove to be transformative in terms of her life's meaningfulness. The other is that if the dying process is a transformative experience, as Thompson (2020) persuasively argues, then that process may itself be a source of meaning, undermining their assertion that their lives can no longer be meaningful. We'll consider implications of these conceptual problems for the scope of arguments to liberalize regulations about access to assisted dying services.

### References

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## Legal Regulation of Institutional Objections to Voluntary Assisted Dying: An International Comparative Analysis

Dr Katrine Del Villar<sup>1</sup>, Dr Eliana Close<sup>1</sup>

<sup>1</sup>Australian Centre for Health Law Research, Queensland University of Technology

An increasing number of jurisdictions are considering enacting voluntary assisted dying ('VAD') laws. While most laws include protections for individual health practitioners to conscientiously object, the position of institutions who decline to participate on religious, moral, or ethical grounds is more controversial. This issue has significant impacts for patients, health practitioners and institutions. At the patient level, evidence from Australia and Canada established that some patients in non-participating institutions experienced harms from objections by institutions, including problems accessing VAD (White et al, 2023; Jeanneret et al 2024; Close et al, 2023). At the institutional level, hospices and hospitals have been sued (*St Raphael's v Quebec* 2023; *O'Neill v St Paul's Hospital* 2025), and institutions have been closed or defunded (*Farrish v Delta Hospice* 2021) for refusing to provide VAD services to patients. In the USA, health practitioners have been dismissed for refusing to comply with institutional prohibitions on participating in VAD (*Morris v Centura Health*, 2023).

The issue highlights tensions in reconciling institutional interests (including religious values), professional obligations, and patient access to lawful health choices. This research examines and systematically maps the range of international regulatory responses seeking to balance these conflicting values or goals. It considers legislative provisions applying to institutional non-participation in VAD in all countries that have legalised VAD.

Drawing on the framework identified by White et al (2023), we identify three primary legal positions: (a) conscience absolutism (Austria and US states), (b) compromise models (in some Australian states), and (c) conscience non-toleration (Quebec and Colombia).

This framework and analysis of different legal models for regulating institutional participation in VAD can be used to inform the debate in Australia and internationally around the role of institutions in providing morally contentious services. It will provide options for jurisdictions seeking to reform their laws or policies.

## Optimal Regulation of Medical Assistance in Dying: Lessons from a Canadian Case Study

Dr Eliana Close<sup>1</sup>, Professor Emerita Jocelyn Downie<sup>1,2</sup>, Professor Ben P White<sup>1</sup>

<sup>1</sup>Queensland University of Technology, Australian Centre for Health Law Research, <sup>2</sup>Faculties of Law and Medicine, Dalhousie University

Canada legalized medical assistance in dying (MAiD) federally in 2016, with key amendments occurring in 2021. Canada serves as a valuable case study for other jurisdictions that are considering legalising MAiD or that are reviewing the operation of existing laws.

This presentation distils findings from a multi-year Canadian case study that formed part of the Australian Research Council funded project, Enhancing End of Life Decision-Making: Optimal Regulation of Voluntary Assisted Dying. This case study sought to investigate how MAiD practice in Canada is shaped by traditional forms of regulation (i.e. law and policy), and an array of other mechanisms that influence behaviour (e.g. education and training, ethical codes, and health system structures).

The Canadian case study utilised three key methods: 1) law and policy analysis; 2) semi-structured qualitative interviews with MAiD assessors and providers (n=32), patients and family caregivers (n=34), and health leaders/policymakers (n=40); and 3) regulatory space mapping. The authors (with colleagues) published a series of peer-reviewed articles examining various aspects of MAiD regulation, including analyses of provincial and territorial legislation, professional standards, and qualitative studies exploring stakeholders' perspectives on optimal regulatory approaches.

This presentation will discuss key lessons learned from the Canadian case study as a whole, which may provide useful insights for other jurisdictions. Lessons include: the importance of coordination mechanisms in a polycentric regulatory system; planning ahead and investing in support structures for support regulatory changes; conditions for effective monitoring and oversight; and the importance of key individuals at the clinical coalface. The findings underscore the need for collaboration, clinical input, and leadership to bridge regulatory gaps. The presentation provides recommendations for policymakers, healthcare professionals, and other stakeholders grappling with the complexities of MAiD regulation and practice.

## Protections from criminal, civil and conduct liability in respect of assisted dying in Australian jurisdictions.

Professor Tina Cockburn<sup>1</sup>, Adjunct Professor Bill Madden<sup>1</sup>

<sup>1</sup>Australian Centre For Health Law Research

Voluntary assisted dying legislation across Australia includes criminal, civil and conduct liability protections for specified persons. The provisions are not uniform as to their nature and scope.

For example, s 148 of the Voluntary Assisted Dying Act 2021 (Qld) (the Qld Act) provides protection from civil liability “for an act done or omission made in good faith and without negligence in accordance with, or for the purposes of, this Act.” However, s 150 of the Qld Act states there is no such protection from disciplinary proceedings, complaints or referrals. By contrast, s95 of the Voluntary Assisted Dying Act 2021 (SA) is broader and provides that no liability arises for unprofessional conduct or professional misconduct; in any civil proceeding; or for contravention of any code of conduct.

There have been as yet no reported decisions in respect of civil liability or disciplinary action in relation to the provision of assisted dying advice and treatment in Australia. This presentation will map the comparative provisions which relate to criminal, civil and conduct liability protections across Australia and evaluate their nature and scope.

## Specialised Training and Support for Pharmacists in Queensland's Voluntary Assisted Dying Service

Mrs Elisha Cole<sup>1</sup>, Prof Liz Reymond<sup>1</sup>, Ms Enna Stroil-Salama<sup>1</sup>, Ms Lesley McLeod<sup>1</sup>

<sup>1</sup>Queensland Voluntary Assisted Dying Support And Pharmacy Service

### Introduction

Centralised clinical services promote safety, standardisation, quality assurance, and clear governance. In Queensland, this approach underpins the establishment of the Queensland Voluntary Assisted Dying Support and Pharmacy Service (QVAD SPS), a dedicated statewide pharmacy service for voluntary assisted dying (VAD). QVAD SPS pharmacists are responsible for dispensing VAD substances and providing in-person standardised education to patients, families, and clinicians to on their safe use. This approach aligns with centralised model adopted by other Australian states and stands in contrast to Canada's decentralised medical assistance in dying (MAiD) system, where pharmacists often work in isolation and report feeling unsupported psychosocially, legally, morally, and clinically.

### Objective

To describe the achievement of the extended scope of practice of QVAD SPS pharmacists, with emphasis on the acquisition of specialised skills and expertise in supporting eligible VAD patients at end-of-life.

### Key Findings

QVAD SPS pharmacists complete a comprehensive onboarding program designed to expand their expertise beyond traditional pharmacy practice. Their role includes contributing directly to end-of-life care by providing safe, holistic, patient-centred support. Training covers Queensland VAD legislation and implementation processes, the pharmacology of VAD substances, substance management, referral pathways to end-of-life and bereavement care services, practical aspects of death and end-of-life communication. Pharmacists develop skills to deliver standardised VAD substance counselling that is compassionate, tailored, and compliant with legislative and professional obligations. QVAD SPS offers ongoing opportunities for debriefing, reflection and supervision to provide psychological support and safeguard workforce wellbeing.

### Conclusion

Through advanced training and structured support, QVAD SPS pharmacists have developed an extended scope of practice that integrates specialist knowledge of VAD with aspects of end-of-life care. Their role is pivotal in collaborating with the wider healthcare teams to ensure that patients, families, and clinicians receive safe, comprehensive and compassionate support with VAD substance supply and administration.

## Healthcare Practitioner Experiences in Organ Donation Following VAD: Insights from Early Australian Cases

Dr Aurélie Copin<sup>1,2</sup>, Dr Wade Stedman<sup>1</sup>

<sup>1</sup>Royal North Shore Hospital (NSW Health), <sup>2</sup>Australian Centre for Health Law Research (ACHLR), QUT

Organ donation (OD) following voluntary assisted dying (VAD) is an emerging and ethically complex practice in Australia, and remains rare and contentious internationally. While limited case reports have been published—primarily from Belgium, the Netherlands, and Canada—this area remains under-researched, particularly from the perspective of healthcare workers (HCWs).

This empirical, dual-methods study explores the views and experiences of HCWs involved in the first six cases of OD after VAD in New South Wales (NSW). A cross-sectional survey and optional semi-structured interview was distributed to all HCWs identified as participating in these cases. The study investigates responses across four key domains: ethical dilemmas, emotional and psychological impacts, professional challenges, and the legal/regulatory environment.

The quantitative component of the study captures data via a structured survey, aimed at identifying common themes and measuring the extent of ethical, emotional, and professional concerns across clinical roles and settings. The qualitative component involved semi-structured interviews with a sub-sample of respondents, offering deeper insights into individual experiences and the nuanced realities of participating in this unique clinical process.

By examining both broad patterns and individual narratives, this study seeks to provide a comprehensive understanding of the professional and emotional landscape surrounding OD after VAD. Findings hope to help inform policy, support systems, and training frameworks for HCWs navigating this evolving intersection of end-of-life care and organ donation.

## “It’s Incredibly Complex”: U.S. Healthcare Professionals’ Perceptions about MAID in Persons with Dementia Policy

Professor Kara Dassel<sup>1</sup>, Professor Teneille Brown, Post-doctoral fellow Amber Thompson, Post-doctoral fellow Sharon Bigger, Post-doctoral fellow Sasha Perez, Post-doctoral Fellow Tood Becker, Professor Rebecca Utz, Professor Timothy Farrell

<sup>1</sup>University Of Utah

**Background:** Expanding “Death with Dignity” legislation across the U.S. necessitates examining the accessibility of hastening death through voluntarily stopping eating and drinking (VSED) or medical aid in dying (MAID) for persons with dementia. To date, no study has specifically focused on U.S. healthcare professionals’ perceptions, experiences, and attitudes about hastening death in persons with dementia.

**Methods:** We employed an inductive content analysis of interview text from a blended nonprobability sample of healthcare professionals (N=12; working directly with patients at the end-of-life) from an existing online survey from which we purposively selected an intensity subsample. Our research question guided the interviews; “What are the legal or policy issues regarding MAID in dementia that are of concern for this sample population?” Interviews were transcribed verbatim and read/re-read, by four team members, for independent and collective identification of codes and categories.

**Results:** The sample identified as White, non-Hispanic, primarily female (83.4%), and well-educated (67% completed post-graduate education). One-third live in states where MAID is legal. The participants have been in their current roles as healthcare professionals for 11 years on average and work primarily in home health and hospice. Based on the analysis of the interviews, three categories emerged: 1) Access barriers (e.g., politicization, exclusion), 2) Ethical considerations (e.g., moral ambivalence, legitimization), and 3) Healthcare system inadequacies (e.g., problematic care quality).

**Discussion:** Interviews with healthcare professionals revealed several areas of concern. Notably, participants expressed concerns regarding equitable access barriers, ethical considerations in terms of implementation, and structural inadequacies in the current healthcare system that result in having to identify “workarounds” to provide optimal person-centered end-of-life care. The data reflect the concerns of this sample surrounding MAID policy for dementia but also highlight the broader concerns around MAID and VSED policies. These findings underscore the complex policy considerations”

## A World-First: Transforming Mental Health Treatment and End of Life Care with Psychedelic-Assisted Therapies

Justine Topfer<sup>2</sup>, Mrs Tania de Jong AM<sup>1</sup>, Mr Peter Hunt AM<sup>1</sup>, Ms Kathryn Tucker<sup>1</sup>

<sup>1</sup>Mind Medicine Australia, <sup>2</sup>End Wise

In 2023, Australia became the first country to reclassify psilocybin and MDMA from prohibited substances to controlled medicines for specific mental-health indications. Regulated treatment commenced in 2024 under the supervision of Authorised Prescribers and multidisciplinary teams. This policy development has unfolded alongside a growing global body of research suggesting that psychedelic-assisted therapy (PAT) may alleviate psychological, existential, and spiritual distress in individuals facing life-limiting illness.

This presentation examines the early Australian implementation of PAT with a particular focus on its relevance to depression, stress and trauma due to an end-of-life diagnosis. We review the international evidence base—including clinical trials demonstrating reductions in depression, anxiety, trauma and demoralisation in palliative populations—and consider how these findings are informing Australian clinical practice, workforce training, and health-system planning. Key components of the national ecosystem developed by leading peak body and charity, Mind Medicine Australia, include structured clinician training, development of clinical protocols, medicine supplies, establishment of specialised treatment settings, and the creation of a national real-world evidence registry at the Australian National University.

In 2025, the End Wise coalition—a network of clinicians and researchers exploring the integration of PAT into end-of-life and palliative-care contexts—began work to assess clinical utility, patient-reported outcomes, ethical considerations, and system-level requirements for safe delivery. Early qualitative insights from clinicians and patients point to both potential therapeutic value and the operational challenges of embedding PAT within existing models of care.

This session presented by Tania de Jong AM, Peter Hunt AM, Justine Topfer and Kathryn Tucker (USA) will explore how psychedelic-assisted therapies are transforming the future of mental health treatment. Australia now leads the world in introducing regulated access to psychedelic-assisted therapies and you will learn what these developments mean for clinicians, patients, and the broader healthcare system.

This session, presented by Tania de Jong AM, Peter Hunt AM, Justine Topfer, and Kathryn Tucker (USA), will synthesise current evidence, describe emerging Australian service models, and outline implications for clinicians, patients, and future research in psychedelic-assisted mental illness and end-of-life care.

## Grieving the Chosen Death: A Synthesised Grief Framework for Assisted Dying

Dr Aida Dehkhoda<sup>1</sup>, Dr Jessica Young<sup>1</sup>, Professor Ben White<sup>2</sup>, Associate Professor Gary Cheung<sup>3</sup>, Professor Kate Diesfeld<sup>4</sup>, Dr Jeanne Snelling<sup>5</sup>, Dr Tess Moeke-Maxwell<sup>3</sup>, Dr Kate Reid<sup>6</sup>, Associate Professor Richard Egan<sup>5</sup>

<sup>1</sup>Victoria University of Wellington, <sup>2</sup>Queensland University of Technology, <sup>3</sup>University of Auckland, <sup>4</sup>Auckland University of Technology, <sup>5</sup>University of Otago, <sup>6</sup>University of Canterbury

The implementation of New Zealand's End of Life Choice Act in 2021 introduced assisted dying (AD) as a legal end-of-life option, fundamentally reshaping experiences of death and grief. By March 2025, 1,210 individuals had died using AD, affecting the grief experiences of both patients and families due to the planned and collaborative nature of the process. Despite families' active involvement in caregiving and AD planning, their grief remains underexplored, particularly in the New Zealand context.

This study explores how grief theories help explain the unique experiences of AD-related grief. Using an appreciative inquiry approach, we interviewed 46 participants (eligible and ineligible for AD) and their families, representing 42 deaths. A whole-team coding approach informed our inductive-deductive analysis of grief expressions through the lens of established grief theories.

Findings reveal that anticipatory grief during AD unfolds through two interconnected sets of activities: advocacy work (e.g., navigating the AD process, sharing information, and planning logistics) and legacy work (e.g., engaging in rituals, memory-sharing, and creating final experiences). These activities support emotional, cognitive, and behavioural preparation for death and contribute to meaning-making. Post-death, families continue this process through public advocacy and remembrance, forming continuing bonds. This grief experience aligns with the dual process model, where individuals oscillate between loss-oriented (focused on confronting and processing the emotional impact of the death) and restoration-oriented (focused on adapting to life changes and rebuilding after the loss) coping. The intentional and often stigmatised nature of AD shapes a distinctive grief trajectory, offering new insights into AD bereavement.

## Attitudes Towards and Participation in Voluntary Assisted Dying: A Pilot Study of Queensland Hospices

Dr Katrine Del Villar<sup>1</sup>

<sup>1</sup>Australian Centre For Health Law Research, QUT

The involvement of faith-based institutions in controversial services such as voluntary assisted dying (VAD) is a vexed issue both in Australia and internationally. It has significant impacts both for patients and institutions. Evidence from Victoria established that a subset of patients in non-participating institutions experienced problems accessing VAD, including delays, lack of choice, transfer between institutions, and emotional impact (White et al, 2023; Jeanneret et al 2024). Evidence from Canada has documented similar problems (Close et al, 2023).

In response to this evidence of harm to patients, when VAD became legal in Queensland in January 2023, the governing legislation incorporated provisions requiring institutions to facilitate access to VAD services. This includes allowing VAD practitioners to conduct VAD consultations and assessments within institutions, and in some instances to allow administration of a VAD substance to occur on the premises.

This project considers the impact of these laws on Queensland hospices, which provide palliative care to persons with life-limiting illnesses. There are 10 hospices in Queensland, many of which are faith-based. These hospices receive support from Queensland Health but are independent community organisations. For faith-based institutions in Australia, these laws represent an unprecedented interference with freedom of religion. Given their newness, the impact of VAD laws on faith-based institutions has not been examined.

This project explores the diversity of stakeholder views within Queensland hospices through a survey of hospice staff - doctors, nurses, social workers, therapists, counsellors, bereavement specialists, educators and trained volunteers. It reports on the impact of these laws requiring hospices to allow aspects of VAD to occur on the premises on a range of stakeholders. This information will elucidate the extent of the burden posed by the current VAD laws on hospices and their staff in Queensland.

## “Navigating the Nuance: Differentiating MAiD Requests from Suicidal Expressions in Mental Illness Contexts”

Mr. Ali Ladak<sup>2</sup>, Dr. Saumil Dholakia<sup>1</sup>, Ms. Bridie Hamilton<sup>2</sup>, Ms. Sara Olivier<sup>3</sup>, Mr. Michael Kekewich<sup>2</sup>

<sup>1</sup>The Ottawa Hospital, University Of Ottawa, <sup>2</sup>Champlain Center for Bioethics, The Ottawa Hospital, <sup>3</sup>Champlain Regional MAiD Network

Distinguishing a genuine request for Medical Assistance in Dying (MAiD) from expressions of suicidality poses a profound clinical and ethical challenge—especially when mental illness is the sole underlying medical condition. This workshop explores the subtle yet critical differences between patients who 'desperately want to live but cannot do so' and those seeking to end a life perceived as having 'open ends'—an essential narrative for accurate assessment and compassionate care. Using an inquiry-based learning model, participants will collaboratively explore anonymized case vignettes informed by real-world experiences to generate and refine their understanding of the distinctions between suicidality and autonomous MAiD requests. Attendees will be guided through a structured process of questioning, evidence gathering, and critical dialogue thereby encouraging deep engagement with clinical uncertainty and moral complexity.

Key areas of focus include:

- Comparative analysis of MAiD request assessments and suicide risk assessments—highlighting where they overlap and diverge in purpose, methodology, and outcomes.
- Criteria to discern when a request represents a considered, autonomous desire for assisted death versus an expression of suicidality.
- Evaluating capacity in fluctuating mental states and the ethical responsibility to protect vulnerable individuals without dismissing genuine suffering.
- Incorporating patient narratives that reflect the paradox of wanting to live yet feeling unable, versus seeking to end an otherwise viable life.

Through small-group inquiry and guided reflection, participants will construct a nuanced understanding of how suffering, capacity, and mental illness interact in the context of MAiD. This approach fosters active learning, critical thinking, and practical application of ethical principles in real-world contexts.

By the conclusion, attendees will be better prepared to differentiate genuine MAiD requests from expressions of suicidality, ensuring ethically sound, patient-centered care that respects both autonomy and the imperative to protect vulnerable individuals.

## Reforming MAiD Oversight in Canada: Bridging Ethical Gaps With Global Policy Lessons.

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Since the legalization of Medical Assistance in Dying (MAiD) in Canada in 2016, regulatory oversight has evolved in a fragmented manner. While the federal government mandates national reporting, the responsibility for MAiD oversight and performance monitoring remains decentralized across provincial and territorial jurisdictions. This has resulted in a patchwork of oversight mechanisms, characterized by retrospective audits, limited prospective review, and significant interprovincial variability in quality assurance practices.

This presentation critically examines the current state of MAiD regulatory oversight in Canada, identifying key policy gaps and ethical tensions arising from this jurisdictional fragmentation. Drawing on a comparative analysis of international oversight frameworks as well as existing provincial oversight policies, it highlights promising models from other jurisdictions that balance provider accountability, patient autonomy, and systemic transparency.

This presentation proposes a reimagined oversight structure: a coordinated federal-provincial governance platform that integrates both non-restrictive prospective review and data-informed retrospective evaluation. This model emphasizes transparency, patient-centered care, and continuous practice feedback for MAiD providers, while maintaining public trust and safeguarding ethical standards.

Ultimately, this policy-focused analysis underscores the urgent need for a more coherent and ethically grounded regulatory framework — one that both reflects Canada's federal structure and offers scalable insights for international jurisdictions navigating similar end-of-life care reforms.

## Holding the conversation open: Clinician hesitation, system gaps, and end-of-life dialogue in a VAD context

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### Introduction

Heart, lung and kidney disease cause substantial physical, psychological and existential burden, yet end-of-life discussions remain under-represented. Voluntary assisted dying (VAD) discussions can act as an entry point to explore unmet needs and concerns about dying. However, clinician confidence and preparedness to engage in conversations is low, and factors influencing perspectives in this clinical workforce remain poorly understood. This study applied the Theoretical Domains Framework (TDF) to explore influences on chronic-disease clinician's views around VAD discussions and to identify ways to support sustained, values-based dialogue.

### Methods

Thematic analysis of free-text data from a National anonymous cross-sectional survey of Australian nurses, physicians and allied-health professionals working in lung, heart and kidney disease. The survey was distributed via organisational emails and snowball sampling. This secondary analysis of free-text data was interpreted thematically using the TDF to explore influences on clinician perspectives, including hesitations, personal and patient-related barriers, rural access, and suggested facilitators.

### Results

Respondents (n=189; 98% of survey cohort) were largely female (88%), aged +40, with +10 years' experience. Most were nurses (70%), and many worked across multiple conditions (38%). 56% reported VAD had been raised, though training was limited (44% no VAD training).

Five domains (TDF) influenced clinician-perspectives: own and community knowledge; hesitations linked to professional role and identity; beliefs about consequences, including concern over distressing patients or family; environmental and organisational barriers, such as workplace culture and training; and social influences, including personal beliefs and perceptions of patient/family values.

### Conclusion

Clinicians are often approached about VAD, yet their capacity to sustain open conversations is constrained by intersecting knowledge, moral, professional and system-level factors. Legislative change creates opportunity, however, training and supportive cultures need to be strengthened to help clinicians recognise VAD queries as opportunities to foster end-of-life dialogue in populations that have historically had limited access to such conversations.

## Conscientious objection: Ensuring patient centrality

Dr Charles Douglas<sup>2</sup>, Ms Kellie Goldsworthy<sup>1</sup>

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Under the Voluntary Assisted Dying Act 2022 (NSW) (“the Act”) a hospital “...may decide that it will not provide services relating to voluntary assisted dying...” As a Catholic hospital operating under the Code of Ethical Standards for Catholic Health and Aged Care Services in Australia, the Calvary Mater Newcastle Hospital does not provide Voluntary Assisted Dying (“VAD”) services. Such a hospital has obligations under the Act, largely written in terms of “reasonable” steps that must be taken to allow patients access to information about VAD, to allow the assessment and approval process for VAD to progress, and to allow patients to proceed with the administration of a VAD substance if they so desire.

The Calvary Mater Newcastle Hospital is the region’s main provider of oncology and palliative care services and so many referrals to the Hunter New England VAD service (from patients, families, GPs and from the NSW VAD Care Navigator service) relate to Calvary Mater Newcastle patients.

The journey that our two services have undertaken together has at times been fraught with ethical, moral, theological and value laden discourse. Yet, with a shared wish to ensure patient centrality, and with honest and open communication, we have been able to provide patient centred care that respects the wishes of our shared patients who are requesting VAD. Given the (historically) volatile debate on voluntary assisted dying (and some anecdotal evidence from other sites), we believe this has been a significant achievement despite some frustrations on both sides.

In this presentation, the two presenters (senior representatives from each institution) will explain how this endeavour has looked from alternative sides of the ‘divide’. We hope this talk will inform mutual understanding and respect between other VAD services and other non-providing hospitals and facilities, and help them to find a ‘middle way’.

## What Is the True Death of a Human Being?

Prof. Jason Eberl<sup>1</sup>

<sup>1</sup>Saint Louis University

Debate regarding the validity of using neurological criteria to determine death – “brain death” – has been central to the field of bioethics since its inception. At the root of this debate are several philosophical claims regarding the definition of human personhood and criterion of personal identity, concepts such as “organism as a whole” and “irreversibility,” and whether death should be understood as a strictly biological fact or a partially socially constructed phenomenon. The brain death debate has been re-energized by recent cases involving apparent post-brain death survival -- e.g., Jahi McMath -- calls to revise the U.S. Uniform Determination of Death Act (UDDA), and the development of a novel means of organ procurement known as normothermic regional perfusion following circulatory determination of death (NRP-DCD). This presentation revisits the arguments for and against brain death, defending not only the conceptual validity of brain death, but also its marking the true death of a human being and that the circulatory criterion is valid only insofar as it may serve as a clinical indicator that brain death has occurred. In arguing for this conclusion, the UDDA's current requirement of "irreversibility" will be defended against the proposed change to "permanent." Also defended will be the current guidelines for determining death from the American Academy of Neurology (AAN), which do not require assessing neuroendocrine function for a valid determination of death. While this presentation's overall conclusion challenges current practices of organ procurement following circulatory determination of death, including NRP-DCD, due to insufficient wait-times following asystole, it preserves current organ procurement practices following the determination of death using neurological criteria following the current AAN guidelines.

## Judicialization and Third-Party Intervention in the Spanish Aid-in-Dying System

Mr Luis Espericueta<sup>1,2</sup>, PhD Iris Parra-Jounou<sup>1,3</sup>, PhD Rosana Triviño-Caballero<sup>1,4</sup>

<sup>1</sup>CYBE-FILOLAB, <sup>2</sup>University of Granada, <sup>3</sup>Universitat Autònoma de Barcelona, <sup>4</sup>Universidad Complutense de Madrid

One of the main challenges facing the Spanish aid-in-dying system is the judicialization of requests initiated by third parties. The “Tarragona gunman” case illustrates this: although his request was approved by the competent medical commission, both the public prosecutor and private prosecutors representing the victims opposed its execution, arguing that euthanasia would preempt the trial. The court ultimately confirmed that aid-in-dying is a healthcare service beyond criminal jurisdiction, setting an important precedent.

Despite this, attempts to halt procedures through judicial channels continue. Media reports document at least three cases in which family members, supported by the ultraconservative association Abogados Cristianos, temporarily suspended euthanasia procedures already approved by healthcare professionals and review commissions through administrative litigation. Two claims were dismissed, while one appeal was admitted for consideration.

Judicial interference can have harmful consequences. Requests approved within established medical and ethical frameworks may be influenced by considerations unrelated to clinical criteria. Legal proceedings, including interrogations and evidence submissions, can physically and emotionally burden vulnerable applicants. Healthcare professionals may experience criminalization, emotional distress described as “judicial clinical syndrome,” or the “second victim” phenomenon after adverse events. These effects may discourage professionals from participating in aid-in-dying evaluations and procedures.

This presentation explores the implications of judicialization in the Spanish aid-in-dying system. It will also examine legislative approaches in the United Kingdom and Portugal, where the involvement of third parties has been explicitly recognized. Drawing on laws and jurisprudence, it seeks to clarify who may legitimately request the suspension of euthanasia procedures, as well as the scope and limits of such interventions.

## Community knowledge and attitudes toward voluntary assisted dying in Queensland, Australia

Prof Ben White<sup>1</sup>, Prof Lindy Willmott<sup>1</sup>, Dr Rachel Feeney<sup>1</sup>

<sup>1</sup>QUT

This study examined public awareness and attitudes toward voluntary assisted dying (VAD) in Queensland, Australia, 17 months after its legalisation. A representative sample of 1,000 adults completed an online survey, with quotas applied for age, gender, and geographic region. Findings revealed limited public awareness of VAD: only 33% of participants correctly identified VAD as legal, and just 26% reported knowing how to access it. Most participants (86%) indicated they would seek VAD-related information online-primarily via search engines-and from health professionals, particularly doctors.

Support for VAD legalisation was high, with 82% of respondents expressing approval. Support was strongest among women, individuals aged 25 and older, and those who primarily speak English at home. Sixty-five percent of participants reported they would likely personally consider VAD if suffering from a terminal illness.

Views on VAD in dementia-related scenarios were more nuanced. Sixty percent supported access to VAD for individuals with decision-making capacity, increasing to 70% when VAD had been requested via an advance directive. Female gender was associated with higher support for VAD when capacity was retained, while the youngest and oldest age groups were more likely to oppose VAD in both dementia scenarios.

These findings have important implications for public education, health professional training, and policy development related to VAD in Queensland.

## Eastern Health experience in establishing a Voluntary Assisted Dying Unit and Clinical Director role

Dr Danielle Ferraro<sup>1</sup>, Ms Eliza Armstrong<sup>1,2</sup>

<sup>1</sup>Eastern Health, <sup>2</sup>Epworth Health

Eastern Health provides care in public inpatient and outpatient facilities across the largest geographical area of any metropolitan health service in Victoria. The introduction of Voluntary Assisted Dying in Victoria in 2019 presented a new challenge for the public healthcare sector to respond to requests for VAD, and to incorporate and facilitate access for eligible patients. The Eastern Health model for Voluntary Assisted Dying has evolved in response to our experience during implementation of this service, and in response to organisational restructure and obstacles encountered over the last 6 years. Eastern Health now has an active Voluntary Assisted Dying Unit, under the auspices of the Cancer Services Unit. The Unit is comprised of a Clinical Director, VAD Coordinator and approximately 20 trained practitioners providing VAD services to our patients. Developing and growing a VAD service has involved significant cooperation, education and support across the service, and there have been numerous obstacles, both expected and unexpected, over the years to navigate. We present our experience in developing a robust, responsive, Director-led Voluntary Assisted Dying Unit in a large and diverse metropolitan health service.

## The MAiD/non-assisted suicide relationship: a new, integrated model proposal for conceptualisation and experimental analysis

Mr Neil Francis<sup>1</sup>

<sup>1</sup>Ghent University, Belgium

The relationship between medical aid in dying (MAiD) and non-assisted suicide (NAS) is complex. However, many commentators, including some scholars, tend to focus on one or other personally salient belief about mediating variables and can even preferentially bring to mind sources or information that appear to endorse their beliefs. These kinds of cognitions can be underwritten by motivated reasoning and confirmation bias. They can occur amongst both promoters and detractors of MAiD, and arise in empirical investigations as well as argumentation.

Lack of a cohesive, robust model of the relationships has significantly hampered research and understanding to date. It can result in dialogue descending into low-value competitions of emphasis, and claims of morally superior terminology at the expense of accurate understanding of underlying factors. It can also lead authors of empirical investigations to confidently opine conclusions that are unwarranted by the data or method.

This session introduces a new integrated model proposal for the MAiD/NAS relationship, designed to help avoid these limitations. The draft model is intended to stimulate conversation and debate towards further robust development.

Constituent elements of Werther (contagion), Papageno (protection), Posner (substitution) and related factors will be presented. Their primary premises and properties will be outlined, each organised into a structured framework linking MAiD and NAS, and situated alongside some critical related subject domains.

Audience discussion is welcomed.

## Medical aid in dying in the US federal system and requirements for residency

Distinguished Professor Leslie Francis<sup>1</sup>, Professor John Francis<sup>1</sup>

<sup>1</sup>University Of Utah

When medical aid in dying was first introduced in the US in Oregon, it came with residency requirements. These requirements might have been justified because the state did not wish to become a magnet for transient and potentially vulnerable patients seeking MAID. In 2022, Oregon settled a constitutional challenge to the requirement by removing it. (As of this writing, Vermont has also ended its residency requirement, but the other US jurisdictions in which MAID is permitted have not. This includes New Jersey, where a federal court's dismissal of a constitutional challenge is currently on appeal.) Patients from elsewhere in the US can now receive MAID in Oregon, so long as they meet other statutory requirements, including requirements for consultation, medication dispensing, and reporting. Oregon now collects residence information for patients at the time prescriptions are received; the 2024 Report indicates that 23/607 (approximately 4%) of prescription recipients were not Oregon residents but Oregon does not track out of state death certificates. Although this was a slight decline from the 5% of out of state MAID recipients in 2023, it remains unknown whether out of state MAID may increase, especially if the possibility becomes more widely known and residency requirements are eliminated in other states permitting MAID.

This presentation will examine the landscape of legal, ethical, and political issues that can be expected to arise if out of state MAID increases in the US. To survey this landscape, it will draw on comparisons with medication abortion across state lines, also a form of health care about which states disagree.

## Checks and Balances on VAD and MAiD: The Important Role of Coroners and Review Boards

Professor Ian Freckelton AO KC<sup>1</sup>

<sup>1</sup>University Of Melbourne

The effectiveness of checks and balances in relation to voluntary assisted dying (VAD) and medical assistance in dying (MAiD) procedures constitutes an important basis upon which the community can repose trust that the criteria for patients' use of the schemes are fair, consistent with contemporary values, and that they are not being misused or abused.

Two important oversight mechanisms in Australia, New Zealand and Canada are VAD review boards and the inquisitorial jurisdiction of the coroner.

This paper identifies the parameters of review boards' jurisdiction and their role in making recommendations for how VAD processes can be improved.

It also scrutinises the role of coroners who are generally excluded from investigating VAD and MAiD deaths as reportable deaths but who are empowered to inquire into such deaths when there is a concern that something irregular or unlawful has taken place in relation to a particular death.

Coroners are empowered by statute to make findings but also recommendations and comments in the public interest. This paper reviews some of the prominent inquests and reports in which Australian and Canadian coroners have utilised their oversight jurisdiction to address issues arising from the operation of VAD and MAiD legislation.

The paper argues that both review boards and coroners have already contributed constructively to oversight in relation to assisted deaths and that they are likely to play a significant ongoing role in enhancing VAD and MAiD legislation and the operation of the schemes.

## Looking back and looking forward: Ten years of Medical Assistance in Dying (MAiD) in Canada

Director, Program for Ethics and Care Ecologies (PEaCE) and MAiD Andrea Frolic<sup>1,5,7</sup>, Professor Marie-Eve Bouthillier<sup>2,3</sup>, Professor Jocelyn Downie<sup>4,8</sup>, Dr Gordon Gubbitz<sup>6,9</sup>

<sup>1</sup>Hamilton Health Sciences, <sup>2</sup>Département de médecine de famille et de médecine d'urgence Faculté de médecine, Université de Montréal, <sup>3</sup>Centre de recherche du Centre hospitalier de l'Université de Montréal (CRCHUM), <sup>4</sup>Adjunct Professor, Australian Centre for Health Law Research, <sup>5</sup>Department of Family Medicine, Faculty of Health Sciences, McMaster University, <sup>6</sup>Division of Neurology, Department of Medicine, Dalhousie University, <sup>7</sup>Department of Bioethics, Dalhousie University, <sup>8</sup>Faculties of Law and Medicine, Dalhousie University, <sup>9</sup>Nova Scotia Health--MAiD Program

This multidisciplinary panel presentation will provide an integrated, thoughtful reflection on the 10 years since the legalization of Medical Assistance in Dying (MAiD) in Canada. It will highlight the evolution of MAiD practice over the decade, lessons learned, and consider the ethical, legal, and clinical challenges that lie ahead.

Speakers will bring the following perspectives:

- a lawyer involved in the litigation that resulted in legalization as well as current legal challenges to barriers and restrictions on access to MAiD;
- a clinician involved in MAiD assessments and provisions, and local / national collaborations to support a community of practice for MAiD care;
- an ethicist/MAiD program director involved in the design and implementation of a hospital-based MAiD program as well as the national MAiD curriculum;
- a researcher/ethicist involved in implementing MAiD in Quebec and studying the ethical and social implications of the introduction of MAiD as an end-of-life care option.

The panel will review the legal history and current legal landscape (both in Canada and Quebec).

They will present data on the evolution of MAiD care in Canada, including who is and is not receiving MAiD, and other results of monitoring and oversight.

The unique aspects of MAiD in Quebec will be featured, including the rapid uptake of MAiD, and the recent introduction of Advance Requests for MAiD for specific conditions.

Evolving challenges in clinical practice (such as caring for diverse patients and managing interprofessional conflict), as well as MAiD program operations (such as inadequate resources and disparities between jurisdictions) will be discussed. Resources and strategies that have supported quality MAiD access and care will also be highlighted.

The panel will conclude with collective reflections on ethical challenges presented by complex cases, the effectiveness of various oversight mechanisms, and possible future directions (mature minors, advance requests, mental disorders).

## Building Moral Community in an Age of Polarization: Reconciling Rights of Conscience in Healthcare

Director, Program for Ethics and Care Ecologies (PEaCE) and MAiD Andrea Frolic<sup>1,2</sup>, Clinical & Organizational Ethicist Winifred Badaiki, MAiD Coordinator Marta Simpson

<sup>1</sup>Hamilton Health Sciences, <sup>2</sup>Department of Family Medicine, Faculty of Health Sciences, McMaster University

Healthcare providers (HCPs) may have strong beliefs and/or personal moral values regarding a wide range of controversial medical procedures, including end of life procedures such as assisted dying, alternative therapies or organ donation after cardiac death. Conscientious objection by HCPs may be a source of moral distress for objectors, and impede access to effective care for patients, leading to poor outcomes, complaints and litigation. Meanwhile, the inability to provide access to care can morally injure conscientiously participating HCPs. Issues of conscience influence organizational culture as the workforce becomes increasingly culturally, religiously and morally diverse, and in the current climate of political polarization, can lead to workplace conflict and fragmentation.

This presentation reflects on the creation of a Right of Conscience (RoC) guideline, resources and infrastructure within our hospital during the introduction of Medical Assistance in Dying (MAiD) in Canada. Rather than focusing on the conflict between the rights of patients and the rights of HCPs, we reframe the issue to consider how collaboration amongst diverse HCPs, teams and organizations can facilitate patient access while accommodating HCP values. This approach extends traditional discourses on conscientious objection, and proposes practical strategies that HCPs and healthcare leaders can employ to manage the challenges of a morally diverse workforce in a way that benefits patients, clinicians and team function.

First we describe the insufficiency of the conventional framing of conscientious objection to address the challenges encountered in the introduction of MAiD. Next we describe the suite of resources and interventions developed to promote moral diversity and an organizational culture of tolerance and respect, while ensuring access to timely and high quality care for patients. Finally we summarize the challenges and facilitators we encountered and lessons for organizations to manage RoC in a range of clinical contexts.

## Medical, ethical and legal issues in voluntary assisted dying for neurodegenerative disorders

Prof Christian Gericke<sup>1,2,5</sup>, Dr Madeleine Archer<sup>3</sup>, Dr Katherine Tan<sup>2</sup>, Prof Merrilee Needham<sup>4</sup>

<sup>1</sup>Australian National University, School of Medicine, <sup>2</sup>University of Melbourne, Melbourne Law School, <sup>3</sup>Queensland University of Technology, Australian Centre for Health Law Research, <sup>4</sup>University of Western Australia, Medical School, <sup>5</sup>University of Queensland, School of Public Health

Several jurisdictions, such as the Netherlands, Spain, and Quebec, permit patients with dementia to access voluntary assisted dying (VAD) through advance requests, replacing advance directives, which are otherwise used in healthcare. However, the eligibility criteria, assessment procedures, and safeguards vary significantly between these jurisdictions.

In Australia, expanding access to VAD for patients with dementia is a topic of public debate and is actively being considered by several legislators, such as in Victoria and the Australian Capital Territory.

Patients with other neurodegenerative disorders, such as motor neurone disease (MND), Huntington's disease, multiple system atrophy (MSA), or Parkinson's disease, currently face similar issues to those with dementia, as many conditions in this group also affect higher cognitive functions and can sometimes cause organic psychiatric symptoms, including depression, paranoid ideation, or hallucinations. Both cognitive impairment and psychiatric symptoms significantly impact patients' mental capacity to consent to VAD, which is currently required for all stages of the VAD assessment process in all Australian jurisdictions.

However, different neurodegenerative disorders have distinct clinical and prognostic features that affect patients' capacity to make decisions about VAD and to communicate them to the assessing practitioners.

In this panel discussion, experts in neurology, psychiatry, medical ethics, and the law will examine the similarities and differences of several neurodegenerative disorders in relation to eligibility for VAD. They will also consider the necessary safeguards to protect patients from coercion, as well as the challenges faced by families, caregivers, treating and assessing doctors, and other healthcare professionals.

Current barriers in VAD legislation that prevent patients with neurodegenerative disorders in several Australian jurisdictions, including the Australian Capital Territory, New South Wales, Queensland, Victoria, and Western Australia, will be discussed, along with the necessary amendments to enable safe access for these vulnerable patients.

## Vulnerability versus Autonomy: Voluntary Assisted Dying and Dementia

Mrs Amanda Gray<sup>1</sup>

<sup>1</sup>University Of Newcastle

What would you do if, faced with a terminal illness, you could legally end your own life? What if you were part of a group with poorer health outcomes than others? The term “disadvantaged dying” has been used to emphasise how lifelong vulnerabilities can significantly impact on end-of-life care. Encouraging autonomous decision-making is often viewed as the anti-thesis to this. This reliance on autonomy however is not without critique, with some feminist authors questioning what influence marginalisation has on autonomy. They argue that lifelong marginalisations and vulnerabilities impact on the ability to be an autonomous agent around end-of-life decisions, especially Voluntary Assisted Dying (VAD). Being a member of a marginalised group such as being female, older, and having a diagnosis of dementia may impact what vulnerability and autonomy means. While some authors have discussed vulnerability and autonomy and VAD, and more authors are discussing possibility of VAD and dementia, no one has combined these areas of enquiry to examine VAD and dementia through the lens of the vulnerability versus autonomy tension. No researchers have completed research regarding VAD and dementia with a gender analysis. Social Workers are uniquely placed to comment on this tension, with their expertise in empowerment and marginalisation. To not discuss this tension with people with dementia, however, reinforces the marginalisation that they experience within the medical field and research. My proposed research aims to address these gaps by interviewing both essential cohorts.

## Could a Person with Severe and Enduring Anorexia Nervosa Access Voluntary Assisted Dying in Australia?

Mr Ethan Green<sup>1</sup>, Senior Lecturer Katrine Del Villar<sup>1,2</sup>

<sup>1</sup>Queensland University of Technology, <sup>2</sup>Australian Centre for Health Law Research

Anorexia nervosa is unusual among mental illnesses, as it causes severe physical consequences, including death in extreme cases. People with severe and enduring anorexia nervosa ('SE-AN') have been granted access to voluntary assisted dying ('VAD') in countries with liberal eligibility criteria, including Belgium and the Netherlands. Recently, and controversially, three people with SE-AN were approved to access VAD in the USA, a country where access is restricted to persons with a terminal illness whose death is expected to occur within six months. Whether persons with SE-AN might be eligible to access VAD has also been a focal point of the debate over the VAD Bill in England and Wales.

Given these precedents, it is inevitable that some people with SE-AN will request VAD in Australia. This presentation synthesises the available medical and psychological literature on SE-AN and evaluates whether persons with SE-AN could meet the statutory eligibility criteria for VAD in the six Australian states and the ACT. This requires consideration of whether anorexia can be expected to cause death within the prescribed timeframe; whether it is 'incurable'; and whether SE-AN compromises a person's decision-making capacity to request VAD.

A particular focus of the presentation is on the legal meaning of 'mental illness'. All Australian jurisdictions expressly preclude a person from accessing VAD solely on the basis of mental illness. The presentation reviews available caselaw and evidence to determine whether SE-AN is properly characterised as solely a 'mental illness', or as both mental and physical illnesses. The outcome of this analysis will be of critical relevance to medical practitioners evaluating VAD requests from persons with SE-AN in Australia.

## Timely Advance Care and Resuscitation Planning in High-Complexity Hospital Inpatients

Dr Rajesh Gupta<sup>1,2</sup>, Dr Manoj George<sup>2,3</sup>

<sup>1</sup>Princess Alexandra Hospital, Metro South Health, <sup>2</sup>University of Queensland, <sup>3</sup>West Moreton Health

**Background:** Advance Care Planning (ACP) and Acute Resuscitation Plans (ARP) are essential components of high-quality end-of-life care, enabling patients to express their values, preferences, and treatment priorities before capacity is lost. In acute hospital settings, these processes guide decisions about resuscitation, ICU admission, and life-sustaining interventions, ensuring care remains ethically sound, legally compliant, and aligned with patient wishes. Delays or omissions can lead to unwanted interventions, emotional distress for families, and increased clinical and legal risks.

**Objective:** This audit evaluated the prevalence, timeliness, and barriers to ACP/ARP completion in high-complexity General Medicine inpatients, aiming to identify system improvements that promote earlier and more consistent integration into end-of-life care planning.

**Methods:** A retrospective audit was conducted over a two-month period in a tertiary hospital General Medicine unit. Eligible patients were older adults with complex medical needs. Data were extracted from the Integrated Electronic Medical Record and discharge summaries, and an anonymous clinician survey explored perceived barriers and improvement strategies.

**Results:** Review of patient records showed that formal advance care documentation was frequently absent at admission. When completed, resuscitation plans were often initiated late in the admission, sometimes only after clinical deterioration. Documentation of discussions with patients or families varied in detail and quality, and pre-existing plans from the community were inconsistently reviewed or updated. Clinician survey responses indicated that workload pressures, competing acute care demands, and limited confidence in navigating sensitive conversations were key challenges.

**Discussion:** Timely ACP/ARP supports patient autonomy, reduces the likelihood of non-beneficial treatment, and provides clarity in the final stages of life. These processes offer a structured, legally recognised pathway for shared decision-making, and are a critical foundation for ethically complex discussions around life-sustaining treatments, comfort care, and—where applicable—assisted dying considerations.

## Voluntary Assisted Dying for Dementia in Australia: Perspectives of People Living with Dementia and Carers

Ms Casey Haining<sup>1</sup>, Professor Lindy Willmott<sup>1</sup>, Professor Ben White<sup>1</sup>

<sup>1</sup>Australian Centre For Health Law Research, Queensland University Of Technology

Voluntary assisted dying (VAD) laws have passed in all Australian jurisdictions, except the Northern Territory. Currently, Australian eligibility criteria are likely to preclude people living with dementia from accessing VAD for their dementia. This presentation will report on the findings of a 2025 qualitative interview study conducted with 30 participants, including individuals living with dementia and carers (past and present). It will report on participants' reflections about whether VAD for dementia should be permitted in Australia and what subset of this cohort should be permitted access. It will also report on participants' suggestions about desirable features of a regulatory framework that may permit this to occur safely.

## Consent, Capacity, and Voluntary Decision-Making in Assisted Dying Contexts: Legal Participation in the Assessment Process

Dr. Margaret Hall<sup>1</sup>

<sup>1</sup>Simon Fraser University, <sup>2</sup>Australian Centre for Health Law Research

The role of law in assessments of capacity, consent and voluntary decision-making about MAiD varies between jurisdictions. Canadian legislation provides that a request for MAiD must be “voluntary”; that informed consent must be given prior to receiving MAiD; and that a person must be “capable of making decisions about their health.” Some Canadian courts have determined that Parliament crafted the legislation to delegate responsibility for assessing capacity and consent to medical professionals, thereby precluding review by the courts (citing “specialised medical knowledge” and “institutional capacity” as rationales for the delegation). The nature and scope of the delegation described in these cases has yet to be conclusively established, however. A recent decision in British Columbia granted an injunction on the basis of “serious questions about judicial oversight” of assessments pertaining to the nature of the applicant’s disorder and its irremediability (among other issues). The courts have yet to consider whether Parliament intended to delegate assessments of voluntariness (re MAiD requests) to medical professionals (precluding review) and if so on what basis. VAD legislation in Queensland provides that assessments of a person’s capacity to make decisions about VAD and the voluntary nature of their request are reviewable by the Civil and Administrative Tribunal (CAT) in the state. Proposed legislation in England and Wales would require approval of MAiD eligibility by an interdisciplinary panel (law, social work, and psychiatry). Assisted dying in these jurisdictions is restricted to persons with terminal illnesses; amendments to the Canadian legislation (subsequent to the legislation crafted in 2016) now allows MAiD where natural death is not reasonably foreseeable (“Track 2”). Track 2 MAiD was not anticipated when the 2016 legislation was crafted and among the questions considered in this paper is whether, for the purposes of assessment delegation and review, a distinction between the two tracks is warranted.

## Trends in Assisted Dying Among Patients with Psychiatric Disorders and Dementia in Belgium

Ms Natasia Hamarat<sup>1</sup>, Dr Jacques Wels<sup>1,2</sup>

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Assisted dying and euthanasia (ADE) for patients with psychiatric disorders or dementia are often cited in debates about the risks of legalisation, particularly concerning a potential "slippery slope" in case numbers. This study examines long-term trends in ADE involving these conditions in Belgium, where euthanasia has been legal since 2002. Using official data from the Federal Commission for the Control and Evaluation of Euthanasia (N = 33,592 cases between 2002 and 2023), we analyse how frequently euthanasia has been performed for psychiatric and cognitive conditions and how those trends have evolved. Psychiatric disorders and dementia accounted for 1.27% and 0.92% of all cases, respectively. We applied zero-inflated negative binomial regression models to examine yearly trends, accounting for demographic changes and patient characteristics through interaction terms and population offsets. The results show that while euthanasia cases for psychiatric disorders have increased slightly, their growth rate is comparable to that of other forms of euthanasia (count ratio = 1.00, 95% CI: 0.98–1.03; rate ratio = 1.02, 95% CI: 0.99–1.04). By contrast, dementia cases show a modest but statistically significant over-increase (count ratio = 1.03, 95% CI: 1.00–1.06; rate ratio = 1.04, 95% CI: 1.01–1.07). Gender and regional breakdowns indicate shifting patterns: while women initially had higher rates of psychiatric euthanasia, the rate among men has been rising. Regionally, euthanasia is more common in Dutch-speaking areas, though faster growth is now seen in French-speaking regions, suggesting population-level convergence rather than unregulated expansion. The findings do not support claims of a steep or uncontrolled increase in ADE for psychiatric or cognitive conditions. Instead, they show a cautious, regulated expansion with demographic and cultural variation. The Belgian experience suggests that including such conditions in euthanasia frameworks can be done without clear evidence of misuse.

## Loss of decision-making capacity and the future of voluntary assisted dying. An Interactive workshop

Ms Jennifer Harland<sup>1</sup>, Ms Hannah Gissane

<sup>1</sup>Act Government

Decision-making capacity (“capacity”) is the focus of growing community interest in the future of voluntary assisted dying (VAD) in Australia. Capacity at every stage of the VAD process is a central eligibility requirement in the Australian model, a key safeguard providing ensuring the choice is autonomous and voluntary. Despite this, there are growing calls from parts of the community to expand VAD access for people who are likely to lose capacity before their condition is advanced, such as people with dementia or other neurodegenerative conditions. This raises some challenging questions. What are our legal, clinical and ethical obligations in considering any change to status quo and what can international experience tell us?

The ACT's VAD legislation comes into effect in November 2025. The legislation includes an undertaking to review VAD access through advance care planning. The ACT Government has also committed to consider VAD access for eligible people who lose capacity before administration of the VAD substance could take place.

In a preliminary examination, the ACT Government canvassed the views of over 100 clinical, legal, ethical and community stakeholders on the question of VAD access for people who become ineligible because of losing capacity after the final approval. The consultation raised issues fundamental across the full continuum of VAD and capacity. Stakeholder views were diverse and contested. Many organisations were yet to develop a firm position. Where there was support, it tended to be highly conditional. The consultation also pointed to a paucity of data and research that was emergent or nascent.

This interactive workshop is an opportunity for the ACT Government to continue to engage and build the evidence base on capacity and VAD. From a range of expertise, participants will share challenges and opportunities. Through hypothetical scenarios, participatory discussion and activities, this workshop will test limits and possibilities.

## Impact of Voluntary Assisted Dying on health professionals: A systematic review

Dr Helen Haydon<sup>1</sup>, Ms Molly Fahey<sup>2</sup>, Mr Si Xiang (Jack) Feng<sup>3</sup>, Mr Flynn Haydon-Beal<sup>4</sup>, Ms Monica Taylor<sup>2</sup>, Ms Imogen Summers<sup>5</sup>, Dr Hanh Dao<sup>2</sup>, Associate Professor Allyson Mutch<sup>6</sup>, Professor Elizabeth Reymond<sup>7</sup>, Dr Centaine Snoswell<sup>8</sup>

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**Background:** Since June 2019, all Australian states and territories except the Northern Territory have implemented Voluntary Assisted Dying (VAD). Implementation was preceded by extensive debate, reflecting a division among health professionals and a small proportion of the community. Practical and emotional impacts of VAD on health professionals were anticipated.

**Objective:** To systematically review the global evidence regarding impacts of VAD implementation on health professionals, and understand how health professionals can be best supported. This review seeks to explore 1) the impacts, if any, experienced by health professionals associated with the implementation of VAD (e.g. palliative care professionals); and 2) whether these impacts shift with time (since implementation) and experience.

**Methods:** Four databases were systematically searched for studies that reported impacts of VAD on health professionals who had experience in the VAD environment. Thematic analysis of extracted data was conducted to establish themes.

**Results:** Of 6182 studies screened, 88 were included. Most studies were from Canada (n=46) and Europe (n=25). Interrelationships between themes and subthemes highlighted the complexity of implementing VAD and its resulting practical and emotional impacts on health professionals. A conceptual model included five main themes: reactions and interactions with patients and families; interprofessional dynamics; fitting into health service systems; uncharted territory and; evolving emotional and ethical adaptation. Moral dissonance infiltrated all themes.

**Conclusions:** Health professionals consistently experienced moral dissonance (i.e. psychological discomfort arising when actions or circumstances conflict with personal moral values) due to broader cultural and peer debates, which was evident across all areas of impact. This review provides a deeper understanding of the impacts of VAD implementation on health professionals and informs potential support interventions as more countries implement VAD.

## Understanding enablers and barriers to practitioner participation in voluntary assisted dying in Western Australia

Ms Sara Heinamaa<sup>1</sup>

<sup>1</sup>WA Department of Health

**Context:** Voluntary Assisted Dying (VAD) was legalised in Western Australia (WA) on 1 July 2021. Since then, the level of VAD activity has exceeded pre-implementation expectations and continues to rise. This has contributed to a workforce shortage. As a relatively new end-of-life choice there is currently limited data on VAD workforce recruitment and retention.

**Purpose:** The purpose of this quality improvement initiative was for the WA Department of Health to identify opportunities and practical strategies for support to increase VAD practitioner uptake and participation in WA.

**Methods:** A mixed-methods web-based survey was circulated through professional networks and institutional mailing lists. Questions aimed to identify barriers to and enablers of undertaking VAD Training (including renewal) and VAD services, for eligible medical and nurse practitioners. Responses were analysed using a combination of descriptive statistics, and inductive thematic analysis, to identify broad patterns in experiences.

**Findings:** 139 medical and nurse practitioners responded to the survey, 62% of respondents had never engaged with VAD before. Key enablers identified included: professional and personal values (i.e. alignment with VAD principles such as autonomy and dignity), accessibility and demand (i.e. supporting patient access or awareness of workforce shortages), psychological and emotional (i.e. finding provision of VAD fulfilling). Common barriers included: professional and personal values (i.e. a lack of willingness to undertake a specific VAD role), practical barriers (lack of time), administrative and procedural (i.e. perception of a high administrative burden), and financial and remuneration (i.e. inadequate compensation or lack of Medicare Benefit Schedule items).

**Significance:** The decision for practitioners to engage with VAD is shaped by an interplay of both logistical and personal considerations. To support interested practitioners to engage with VAD in WA, opportunities to embed and promote awareness of organisational support, education and training, and sufficient compensation should be explored.

## Nurses' Willingness to Participate in Voluntary Assisted Dying in Australia: A Qualitative Descriptive Study

Dr Jayne Hewitt<sup>1,2</sup>, Professor Melissa Bloomer<sup>1,5,6</sup>, Professor Ann Bonner<sup>1,3</sup>, Emeritus Professor Margaret O'Connor<sup>4</sup>, Dr Joan Carlini<sup>7</sup>, Ms Ilse Berquier<sup>3</sup>

<sup>1</sup>Griffith University, <sup>2</sup>Queen Elizabeth II Jubilee Hospital, <sup>3</sup>Metro North Hospital and Health Service, <sup>4</sup>Monash University, <sup>5</sup>Princess Alexandra Hospital, <sup>6</sup>Deakin University, <sup>7</sup>Bond University

**Background:** Voluntary assisted dying is a legal end-of-life option in most of Australia. The limited number of medical practitioners willing to participate in Voluntary Assisted Dying (VAD) impacts access to these services. Some Australian VAD laws allow nurse practitioners (NPs) and registered nurses (RNs) to assess eligibility or administer VAD substances to mitigate this issue. However, globally, the roles of nurses in VAD are still limited and underdeveloped, with little evidence about their willingness to participate.

**Aim:** To identify NPs' and RNs' willingness to, and reasons for, participating in VAD.

**Methods:** A national qualitative descriptive study using semi-structured interviews was conducted between April and August 2024. Data were analysed using Framework Analysis.

**Results:** 61 individual interviews and one group interview were conducted with 58 RNs and 7 NPs. Interviews ranged from 17-50 (mean 27.9 mins). The analysis identified three themes. First, "The System" describes gaps between policy law and practice. Next, "The Workforce" captures the tensions around death and dying conversations and VAD, the emotional labour of caring and importance of support. The final theme, "The Patient and Family", reflects the importance of seeing the whole person and prerequisites for choice.

**Conclusions:** Most nurses supported VAD and were willing to participate in VAD processes and procedures. Their experiences offered valuable insights into how VAD systems in Australia are working and reinforced the importance of collaborative interdisciplinary care to support patients to navigate VAD systems and achieve the death they desire.

## Establishing a Framework for ethical and impactful research on VAD in South Australia

Ms Melanie Turner<sup>1</sup>, Ms Helen Walker<sup>1</sup>

<sup>1</sup>Voluntary Assisted Dying Review Board South Australia

The Voluntary Assisted Dying (VAD) Review Board was established under the Voluntary Assisted Dying Act 2021, with VAD commencing in South Australia on 31 January 2023. Section 113(g) of the Act mandates the Board to conduct research using information submitted via the VAD Clinical Portal by medical practitioners and VAD clinical and operational staff.

To support this function the VAD Research Framework outlines a strategic and ethical approach to research on VAD in South Australia. The Framework aligns with the five priorities in the VAD Review Board Strategic Plan 2025–2027 and provides guidance on research principles, focus areas, priorities, data sources and enablers and ensures research contributes to the continuous improvement, safety, and sustainability of VAD services.

To oversee and facilitate research activities in accordance with the Research Framework, a Research Subcommittee has been established. Reporting to the Review Board the Subcommittee meets quarterly and is responsible for reviewing and approving research proposals, providing guidance to research partners, and making recommendations to ensure quality and relevance of research. Membership of the Subcommittee includes representatives from the Review Board, and individuals with legal and clinical backgrounds and academic experts. Members are appointed by the Presiding Member of the Review Board.

The Subcommittee is currently supporting the following research partnerships:

- The Queensland University of Technology Australian Research Council (ARC) Data Linkage Project assessing the operation of voluntary assisted dying laws in Australia.
- A student project with the University of South Australia to undertake a scoping review of literature to identify themes that have emerged as VAD has commenced across Australia.
- A project proposal to explore VAD pathway non completion.

This research framework and governance model position South Australia as a leader in ethical, evidence-based VAD research and ensure a coordinated and collaborative approach to research on VAD.

## Moral Distress in End-of-Life Decision-Making; Lessons to be Learned from Veterinary Medicine for Human Practice

Dr Tessa Holzman<sup>1</sup>

<sup>1</sup>Charles Sturt University

Veterinarians have the highest rate of suicide among any profession, and also report extremely high rates of moral distress, burnout, fatigue, and intentions of leaving the field. This is suggested to be due to how frequently vets are required to euthanise (sometimes otherwise healthy) animals. Interestingly, the same is not the case for human practitioners specialising in end-of-life care. Moral distress is not often cited as a primary issue for practitioners who perform voluntary assisted dying procedures on humans. However, this may change. There are already some factors that veterinarians have reported to be a contributor to moral distress that are also observable in human medicine. While these factors do not currently appear to be contributing to moral distress in the same way, they may become more problematic as the legislative and regulatory landscape around VAD changes and evolves to more closely resemble regulatory frameworks found in veterinary medicine. For this reason, it is important to consider these factors now, as well as resources and measures veterinarians have identified as potentially useful in mitigating moral distress, in order to prevent similar patterns from developing in human medicine as VAD legislation and practice changes on a global level. In this talk, I will provide a brief overview of the literature on moral distress and clarify how I will be using the term. Then, I will outline the factors veterinarians have identified as contributing to moral distress and describe their human medicine counterparts. These factors include, 1. The kind of person who does this job, 2. Bad reasons for providing non-ideal care, and 3. Lack of resources. Finally, I will put forward some possible pathways identified by veterinarians that might be helpful in preventing excessive or burdensome levels of moral distress from developing in human end-of-life care.

## Advising Voluntary Assisted Dying Patients about Organ Donation: Ethical and Practical Considerations.

Dr Fabian Jaramillo<sup>1,2,3</sup>, Dr Leo Nunnink<sup>3,5,6</sup>, Dr Fabian Jaramillo<sup>7,8</sup>, Dr Wade Stedman<sup>4</sup>

<sup>1</sup>Gold Coast Health, <sup>2</sup>Queensland Children's Hospital, <sup>3</sup>University of Qld, <sup>4</sup>Royal North Shore Hospital, <sup>5</sup>Princess Alexandra Hospital, <sup>6</sup>Donate Life, <sup>7</sup>Brisbane North Primary Health Service, <sup>8</sup>Metro North Health Service

Voluntary Assisted Dying (VAD) now makes donation possible for people without a medical contraindication, who make up approximately 20% of VAD patients in Australia. As VAD becomes embedded as an end-of-life choice, a question arises as to the provision of information about organ donation to people pursuing VAD. Options range from only responding to patient-initiated requests to having a mandated process for notification of eligible patients. Ethical concerns about organ donation in the VAD context include the risk of coercion; the possibility of entanglement of the decision to pursue VAD with the decision to become an organ donor; and the concern that organ donation may impact on the timing of death in such a way as to violate the spirit of the dead donor rule.

We consider and respond to ethical concerns about organ donation and VAD, making the case that provision of information about the option of organ donation should be a standard part of the VAD process. As a group comprising VAD practitioners, intensive care specialists, a donation doctor, and an ethicist, we recommend ethically sound practices regarding how and when information is provided to people seeking VAD.

## Identifying Strategies to Sustain the Medical Voluntary Assisted Dying Workforce in Victoria

Ms Kristen Kappel<sup>1,2</sup>, Mr Sean Jian Lee Yaw<sup>1</sup>, Ms Tennille Lewin<sup>1</sup>, Ms Susan Jury<sup>1,2</sup>, Ms Lisa Guggione<sup>1</sup>, Professor Ben White<sup>3</sup>

<sup>1</sup>Peter MacCallum Cancer Centre, <sup>2</sup>Department of Health, <sup>3</sup>Queensland University of Technology

### Background:

Voluntary Assisted Dying (VAD) has been legally available in Victoria since 2019, requiring a willing and trained medical workforce to ensure safe, accessible, and patient-centred care. However, many medical practitioners (MPs) who complete the required training do not go on to participate in VAD service delivery, while others discontinue their involvement due to systemic, personal, or organisational barriers. Delivering ongoing support to the VAD workforce is essential for the sustainable, equitable and effective delivery of services across Victoria.

### Aims:

This study aims to 1) explore the barriers and enablers to participating in VAD work for VAD-trained MPs in Victoria, and 2) co-design strategies and resources informed by these insights, to support the VAD workforce for a sustainable future.

### Methods:

Phase 1: Semi-structured interviews with 15-20 VAD-trained MPs. The interview schedule will be guided by the Consolidated Framework for Implementation Research (CFIR) to explore motivations, challenges, and supports in relation to VAD practice. Thematic analysis will identify key factors influencing participation across CFIR domains.

Phase 2: Two co-design workshops with 10-20 MPs from across Victoria. Phase 1 results will be reviewed in workshop one to generate strategies to address challenges. Workshop two will assess feasibility and usability of these strategies, with participants prioritising the most impactful solutions. Findings will be synthesised into actionable recommendations to inform policy, training, and support structures.

Results: Data collection has commenced for Phase 1 interviews. Findings from the interviews and workshops, including how Phase 1 informed Phase 2, will be available in time for the conference.

Conclusion: This study will generate insights into why VAD-trained MPs engage or disengage in VAD practice and offer practical strategies to improve workforce sustainability. By identifying barriers and co-developing solutions, the research provides an evidence-based roadmap to strengthen VAD service delivery, with relevance internationally.

## Card-carrying advance care planning: Incorporating driver's license renewal into discussions on advance care planning

Adjunct Professor of Law Oliver Kim<sup>1</sup>

<sup>1</sup>University Of Pittsburgh Law School

In the United States, numerous stakeholders have looked for public policy solutions to encourage more Americans to engage in advance care planning for ethical, legal, and medical reasons. Efforts to encourage advance care planning have resulted in about one in three Americans having some sort of advance directive with variations depending on race, education, and age. Barriers to advance care planning include individuals' concerns about the accessibility of a directive and its ability to reflect contemporaneous views. These concerns are understandable as those in aging policy often encourage individuals to ensure their directives and wishes are known, accessible, and routinely updated. Further, advocates encourage individuals to engage in advance care planning throughout their lives.

One potential could be to look at how public policy has encouraged certain activities by tying it to a routine that many of us engage in: renewing a driver's license. Such licenses must be periodically renewed as individuals age and move to different communities. Most Americans carry their licenses on their person for a variety of reasons beyond simply driving. Further, government has used drivers' licenses to drive certain policies such as organ donation, voter registration, or failing to pay certain penalties such as child support.

This proposed presentation will explore how certain activities such as organ donation were tied to license renewal and what the barriers and opportunities would be if an individual's advance care planning could be tied to a license renewal. The presentation also would discuss legal and policy challenges and potential ways to overcome these issues.

## How Long is Too Long? A case of Prolonged Time to VAD Death

Ms Carly Kippist<sup>1,2</sup>, Dr Catherine Bendall<sup>1</sup>, Dr Charles Douglas<sup>1</sup>, Ms Niamh O'Neill<sup>2</sup>

<sup>1</sup>Hunter New England Local Health Service, <sup>2</sup>New South Wales Voluntary Assisted Dying Pharmacy Service

A case is presented of prolonged time to death after oral self-administration of a Voluntary Assisted Dying (VAD) substance in NSW, Australia.

Patient X was a mid-70s male with locally advanced pancreatic cancer. Oral administration was chosen by the patient after a standard discussion, including the possible risk of a delayed death. Two months following VAD approval, the patient consumed the entire VAD substance and did not vomit. He was reported to have lost consciousness within 30 minutes however took almost 27 hours to die.

The prolonged time to death caused significant distress for the family and uncertainty for the VAD team and the palliative care team regarding the best course of action. To our knowledge, this is the longest time to VAD death in NSW.

The possible reasons for delayed death, as well as the practical, legal and ethical difficulties arising in this situation are discussed.

## Voluntary assisted dying: challenges in Northern Territory remote Aboriginal communities

Dr Geetanjali Lamba<sup>1</sup>

<sup>1</sup>Monash University, <sup>2</sup>NT Health

Voluntary assisted dying (VAD) legislation has now been passed in all Australian jurisdictions, except for the Northern Territory. The Voluntary Assisted Dying Independent Expert Advisory Panel led public consultations in the NT to inform development of NT VAD legislation, submitting their report to the Chief Minister in July 2024, which has been publicly released. This presentation will reflect on the VAD implementation challenges highlighted in this public report, and is drawn from a perspective piece recently published in the MJA. <https://www.mja.com.au/journal/2025/223/6/voluntary-assisted-dying-challenges-northern-territory-remote-aboriginal#:~:text=The%20NT%20was%20the%20first,Parliament%20of%20Australia>. It will discuss the unique demographics of the NT, including a significant Aboriginal population living in remote areas coupled with a high burden of chronic disease, which poses difficulties for equitable access to end-of-life services. "Cultural safety" is critical for Aboriginal peoples but application is contextual. Telehealth, which may help increase access, also presents challenges.

## Embedding the Consumer Voice in Voluntary Assisted Dying: A CFIR-Guided Qualitative Study from Victorian Patients

Dr Geetanjali Lamba<sup>1</sup>

<sup>1</sup>Monash University

**Introduction:** Voluntary Assisted Dying (VAD) has been legislated across nearly all Australian jurisdictions, yet implementation remains complex, with limited research centring patient perspectives. This qualitative study explores the experiences of Victorian patients engaging with VAD, using the Consolidated Framework for Implementation Research (CFIR) to identify multilevel barriers and facilitators to implementation.

**Methods:** Thirty-one semi-structured interviews were conducted with end-of-life patients between June 2020 and February 2022. Participants were purposively sampled through social media, health professionals, and end-of-life organisations to capture diverse demographics and diagnoses. Data were analysed using a hybrid inductive–deductive approach, with emergent themes mapped against CFIR domains.

**Results:** Findings demonstrate that while patients valued VAD as a means of autonomy, dignity, and psychological reassurance, they encountered significant barriers. Legislative constraints—including Section 8 (“gag clause”), strict eligibility criteria, and the prohibition of telehealth—impeded access, particularly for those in rural or remote regions. Organisational culture, especially within faith-based institutions, created further misalignment between patient autonomy and institutional values, leading to secrecy and perceptions of abandonment. Workforce limitations, variable clinician training, and reluctance to participate added to patient burden. Conversely, state-funded Care Navigators and centralised pharmacy services were consistently described as supportive, efficient, and enabling. Patients highlighted inequities in access for culturally and linguistically diverse and Aboriginal communities, underscoring the need for broader system engagement.

**Conclusions:** This is the first study to apply CFIR to patient perspectives on VAD implementation. By embedding consumer voices within an implementation framework, our findings reveal unique insights into how legislation, culture, and clinical practice converge to shape access. Implementation strategies must address legal and institutional barriers, expand clinician training, and strengthen equity-focused supports. Embedding patient perspectives into planning and evaluation is essential to ensure VAD systems remain responsive, accessible, and aligned with the needs and values of those they are designed to serve.

## Evolution of organ donation after MAiD/VAD in Canada and Australia – Opportunities and lessons learned

Dr. Kim Wiebe<sup>1</sup>

<sup>1</sup>Medical Assistance in Dying Shared Health Services

Victoria was the first state in Australia to pass a voluntary assisted dying (VAD) law in November 2017, with the law coming into effect in June 2019. Since then, all other states have followed suit and passed very similar laws, with all in effect except for NSW which will take effect later this year. Additionally, Victoria was the first state to facilitate organ donation following VAD in 2023. Australia is now the fifth country in the world to enable this practice.

Canada are world-leaders in this space, reporting that 6% of their total organ donor numbers came from the generosity of those who chose Medical Assistance in Dying (MAiD). Canada facilitated their first organ donor following medical assistance in dying in 2017. Subsequently, Canada has developed expert guidance for policy published in 2019 and updated in 2023 providing two updated recommendations and eight new recommendations in the following areas: referral, consent, directed donation, MAiD procedures, support for health-care professionals, and reporting.

This panel will provide an overview of the two countries' journey with organ donation after assisted dying highlighting opportunities and lessons learned.

## Her Last Project: Film Screening and Q&A

Dr. Kim Wiebe<sup>1</sup>, Ken Lotherington<sup>2</sup>

<sup>1</sup>Medical Assistance in Dying Shared Health Services, <sup>2</sup>Canadian Blood Services

This film is the extraordinary story of Dr. Shelly Sarwal, a physician from Halifax, Nova Scotia. Diagnosed with Multiple System Atrophy (MSA), an incurable disease, Shelly chose to undergo the recently legalized Medical Assistance in Dying (MAiD) procedure and become an organ donor. As the first person in Nova Scotia to undergo this unique medical journey, she dedicated the short time she had left on this earth to educate health professionals and the public about being in control of your death and creating a meaningful legacy through organ donation.

Dr. Sarwal's experience was instrumental in a larger initiative by Canadian Blood Services to develop guidelines for organ donation after MAiD, which were formally published in 2019 and revised in 2023.

The proposed session includes a short introduction to the film, a screening of the 45-minute film, followed by a Q&A period.

## A pathway into the unknown..Organ and tissue donation after voluntary assisted dying

Ms Kelly Lewis<sup>1</sup>

<sup>1</sup>NSW Organ And Tissue Donation Service

This presentation examines two closely related cases from the early months of voluntary assisted dying being legalised in NSW. These rare cases highlight the beginnings of new connections, new opportunities and new work processes.

The Voluntary Assisted Dying Act in NSW was legislated on November 28th, 2023 allowing eligible adults to request medical help to end their life.

NSW became the 5th state to legalise VAD, introducing a new framework in how end of life care (EoLC) is approached.

Prior to 2023, Organ and Tissue Donation's (OTD) focus was within intensive care units where time sensitive decisions were critical. In routine EoLC, a collaborative approach involving the Donation Specialist Nurse (DSN) and senior treating doctors was used to discuss patients wishes and potential donation options with families. By the end of 2023 our scope of patient care and opportunities has expanded into a new realm – driven by patient requests.

Although distinct processes, recent advancements and ethical considerations are bringing VAD and OTD systems closer together creating new opportunities for patient centred care and addressing organ transplantation needs. A new collaboration of voluntary assisted dying with organ donation is an emerging and significant area of exploration within end-of-life care. Traditionally viewed as separate processes, the collaboration between these two areas offers the potential for transformative outcomes.

Both organ donation and voluntary assisted dying reflect a broader societal value of empathy, compassion, and respect for individual rights. They address the complex intersection of personal choice, human dignity, and medical technology.

These cases highlight the importance of respecting patient autonomy while navigating the complexities of organ donation protocols, particularly in cases involving terminal illness.

Furthermore, it underscores the need for healthcare systems to adapt, better connect to evolving patient needs and wishes, ensuring compassionate and ethical care at the end of life.

## Ethical Dilemmas in the Supply of the Voluntary Assisted Dying Substance – A Pharmacist’s Experience

Ms Catherine Li<sup>1</sup>, Ms Elisha Cole<sup>1</sup>, Prof Elizabeth Reymond<sup>1</sup>

<sup>1</sup>Queensland Voluntary Assisted Dying Support And Pharmacy Service (qvad Sps)

**Background:** State-wide pharmacists play a critical role in ensuring the safe, compassionate and lawful supply of the Voluntary Assisted Dying (VAD) substance while navigating complex situations that challenge professional ethics and conduct.

**Aim:** To explore the ethical tensions a pharmacist encounters when supplying the VAD substance.

**Methods:** A reflexive journaling approach was used to document one pharmacist’s experiences in ethically challenging VAD supply scenarios. Braun and Clarke’s thematic analysis was applied to identify and interpret emerging themes.

**Findings and Discussion:** Three key themes emerged.

First, becoming the bearer of bad news. Withholding VAD supply required informing families that supply could not proceed, an emotionally demanding task. As one reflection noted: “I became the bearer of disappointment yet also tried to reassure them they had honoured their loved one’s wishes.” This theme highlights the pharmacist’s dual role – upholding legal requirements while simultaneously providing emotional support within the evolving culture of VAD pharmacy practice.

Second, communicating certainty in uncertainty. Unpredictable events—such as vomiting after ingestion or concerns about safety—demanded immediate responses without the luxury of reflection. “I must find a solution quickly and communicate soundly—if they vomit, what am I going to do next? If I feel like it’s unsafe, how do I communicate this?” This theme illustrates the pharmacist’s professional obligation to project calm authority and reassurance, even while improvising in moments of uncertainty.

Third, the weight of second-guessing. Even when acting within legislative and clinical boundaries, lingering doubts persisted. “Pain was his trigger for using his VAD substance, I had no grounds to not leave his substance [...] I just hope he does not use it out of impulsivity.” Second-guessing added emotional weight, unsettling the pharmacist’s traditional role of certainty and safety.

**Conclusion:** A pharmacist’s involvement in VAD extends beyond technical supply, encompassing emotional, ethical and communicative responsibilities.

## Strategic Litigation as a Catalyst for Medical Assistance in Dying Reform: Lessons from Canada

Ceo Helen Long<sup>1</sup>, Professor Emeritus Jocelyn Downie<sup>3,4</sup>, Professor Daphne Gilbert<sup>1,2</sup>

<sup>1</sup>Dying With Dignity Canada, <sup>2</sup>Faculty of Law, University of Ottawa, <sup>3</sup>Faculties of Law and Medicine, Dalhousie University,

<sup>4</sup>Australian Centre for Health Law Research, Queensland University of Technology

When democratic processes fail to reflect public will, litigation may emerge as a powerful alternative tool for law reform. Canada's journey toward legalizing medical assistance in dying (MAiD) exemplifies this phenomenon, offering valuable insights for international advocates navigating similar challenges (especially in jurisdictions with a constitutional rights-protecting document).

Despite decades of majority public support for MAiD legalization and the introduction of multiple bills, Canada's Parliament remained stalled, maintaining criminal prohibitions that prevented individuals with grievous and irremediable medical conditions experiencing intolerable suffering from accessing end-of-life care aligned with their beliefs and values. Faced with legislative inaction, advocacy organizations pivoted to litigation, transforming Canada's legal landscape through the courts rather than the legislature.

Dying with Dignity Canada (DWDC) has been instrumental in the pursuit of the litigation strategy, serving as an intervenor in landmark cases including *Rodriguez v British Columbia* (1993), *Carter v Canada* (2015), *The Christian Medical and Dental Society of Canada v College of Physicians and Surgeons of Ontario* (2018), and *Truchon c Procureur general du Canada* (2019). The organization is currently the public interest litigant in two active Canadian Charter of Rights and Freedoms challenges, continuing to push legal boundaries where law and policy fall short of constitutional requirements.

This session will examine the practical realities of pursuing social reform through litigation rather than traditional legislative channels (e.g., gathering evidence and developing compelling arguments, managing public discourse during high-stakes cases, and navigating the complex relationship between victories in court and subsequent legislative implementation). It will also address both the remarkable successes of Canada's litigation approach and its inherent limitations, providing a balanced assessment of when courts can - and cannot - substitute for democratic processes. This case study offers international advocates practical insights for evaluating strategic litigation as a tool for advancing end-of-life rights in their jurisdictions.

## Monitoring MAiD in Spain: Insights from the 2024 Annual National Report

Dr. Nerea M. Molina<sup>1</sup>, María Belmonte-Herrera<sup>1</sup>, Jorge Suárez<sup>1</sup>, Luis Espericueta<sup>1</sup>, Sean Riley<sup>2</sup>, Dr Joaquín Hortal-Carmona<sup>1</sup>, Prof David Rodríguez-Arias<sup>1</sup>

<sup>1</sup>C Y B E - Filolab, University Of Granada, <sup>2</sup>The Ohio State University Medical Center

Spain's Organic Law 3/2021 on the regulation of euthanasia came into force in June 2021, establishing MAiD as an individual right within the publicly funded national health system. Since its implementation, the Ministry of Health has issued annual reports that compile and systematise data provided by regional health systems. These reports constitute the main public source for monitoring how the law is being applied and for understanding its development within the Spanish healthcare context.

The 2024 Annual Report of MAiD is the most comprehensive to date. Drawing on this source, together with previous editions, the presentation will provide national data on requests and their outcomes, demographic and clinical characteristics of applicants and recipients, the role of health professionals, and the settings and modalities of provision. It will also cover procedural aspects such as waiting times, denials, withdrawals, deaths during the process, and cases of organ donation following MAiD. In addition, the analysis will show the evolution of these indicators over time and their distribution across regions.

By presenting the monitoring system developed in Spain and the evidence it generates, this contribution aims to make available a structured account of how MAiD has been implemented and evaluated across Spain's regional healthcare system. The findings will offer an empirical basis to enrich international discussions on assisted dying and to contribute to broader debates on end-of-life care.

## 10 Lessons learned: 9 years of MAID, palliative care and the intersection of dying

Dr Susan MacDonald<sup>1</sup>

<sup>1</sup>Memorial University of Newfoundland

Medical Aid in Dying became legal in Canada in 2016. Palliative care clinicians across the country were concerned for the profession and their patients. In the almost ten years since legalization, there have been significant changes to palliative care services. The province of Newfoundland, with its huge size and limited population, is somewhat of a reflection of the larger country. In reviewing how our palliative care service adapted to patient's requesting MAID, how we navigated working with clinicians and patients who did not want MAID, we learned valuable lessons, that could be of benefit for places who are considering this legal end of life option.

Ten key lessons were learned in reviewing the implementation and growth of MAID.

1. New laws require new funding
2. Palliative care did change: just not the way we anticipated
3. Medical College policies should be written by an active MAID practitioner.
4. Patients like to be creative: do what you can to facilitate this
5. The fewer providers, the greater the strain
6. Non-terminal cases can be fraught with concerns: teamwork is key
7. Keep thorough statistics and data
8. Develop protocols and guidance for staff dealing with mental health patients
9. All palliative care clinicians can work collegially together, regardless of their involvement with MAID
10. Patients and staff drive change. (Where you start isn't necessarily where you end up)

## A Grounded Theory Ethnography Exploring Complexities, Synergies and Challenges between Assisted Dying and Palliative Care

Dr. Marjolein Matthys<sup>1,2</sup>, Prof. dr. Kenneth Chambaere<sup>1,2</sup>, Prof. dr. Luc Deliens<sup>2</sup>, Prof. dr. Marie-José Gijssberts<sup>2</sup>, Prof. dr. Peter Pype<sup>1</sup>

<sup>1</sup>Ghent University, <sup>2</sup>End-of-Life Care Research Group

Amid ongoing international debate about the relationship between palliative care and assisted dying, the Belgian model—often described as synergistic—offers a distinctive case. Research indicates that most Belgian patients who express a wish for assisted dying also receive palliative care, and that palliative care services are frequently involved in both decision-making and the performance of euthanasia. Yet there remains a critical lack of empirical research that explores the practical experiences, challenges, and synergies emerging from this reality.

This project addresses this gap through an in-depth ethnographic study guided by constructivist grounded theory. Fieldwork combines participant observation and unstructured interviews in three distinct Flemish palliative care settings, complemented by focus groups with professionals across different settings. This design enables a contextualized exploration of the communicative, relational, and moral dynamics surrounding assisted dying, while integrating multiple perspectives—those of patients, their (chosen) families, and palliative care professionals. The project seeks to illuminate not only how palliative care and euthanasia are negotiated in practice, but also what this means for future models of care, ethical guidance, and ongoing debates.

The presentation will share central findings which, beyond their local relevance, contribute to wider international discussions about whether, and how, assisted dying can be integrated with palliative care. In addition, we will reflect on the methodological and ethical challenges of studying this inherently complex topic, and consider what ethnography—with its attention to lived experience and social process—can uniquely contribute to this field.

## Organ donation after Voluntary Assisted Dying (VAD)

Dr Dale Gardiner<sup>2</sup>, Professor Andrew McGee<sup>1</sup>, Dr Melanie Jansen<sup>3</sup>, Professor John Lizza<sup>4</sup>

<sup>1</sup>Australian Centre For Health Law Research, QUT, <sup>2</sup>NHS Blood and Transplant, <sup>3</sup>Paediatric intensive care consultant at the Queensland Children's Hospital, <sup>4</sup>Kutztown University of Pennsylvania

Organ donation after voluntary assisted dying (VAD) is an evolving practice in countries where VAD is legal. In Canada donation after VAD reached 8% of all deceased donors nationally in 2021 (Weiss et al, 2024), while in Australia numbers are low but are expected to rise (Bollen et al 2023).

Donation after VAD uses the donation after circulatory death (DCD) pathway. Critics argue that the standard five-minute observation ('no-touch') period used to determine death in DCD is too short to establish irreversibility as required by statute in many jurisdictions (including Australia), and therefore violates the Dead Donor Rule (DDR). Proponents (Bernat et al 2010) counter that, in DCD, "irreversibility" is best understood as permanence: "the function will not be restored because it will neither return spontaneously, nor will it return as a result of medical intervention because resuscitation efforts will not be attempted."

The permanence standard has more recently come under scrutiny, however, with the use of normothermic regional perfusion (NRP) to improve organ quality. NRP restores circulation to the body while preventing it from reaching the brain. This practice is used in donation after VAD in Spain but not yet in Canada or Australia. Unlike typical DCD patients, VAD donors generally have healthy and functioning brains, raising concerns that if NRP fails to block cerebral circulation brain function could theoretically be restored, with profound ethical implications.

Should organ donation after VAD proceed with NRP or does it further undermine the DDR? Given that VAD patients have chosen to end their own lives, does the DDR remain just as important for these patients or should it be relaxed?

Session Format: Three short presentations (by two clinicians and two philosophers, one joint) followed by open panel discussion. The goal is to illuminate this timely issue from multiple perspectives.

## While the Whole World Was Watching: Missed Opportunities in Assisted Dying Implementation

Mrs Rosalie McLauda<sup>1,3</sup>, Dr Rhona Winnington<sup>2,3</sup>

<sup>1</sup>University Of Waikato, <sup>2</sup>University of West of Scotland, <sup>3</sup>Auckland University of Technology

The legalisation of assisted dying in New Zealand attracted national and international scrutiny, creating a rare mainstream public conversation about death and dying. This offered a unique opportunity to strengthen public understanding of end-of-life care options. Instead, the discourse narrowed to a polarised “for or against” debate, rather than situating assisted dying within the wider continuum of end-of-life care. As a result, a chance to improve awareness of palliative care, advance care planning, and culturally responsive support was missed.

This study employed narrative inquiry to explore the experiences of ten nurses working in end-of-life care, conducted after the passing of assisted dying legislation but before the enactment of the End-of-Life Choice Act (2019). Despite being senior nurses, participants reported exclusion from organisational planning and policy discussions. Preparatory efforts largely focused on doctors, dismissing the central and often frontline role of nurses in supporting patients, families and wider healthcare teams. Participants described lacking educational support to prepare for this new practice, a gap with implications for ongoing service equity and accessibility.

Findings highlight how overlooking nursing roles risks undermining implementation by failing to equip those involved in everyday end-of-life care. Nurses are well placed to provide education across primary and tertiary care settings, yet their expertise was not recognised in system-level planning.

For future legislative reviews in New Zealand and other jurisdictions considering or implementing similar legislation, recognising nurses as key stakeholders is critical to achieving inclusive and sustainable end-of-life care. Harnessing the visibility of current assisted dying public discourse in other jurisdictions represents a timely opportunity to build both professional capacity and public awareness around the full spectrum of end-of-life care.

## Health literacy, end-of-life health literacy and assisted suicide: attitudes in older adults

Dr Clément Meier<sup>1,2</sup>, Dr. Giulia Mac Dermott<sup>3</sup>, Solenne Blanc<sup>3</sup>, Prof. Claudia Gamondi<sup>3</sup>

<sup>1</sup>University of Lausanne, <sup>2</sup>Swiss Centre of Expertise in the Social Sciences (FORS), <sup>3</sup>Palliative and Supportive Care Service, CHUV, Lausanne, Switzerland

### Objectives

As societal debates around assisted suicide persist, understanding the factors influencing individual attitudes is essential. Health literacy (HL) and end-of-life HL (EOL-HL) are critical for informed decision-making but remain underexplored in relation to attitudes towards assisted suicide. This study investigates the association between HL, EOL-HL and attitudes towards assisted suicide among older adults in Switzerland.

### Methods

Data were derived from 1461 participants aged 58+ from the Swiss component of the Survey of Health, Ageing, and Retirement in Europe, 2019/2020. Attitudes towards assisted suicide were assessed using three measures: support for its legality, consideration of personal use and membership in a right-to-die organisation. HL and EOL-HL were assessed using standardised scales. Probit regression models analysed the associations, controlling for sociodemographic and health characteristics.

### Results

The majority supported the legality of assisted suicide (82%) and could consider asking for it (64%), while 9% were members of a right-to-die association. Higher EOL-HL was significantly associated with greater support for assisted suicide ( $\beta=0.05$ ,  $p<0.001$ ), consideration of personal use ( $\beta=0.08$ ,  $p<0.001$ ) and membership in a right-to-die organisation ( $\beta=0.06$ ,  $p<0.001$ ). However, general HL was not statistically significantly associated with membership in such organisations.

### Conclusions

The findings underscore the distinct role of EOL-HL in shaping attitudes towards assisted suicide, particularly in decisions involving active engagement, such as joining right-to-die organisations. Enhancing EOL-HL among older adults could empower informed decision-making and promote meaningful engagement in end-of-life planning. These insights contribute to ongoing ethical and policy discussions surrounding assisted suicide in Switzerland and beyond.

## The International Observatory on Assisted Dying: A Collaborative Platform for Research, Policy, and Practice

Paola Sillitti<sup>1</sup>, Dr Clément Meier<sup>1</sup>, Solenne Blanc<sup>2</sup>, Dr. Laura Jones<sup>2</sup>, Prof. Jürgen Maurer<sup>1</sup>, Prof. Claudia Gamondi<sup>2</sup>  
<sup>1</sup>University of Lausanne, Faculty of Business and Economics (HEC), <sup>2</sup>Palliative and Supportive Care Service, Lausanne University Hospital and University of Lausanne

### Background

Assisted Dying (AD) is a rapidly evolving practice, with more than 250 million people worldwide living in jurisdictions where different models have been legalized. However, substantial variation exists in terminology, legal frameworks, eligibility criteria, monitoring, and clinical practices. Few jurisdictions provide clinical guidance or support for health professionals, patients, and families, leaving important gaps in care. To address this, we propose the creation of an International Observatory on Assisted Dying (IOAD) to monitor AD practices across jurisdictions. The Observatory will inform scientific and policy debates and provide a platform for the exchange of experiences among patients, families, professionals, and society.

### Method

The IOAD will be developed through international consensus among key stakeholders as a virtual, collaborative platform linking researchers, clinicians, policymakers, and the public. Its activities will include: (a) establishing an international register of AD statistics and practices by collating existing databases and repositories; (b) building a global network of stakeholders to exchange experiences, inform policy, and support new frameworks; and (c) providing training and resources for health professionals, alongside accessible information for patients, families, and the public.

### Results

The IOAD will serve as a knowledge hub to advance research, policy, and clinical practice worldwide. Researchers will benefit from shared data and methodologies, policymakers from evidence-based insights, and health professionals from training and peer support to enhance quality of care. For patients and families, the IOAD will offer unbiased information to reduce stigma and isolation. Initial steps include a stakeholder meeting to define the Observatory's scope, structure, and funding strategy with engagement from experts in Europe, North America, and Australia.

### Conclusion

By consolidating global expertise and data, the IOAD will guide and improve AD practices and professional training worldwide. It represents a timely, collaborative response to a pressing global issue, ensuring AD is practiced with transparency, safety, and compassion.

## 'A different type of death'. Māori bereavement experiences following an assisted death

Dr Tess Moeke-Maxwell<sup>1</sup>

<sup>1</sup>University Of Auckland

### Background

The End of Life Choices Act (2019) provides a new end-of-life option for New Zealanders. Without appropriate information and navigational support to guide and prepare whānau (Māori families, including extended family), the Act can create further inequities for Māori. Indeed, the voices of bereaved whānau need to be heard to ensure they are adequately supported in their loss and grief.

### Objectives

The Waerea study explored Māori whānau experiences of accessing and engaging with Assisted Dying services and how they used and adapted their tikanga (customs) to navigate this new end-of-life option. We also wanted to understand their bereavement experiences.

### Design

Qualitative Kaupapa Māori Research methods were used to investigate Māori whānau experiences of using Assisted Dying services and bereavement.

### Methods

Thirty six interviews were undertaken with over fifty whānau participants who were recruited from across New Zealand using Māori research and community networks. Over twenty support workers (assisted dying clinicians, rongoā (natural healing) practitioners, spiritual leaders, health professionals and funeral directors), were interviewed about their experiences of caring for people who had an Assisted Death. An inductive thematic analysis was used to analyse the data.

### Findings

Assisted dying is a different type of death, and new to Māori families. Although the number of whānau using Assisted Dying services is comparatively lower than non-Maori, the impact of loss and grief on whānau is significant. Whānau were proud of their deceased family member's decision to have an Assisted Death however, the shock, trauma, guilt, and distress they experienced was overwhelming. They identified a lack of bereavement support.

### Conclusion

Whānau require access to culturally appropriate information and resources about Assisted Dying's criteria, safeguards, assessment processes and the procedure to help them plan and prepare for an Assisted death as this will also support bereavement. New healing approaches are urgently needed.

## Indigenous researcher insights into researching Māori family experiences of assisted dying in Aotearoa New Zealand

Dr Tess Moeke-Maxwell<sup>1</sup>

<sup>1</sup>University Of Auckland

### Background

The End of Life Choice Act (2019) presents a new way of dying for Māori adults who have a terminal illness who meet the strict eligibility criteria. How are Māori whānau navigating and using this new end-of-life option? In this presentation, the lead investigator provides an overview of a qualitative project that aimed to explore Māori whānau' (family) experiences of assisted dying.

### Objectives

Tess will provide an overview of the 'Waerea: Māori whānau experiences of assisted dying' study. She will highlight the study's aims, methods and creative arts approaches employed by the team to translate the research findings into culturally appropriate assisted dying discussion tools for Indigenous families.

### Design

Qualitative Kaupapa Māori Research (KMR) methods were used to explore whānau experiences of accessing and using the assisted dying service in Aotearoa New Zealand and creative arts research methods were employed to disseminate findings.

### Methods

We conducted thirty six face-to-face interviews with over fifty whānau participants who were recruited from across New Zealand using Māori community networks and palliative care services. Twenty support workers (assisted dying attending medical practitioners, rongoā practitioners, spiritual leaders, health professionals, and funeral directors), were interviewed for their perspectives. KMR methods informed an inductive thematic analysis of data coded using NVivo 14 software.

### Findings

Assisted dying is a "new" and "different" way of dying. Whānau became trusted kaitiaki (guardians) on the Kaitiakitanga Assisted Dying Pathway. Four Indigenous advisory group elders withdrew their cultural support. Recruitment was hampered because; assisted dying was not openly discussed in Māori communities; only small numbers of whānau used the assisted dying service and not all health professionals referred people. Some grief-stricken whānau were unable to take part and others refrained to protect the privacy of the person who had an assisted death.

### Conclusion

Despite cultural and recruitment challenges the team interviewed people who wished to hasten their death using the assisted dying service, bereaved whānau who navigated the Kaitiakitanga Assisted Dying Pathway and support workers. Extra care was taken to navigate the Indigenous assisted dying study and confidentially recruit, interview, analyse and disseminate the Waerea study findings.

## Navigating Personal Boundaries: How Physicians Manage the Influence of Their End-of-Life Preferences on Patient Care

Dr Sarah Mroz<sup>1</sup>, Dr Frederick Daenen<sup>1</sup>, Dr Sigrid Dierickx<sup>1</sup>, Dr Freddy Mortier<sup>1</sup>, Dr Ludovica De Panfilis<sup>2</sup>, Dr Luca Ghirotto<sup>3</sup>, Dr Toby Campbell<sup>4</sup>, Dr Luc Deliens<sup>1</sup>, Dr Kenneth Chambaere<sup>1</sup>

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**Background:** Physicians are regularly asked what they would do in the position of their patients. They are uniquely positioned to influence important medical decisions, which may involve complex end-of-life decisions including life-sustaining treatment or assisted dying. Their responses often reflect deeply held personal beliefs, shaped by clinical experience and cultural context, raising important questions about how physicians manage the influence of their own preferences on patient care.

**Methods:** This qualitative study explored how physicians perceive and manage the impact of their personal end-of-life preferences on clinical practice. In-depth interviews were conducted with 45 physicians, including general practitioners, palliative care specialists, and other medical professionals across Belgium (Flanders), Italy, and the United States (Wisconsin). Using a reflexive thematic analysis approach, we examined how physicians interpret, negotiate, and reflect on their role in patient decision-making.

**Results:** Participants acknowledged that their personal views inevitably shape their approach to end-of-life care but emphasized the need to center clinical decisions on patients' values. Many described strategies for maintaining professional boundaries and mitigating bias, particularly when patients explicitly ask what the physician would choose in their place. Views diverged on whether sharing personal preferences in such moments builds trust or risks exerting too much influence on patients. Physicians also reported ethical tensions and moral discomfort, particularly when patients' requests conflict with their beliefs. Physicians described how end-of-life discussions and personal reflection fostered their personal and professional growth.

**Conclusion:** These findings reveal a divergence of opinion among physicians about whether it is appropriate to share when asked what they would do if they were in their patients' position. Most believe that focusing on patients' values and priorities should take precedence, while some feel that sharing is necessary to maintain an open, trusting patient-provider relationship.

## Defining, contextualizing, challenging 'terminality' in the Terminally Ill Adults (End of Life) Bill

Dr Nataly Papadopoulou<sup>1</sup>

<sup>1</sup>University of Leicester

The Terminally Ill Adults (End of Life) Bill is currently going through the Parliamentary process, and if introduced, will apply to England and Wales. A key access criterion in the Bill is the one requiring 'terminality', that is, that the individual has an inevitably progressive illness or disease which cannot be reversed by treatment, and whose death can reasonably be expected within six months. The criterion describing the condition of the individual is likely that for which most divergence is noted across regulatory frameworks because of legal, medical, socio-cultural reasons.

This presentation first defines and conceptualizes 'terminality' within the broader end-of-life context in England and Wales. It then unpacks its current legal definition in the Bill drawing from past domestic reform proposals and other jurisdictions that use terminality to describe the physical condition of the individual requesting assistance. The analysis then moves to the most controversial elements of this legal definition, including problems with the prognostication requirement. It draws from clinical studies to show difficulties with the six-month requirement, from studies to show how healthcare professionals and some patients perceive it where is already in use, and highlights problems with its narrow scope drawing on jurisdictions such as Canada, where a version of the criterion was challenged on constitutional grounds.

It is suggested that while legal, medical, socio-cultural factors likely mean that this access criterion is unlikely to be substantially modified for England and Wales, some adjustments are still possible both in its legal definition, but also in its implementation, the latter especially putting healthcare professionals at the forefront, recognising the inherent medical nature of this particular access criterion.

## “Why Is My Suffering Unbearable?” Patients’ Perspectives on Assisted Dying in Spain and Switzerland

Dr. Iris Parra Jounou<sup>1</sup>, Ms. Solenne Blanc, Dr. Janet Delgado, Ms. Mar Vallès-Poch, Dr. María Victoria Martínez López, Dr. Rosana Triviño Caballero, Dr. David Rodríguez-Arias, Dr. Claudia Gamondi

<sup>1</sup>Universitat Autònoma De Barcelona

### Introduction

Unbearable suffering is widely recognized as a key driver behind requests for assisted dying. However, assessing such suffering remains a significant challenge, as it is deeply subjective and shaped by each individual’s context. While previous research has acknowledged the multifaceted nature of this suffering—spanning physical, emotional, social, and existential domains—few studies have offered rich, first-person accounts from those directly experiencing it.

### Method

This study explores how patients who request assisted dying define "unbearable suffering," and identifies the contributing factors behind it. Drawing from two parallel qualitative studies conducted in Switzerland and Spain, we analyzed 35 in-depth semi-structured interviews using thematic analysis.

### Results

The analysis revealed several intersecting and recurrent themes across both datasets:

1. Exhaustion, Accumulation, and Impossibility of Alleviation – Suffering emerges from a cumulative burden of experiences across time and life domains, leading to profound exhaustion and a desire for death.
2. Confronting Dependency – As a deeply relational experience, increasing reliance on others can be a source of suffering, both in present limitations and the anticipated loss of autonomy.
3. Erosion of Personhood and Identity – Patients expressed a sense of no longer recognizing themselves or being able to live in accordance with their core values and personal identity.
4. Hopelessness – A pervasive sense that "it is too late for change," often accompanied by emotional fatigue and the belief that current life is no longer worth living.
5. Death as Relief – Death is envisioned not as an end to life but as a form of rest—offering peace, relief, and liberation.

### Discussion

Understanding this suffering in its full complexity can support healthcare professionals, families, and broader support networks in responding more empathetically and effectively. Beyond clinical contexts, this results may inform public discourse and deepen societal awareness around the lived realities behind assisted dying requests.

## Demedicalizing MAiD: Reframing Autonomy and Accountability in Assisted Dying

Dr Amirala Pasha<sup>1</sup>, Dr Richard Silbert<sup>2</sup>

<sup>1</sup>Mayo Clinic, <sup>2</sup>Mayo Clinic

Medical Assistance in Dying (MAiD) has traditionally been governed and administered within a heavily medicalized framework, placing physicians and other healthcare professionals at the center of both decision-making and delivery. This abstract explores the concept of demedicalizing MAiD—shifting the focus from a purely clinical model to one that more fully incorporates other legal and ethical considerations with a particular emphasis on autonomy in decision-making. Demedicalization questions whether decisions around assisted dying should rely so heavily on medical judgment. This is especially important as clinician shortages erode the access and familiarity between patients and their medical providers, which is more acute in individuals with lower socioeconomic status and minorities. In many instances, this serves as a barrier to MAiD, resulting in inequitable access. The discussion highlights alternative frameworks that strike a balance between individual autonomy and appropriate safeguards, including legal mechanisms, community-based support, and interdisciplinary review processes. Ultimately, demedicalizing MAiD challenges us to rethink whose voices count in end-of-life decision-making and how systems of care can support individuals without devaluing autonomy and erecting additional barriers through medical gatekeeping.

## Whānau and assisted dying: A qualitative study of family experiences in Aotearoa New Zealand

Mr Manu Pelayo<sup>2</sup>

<sup>1</sup>Victoria University Of Wellington, <sup>2</sup>Health New Zealand

While the End of Life Choice Act 2019 legalised assisted dying (AD) in New Zealand as an individual choice, findings from this study show that the process is rarely experienced in isolation.

Using Interpretive Description, in-depth interviews were conducted with family members, either individually or in family groups (n= 17 to date). The findings show that AD is deeply relational and often a complex family journey.

Participants described assisted dying as a collective process involving open conversations, shared responsibilities, and opportunities for planned closure. Being able to say goodbye in advance was described as profoundly meaningful — something that brought peace, helped with grief, and offered a sense of conclusion. Families also described emotional duality of relief and anticipatory grief in the lead-up to a death that had a set date. For some, witnessing their relative's deterioration and suffering helped them come to terms with the decision. Many described the experience as surreal, particularly when selecting the date and preparing for the final day.

After the death, several participants described a noticeable silence from the AD service, with no structured follow-up. In the absence of formal support, families relied heavily on one another and their communities. Engagement experiences with the AD service ranged from compassionate and personal to procedural and cold. Despite these challenges, many families described the experience as one of control and dignity.

The participants' stories highlight the need to recognise assisted dying as a relational experience with their families, providers, and communities, and the need for follow-up care.

## Toward a better understanding of Assisted Dying Use: Experiences and Perspectives of International Professionals

Pre Catherine Perron<sup>1</sup>, Pre Marie-Eve Bouthillier<sup>2</sup>, Pre Isabelle Marcoux<sup>3</sup>, Mrs Alexandra Beaudin<sup>3</sup>, Mr Simon Lemyre<sup>2</sup>

<sup>1</sup>University of Sherbrooke, <sup>2</sup>University of Montreal, <sup>3</sup>University of Ottawa

**Background:** Since 2015, medical assistance in dying (MAiD) has been authorized in Quebec for individuals meeting the criteria outlined in the Act respecting end-of-life care. Over the past decade, its use has steadily increased, placing Québec first worldwide in the proportion of deaths attributed to MAiD. The Interdisciplinary Research Consortium on MAiD (CIRAMM)—bringing together 75 members—was formed to study MAiD use in the province.

**Methods:** This presentation reports on one (among four) of the CIRAMM's cross-thematic methods. 20 focus groups were conducted with healthcare professionals (physicians, nurse practitioners, nurses, social workers, clinical ethicists, etc.) involved in or concerned by MAiD from the following jurisdictions: Quebec, other Canadian provinces, California, the Netherlands, Belgium, Switzerland, and Victoria (Australia). The interview guide drew on Bronfenbrenner's ecological model, and was adapted to the MAiD context. Discussions explored, among others, social determinants of health, vulnerability factors, personal experiences, nature of suffering, social values and norms affecting the acceptability of MAiD, the impact of roles changing (patients/professionals) in decision-making concerning end-of-life care, accessibility and continuity of care, and the role of end-of-life care support structures. Key findings were identified through deductive–inductive thematic analysis.

**Results:** Preliminary results revealed that factors influencing the use of MAiD can be divided in four themes: 1) laws and policies on MAiD, 2) the impact of the organization of care and services, 3) individual characteristics of people who make MAiD requests, and 4) social dimensions that influence the use of MAiD.

**Discussion:** By shedding light on the factors influencing the use of MAiD, we can provide valuable insights to policymakers and healthcare providers for a more responsible delivery of MAiD. This study offers an international comparison between jurisdictions with established MAiD legislation.

## Ensuring timely compassionate and legally compliant support for people's written VAD declaration

Mr David Pieper<sup>1</sup>

<sup>1</sup>Dying with Dignity NSW

The DWD NSW Witness Program matches trained volunteer witnesses with a person who is requesting VAD and needing two independent people to witness their written declaration, as required by NSW legislation.

The program is designed to uphold the dignity, autonomy and privacy of individuals choosing VAD, while also ensuring that volunteers are prepared, supported and confident in their role. As demand grows, we continue to refine the program in collaboration with regional groups, health practitioners and volunteers

The program includes the following components:

- \*Central coordination
- \*Volunteer network
- \*Training
- \*Ongoing engagement and support
- \*Confidential request process and documentation
- \*Matching and allocation
- \*Debrief and feedback
- \*Safeguarding and accountability

Since November 2023, Dying with Dignity NSW has delivered 16 training sessions across NSW in collaboration with Local Health District teams and two with Private Health providers.

A total of 202 witnesses have been trained and 180 declarations witnessed.

Looking ahead the DWD Witness Program will continue to respond to the needs of applicants, volunteers and healthcare professionals as demand for VAD grows across NSW

## Assisted Dying in Detention in the Netherlands: Legal Framework, Practice, and Ethical Dilemmas

MA LLM PhD Liselotte Postma<sup>1</sup>

<sup>1</sup>Erasmus School Of Law

In the Netherlands, euthanasia in detention is rare but not inconceivable. As with individuals living in freedom, prisoners may also qualify for euthanasia. Yet such cases raise distinctive issues that do not emerge in free society.

This session examines the legal framework, practical considerations, and ethical dilemmas surrounding euthanasia in detention. Central questions include: To what extent do such requests arise from the fact of imprisonment, sometimes with no realistic prospect of release? Can a detainee's request genuinely be regarded as voluntary? Who determines whether such a request may be granted, and how are assessment and potential implementation organized?

Particular attention will be paid to relevant case law of the Regional Euthanasia Review Committees and to the Euthanasia Work Instruction of the Dutch Custodial Institutions Agency.

## Nurse Practitioners and Voluntary Assisted Dying: ACT leading the way in multidisciplinary authorised practitioner workforce

Ms Kate Reed<sup>1</sup>

<sup>1</sup>Health And Community Services Directorate

Voluntary assisted dying became operational in the ACT on 3 November 2025 after an 18-month implementation period led by the Health and Community Services Directorate. As a progressive iterative legislative framework, the ACT was the first jurisdiction in Australia to allow eligible nurse practitioners to apply and undergo the authorisation practitioner process to work in all the roles of the voluntary assisted dying service. With four nurse practitioners successfully completing the authorised practitioner training at commencement of services, their role in the provision of services was integral to the workforce roll out.

This presentation provides an overview of the authorisation process and the workforce trial that was developed as part of implementation. It explores the innovative process, the lessons learnt, and the responsive adaptations required to ensure the needs of the ACT community were, and continue, to be met. Additionally, a snapshot of the medical practitioner, nurse practitioner and registered nurse authorised practitioner participation in the voluntary assisted dying services in the ACT will be discussed along with an up-to-date breakdown of workforce utilisation across the sector and support mechanisms for practitioner sustainability and retention.

Finally, the presentation will provide insight into the personal and professional journey of the lead up to implementation and then the provision of services, through my clinical decision making to increase my scope of practice include voluntary assisted dying services into my practice as a palliative care nurse practitioner within the ACT health system.

## 'Not a pretty picture' - VAD information and access in Australian residential aged care

Ms Frankie Bennett<sup>1</sup>

<sup>1</sup>Go Gentle Australia

Voluntary Assisted Dying (VAD) is legal in all Australian states and also in the ACT. Nationally more than 8000 people have applied to access VAD since 2019. Applicants typically are aged in their 70s, have terminal cancer and are receiving palliative care. Around 1/10 applicants live within residential aged care (RAC). The Aged Care Quality and Safety Commission has made it clear that eligible residents have the right to choose VAD even where a provider has made the decision not to participate. The Aged Care Act 1997 mandates that aged care providers must support residents in understanding their rights and ensure transparency in services provided. Similarly the Aged Care Act 2024 stipulates that care should be person-centred and tailored to the individual.

**Aims:**

To determine if RACs have public information about VAD; the quality of that information; and the level of VAD access they offer.

**Method:**

We investigated 25 of the largest RACs nationally, and the 20 largest providers in each state. This equated to 72 unique providers (130,000 beds and 70% of the national RAC population). Website information was analysed and providers contacted directly at least three times and asked what information they had available. All providers were given an opportunity to update information on their websites.

**Outcomes:**

Results were translated into 'traffic light' ratings (red, amber, green) based on quality of information and level of VAD access. In all states there was a paucity of public information. What was available was of poor quality or difficult to find. Of the 72 providers, only three (4%) had comprehensive information and full VAD access.

**Conclusion:**

RACs have an obligation to give residents clear and accessible information about VAD. Yet a large majority of providers either offer no information or information of poor quality.

## State of Voluntary Assisted Dying: An Australian snapshot

Dr Linda Swan<sup>1</sup>

<sup>1</sup>Go Gentle Australia

### Background and aims

With voluntary assisted dying (VAD) now available in every state and the ACT, Go Gentle Australia's annual State of VAD report (inaugural report published in August 2024) is a timely look at more than six years' of this end-of-life choice in Australia; how is it working in practice and what can be improved?

### Method

The report, collates and compares data from each jurisdiction's oversight bodies in one place to provide insights into the operation of VAD across Australia and assess how the systems and services serve dying people, their families and the carers and health care professionals who assist them.

### Results

We will provide a 2025 snapshot of the report's key findings including:

- Are VAD laws working safely and as intended?
- The most recent figures on the number of people who have died using VAD
- The average applicant age and primary diagnosis
- % of VAD applicants who had accessed palliative care
- The number of health practitioners who are VAD trained (including nurses, who may act as administering practitioners in some states)
- Demand for VAD
- Challenges and areas for improvement

We will also explore the strong intersections between VAD, palliative care and end-of-life care, and consider how we can better integrate VAD into existing care to the benefit of all involved.

### Conclusion

The 2025 State of VAD report reinforces the findings of the original report and offers a unique opportunity to work together to improve the way systems, services and clinical practice align to improve the choices, pathways and experiences for dying people at the end of their lives.

## The complexity of Voluntary Assisted Dying and dementia

Dr Linda Swan<sup>1</sup>

<sup>1</sup>Go Gentle Australia

Dementia (and related diseases) will soon become the leading cause of death for Australians. Increasing prevalence causes understandable concern about the impact of living with dementia and what this means for end-of-life choice. Whether someone with dementia can access Voluntary Assisted Dying (VAD) and include such a request in an Advance Care Directive, is the question most often asked to advocacy groups. The answer – that the architecture of Australia’s VAD laws excludes most people with dementia – is met with anguish and disbelief.

Aim:

To prepare an Issues Paper to help the community understand – through informed conversations – the complexity of VAD access for people with dementia and explore why dementia is not an eligible condition.

Method:

Information and comparative data were collated via desktop research, an extensive literature review and targeted interviews. The key challenges of allowing VAD access for dementia and how these are approached internationally were also explored.

Results: The paper explored why dementia is excluded from VAD laws and why allowing access would present significant practical, political, medical and ethical challenges. Two primary hurdles were identified:

1. Australia’s VAD laws require a person to have capacity to make and communicate their decisions every step of the way.
2. VAD laws are designed for people at the very end of life. For most, this means being within 12 months of a natural death. Dementia doesn’t fit this framework. Significantly, the paper found that, even in countries where people with dementia can access VAD, uptake is limited, and doctors and families are reluctant to be involved.

Discussion:

VAD for dementia is complex and contentious. The nature and trajectory of dementia characterised by a gradual loss of cognitive capacity complicates notions of informed consent. Ethically, there is a tension between respecting personal choice and safeguarding the vulnerable.

## Voluntary Assisted Dying and General Practice: preferences for education and perceptions in Queensland

Ms Enna Stroil-Salama<sup>1</sup>, Ms Georgia White<sup>1</sup>, Dr Megan Ashcroft<sup>1</sup>, Dr Fabian Jaramillo<sup>2</sup>, Professor Liz Reymond<sup>1, 3</sup>

<sup>1</sup>Queensland Voluntary Assisted Dying Support and Pharmacy Service, <sup>2</sup>Voluntary Assisted Dying Metro South Hospital and Health Service, <sup>3</sup>Griffith University, School of Medicine

### Background and Aim

Voluntary assisted dying (VAD) was enacted in Queensland in 2023 and provides an additional end-of-life option for eligible individuals. General practitioners (GPs) play an important role in the planning and provision of end-of-life care, yet they report a lack of confidence when responding to patients seeking VAD. GPs need to be well educated about VAD legislation and related professional obligations to ensure patients are well-informed about end-of-life options. This study considered GPs' preferred learning methods about end-of-life care and explored GPs' perceptions of VAD.

### Methods

GPs chose one of three educational modalities (in-clinic academic detailing, lunch and learn sessions with their peers or an educational dinner) and then completed a voluntary survey. Survey data was analysed using both descriptive statistics and the Consolidated Framework for Implementation Research (CFIR). CFIR allowed for assessment and categorisation of barriers and facilitators for GPs discussing VAD in their clinical practice.

### Findings/Results

197 of 789 invited GPs attended educational sessions, 183 completed the survey. Lunch and learn sessions were the preferred modality (n=116, 59%), however all modalities increased knowledge and confidence about VAD. Only academic detailing changed GPs' consideration of becoming VAD practitioners (n=23, 61%). Most barriers and facilitators for VAD conversations related to individual factors including personal beliefs, motivation, knowledge, and clinician-patient relationships.

### Conclusion

All three education modalities improved GPs' knowledge of VAD in the end-of-life care context, although small-group interactive lunchtime session was a preferred modality. For clinicians, increasing knowledge and confidence about VAD can help them inform patients about their end-of-life options and to make informed decisions about their future care. GP educators could consider offering multiple modalities incorporating elements of convenience and peer interaction, to suit individual preferences. VAD discussion barriers and facilitators could facilitate future implementation strategies for education and behaviour change interventions.

## Exploring the voluntary assisted dying medical authorised practitioner workforce in Queensland, Australia

Prof Liz Reymond<sup>1</sup>, Ms Enna Stroil-Salama<sup>1</sup>, Ms Georgia White<sup>1</sup>, Dr Megan Ashcroft<sup>1</sup>

<sup>1</sup>Queensland Voluntary Assisted Dying Support and Pharmacy Service, <sup>2</sup>Griffith University, School of Medicine

### Background and Aim

Australia's ageing population is driving greater demand for health services, including voluntary assisted dying (VAD). In Queensland, VAD script activity increased by 54% from 2023 to 2024, while the medical authorised VAD workforce grew by only 14% over the same period. Emerging literature suggests that service provision barriers may impact the VAD workforce. These include lack of remuneration, administrative burden, emotional fatigue, and a limited number of authorised practitioners within rural and remote areas. These factors pose a threat to the longevity and retention of the VAD workforce. To better understand future risks to VAD service delivery in Queensland, this research examined medical authorised practitioners' perspectives by assessing enablers and barriers to their participation in VAD.

### Methods

All medical VAD authorised practitioners in Queensland were invited to complete an online survey. Descriptive statistics and content analysis were conducted.

### Findings/Results

Ninety authorised medical practitioners completed the survey (40% response rate). The most frequent enablers to VAD service provision included the work being professionally rewarding (n=56, 76%), VAD aligning with personal values (n=53, 72%), the practitioners' connection with the local hospital service (n=50, 68%), and support from the statewide VAD service (n=45, 61%). Barriers included lack of clinical availability (n=43, 54%), lack of remuneration (n=23, 29%), and challenges navigating VAD processes or systems (n=19, 24%). Despite highlighted barriers, most practitioners desired to either do the same amount (n=40, 44%) of VAD work or more (n=34, 38%); however, a greater workload would benefit from remuneration (n=18, 25%).

### Conclusion

Medical VAD practitioners in Queensland experience barriers similar to those reported in other jurisdictions. To meet increasing VAD demand in Queensland, both barriers and facilitators need to be addressed to further underpin the sustainability of the workforce.

## End of life decisions in mental health care: perspectives of relatives and health care professionals

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<sup>1</sup>Amsterdam UMC, <sup>2</sup>University Medical Center Groningen (UMCG), <sup>3</sup>GGZ Centraal

**Background** – Medical Assistance in Dying (MAID) has a profound emotional impact on patients and their relatives. Although not formally involved, guidelines recommend including relatives. This workshop explores relatives' and health care professionals' experiences with MAID and advance care planning (ACP) in persons with a psychiatric condition in the Netherlands.

**Design** – An online survey in the general population (n=2392) compared relatives' emotional responses to MAID, based on somatic versus psychiatric grounds. Linear regression assessed whether the underlying condition influenced relatives' emotions after and involvement in the MAID process. Next, a Group Concept Mapping (CGM) study (mixed-methods participatory design) engaged 163 mental health professionals and relatives to identify views on good ACP/MAID in mental health care. Finally, a qualitative case study examined relatives' and key actors' perspectives during the end of life phase of a patient with psychiatric illness.

**Results**– The survey included 616 relatives who had experienced MAID (n=110; 17.8% due to a psychiatric condition). Relatives' emotional experiences were largely similar regardless of the underlying condition, suggesting that the generally neutral to positive attitudes towards euthanasia seen in somatic cases also apply to psychiatric cases. However, stronger feelings of powerlessness and guilt in relatives involved in psychiatric MAID may require targeted attention. This was underscored by the CGM study, which emphasized the importance of self-care for health care professionals involved in end of life decisions, and by the case study, which highlighted feelings of powerlessness among relatives and health care professionals during en-of-life care.

**Conclusions** – Together, these three studies show that feelings of powerlessness and guilt among relatives and health care professionals require targeted support and guidance throughout both palliative care and MAID in psychiatric patients.

## The State of Empirical Research on Assisted Dying: A Scoping Review and Evidence Map

Mr. Sean Riley<sup>1</sup>, Dr. Gianna Strand<sup>2</sup>, Dr. Iris Parra Jounou<sup>3</sup>, Dr. Marta Perin<sup>4</sup>, Dr. Chiara Crico<sup>4,5</sup>, Ms. Fenne Bosma<sup>6</sup>, Dr. Janet Delgado<sup>7</sup>

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**Background:** Policy change has outpaced evidence on medical assistance in dying (MAiD). To clarify the current landscape, identify gaps, and inform research priorities, we conducted a scoping review to characterize what has been studied, where, how, and in which populations, as well as how these elements have changed over time.

**Methods:** Following the Arksey and O'Malley framework, we conducted a comprehensive literature search followed by dual-reviewer screening at title/abstract and full text levels. We charted data by jurisdiction, language, population, study design, research methods, and temporal orientation; study aims were coded thematically via content analysis.

**Results:** After screening 6,877 records, we included 1,471 studies. Empirical MAiD research has increased steadily over three decades, with a sharp rise after 2018. Surveys were the most common study procedure (900; 61%), while interviews (359; 24%), chart review (90; 6%), document analysis (67; 5%) and focus groups (46; 3%) are less common. Experimental (14; 1%) and quasi-experimental (7; 0.5%) studies were rare. Most designs are observational (1,448; 98%) and cross-sectional (1,152; 78%). Most studies investigated healthcare providers (876), patients (251), caregivers (132), and the public (242). As for research questions, a plurality of studies focused on attitudes or opinions (686; 47%). Studies investigating clinical practices and care delivery (349; 24%) were prevalent, while policy/regulation, access/barriers, psychiatric MAiD, dementia, and costs remain understudied.

Evidence maps will illustrate the key relationships, trends, and gaps.

**Conclusions:** Despite rapid growth, the evidence base remains largely descriptive and cross-sectional. This leaves important epistemic gaps: study designs rarely permit causal inference, temporal and international comparison remains difficult, and research questions emphasize attitudes rather than clinical processes or outcomes. Addressing these deficits requires deploying methodologically rigorous research designs, standardizing measures, and promoting inquiry into how policies and practices impact access, equity, and quality of care.

## The Bureaucratization of MAiD Oversight: Lessons from Tuscany's Third-Party Prior Authorization Model

Mr. Sean Riley<sup>1</sup>

<sup>1</sup>The Ohio State University Wexner Medical Center

As the tides of MAiD oversight continue to change, prospective case approval by third parties, such as health department registrars, interdisciplinary tribunals, or legal professionals, is increasingly required. In 2025, Tuscany became the first Italian region to legalize MAiD, adopting a unique approach to prospective case assessment. This paper uses Tuscany as a lens to examine how oversight design choices must consider the role of expertise, the balance of safety and access, and the limits of the bureaucratization of MAiD oversight.

The Tuscan system has three distinctive design features. First, medical assessment by the applicant's own care team is not required before application to the local health authority (ASL), which appoints a Multidisciplinary Commission to conduct clinical assessment. Bypassing independent medical assessment might streamline applications and avoid conscientious objection clashes, but may also undermine the independence of the medical system and the benefits of physician-patient relationships. Second, the Commission has strict membership requirements: at least one palliative-care physician, psychiatrist, anesthetist, psychologist, forensic physician, nurse and a case-specific specialist. This permanent, diverse bench of expertise may enhance scrutiny by building institutional knowledge and domain expertise, while reducing risks of doctor shopping or assessor shortages. Third, assessment functions are split: the Commission conducts legal and clinical eligibility review, while the Clinical Ethics Committee evaluates ethical components. By contrast, most systems blend medical, ethical, and legal review, assuming cross-domain competence.

These departures highlight unresolved questions for MAiD oversight everywhere: Does specialization across ethical, legal, and clinical domains improve oversight outcomes? Can third-party authorization be streamlined without sacrificing rigor? Which design features support access while sustaining credible scrutiny? Tuscany illustrates how altering system design clarifies such trade-offs, offering insights into scaling effective oversight.

## Is continuous deep sedation perceived as morally distinct from MAiD? Folks' views, and confounding factors

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Continuous deep sedation until death (CDS) and medical aid in dying by drug administration (MAiD-euthanasia) are clinically diverse (e.g. different pharmacology involved, different pace of the dying process) and legally distinct practices (i.e. MAiD being illegal in some jurisdictions or regulated by stricter approval procedures). However, empirical studies refer to a “grey zone” (Rys et al, 2015) describing conceptual confusion and some clinical indistinctness between both practices, particularly when some circumstances are at play (Locatelli et al 2025). Health professionals' tend to assimilate CDS to MAiD or to consider them as variants of the same technique (Koksvik et al) when the sedation level is increased rapidly or disproportionately (Anquinet et al), when CDS is not performed in accordance with relevant guidelines (Bruinsma et al.), when CDS is primarily used to address family distress (Rietjens et al 31) or patients' nonphysical suffering (Voeuk et al, Rietjens et al 31), when the CDS decision is made partly with the intention of hastening death or is perceived to have a life shortening effect (Inghelbrecht et al.), when CDS is combined with withdrawal of mechanical ventilation (Auffray et al), when the patient had requested MAiD (Lokker et al), and when health professionals feel unduly pressured by families to increase of the sedation level (Lokker).

This ambiguity accounts for a decades-long controversy on whether both practices are morally distinct and should receive a different legal consideration (Sterckx, Raus, Mortier, eds).

The purpose of this experimental study is to test whether and to what extent intentionality, pace to death and the irreversibility of the intervention impact on folks' views regarding a) the morality of CDS and MAiD, and b) the opportunity to regulate MAiD. A 2 (intent) x 3 (short-irrev vs long irrev vs long rev) between-subjects study design is used to experimentally address that question.

## Toward a Global Consortium on MAiD: A Co-Design Workshop

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### Abstract

Variation in MAiD policy, practice, and reporting across jurisdictions creates real blind spots: incomparable data, uneven oversight, and policy debates driven by anecdotes. Envisioned as an independent international organization, such a Consortium could foster international collaboration, enable empirically driven and comparable assessments of MAiD oversight, and support evidence-based policy discussions.

We will begin with a 10-minute overview of the Consortium as first detailed in an AJOB commentary (doi:10.1080/15265161.2025.2488272), including an outline of the potential value (comparability, transparency, early-warning signals, methodological standards) versus practical challenges (governance, attracting collaborators, researcher bandwidth, funding, language and cultural differences, and institutional support).

We will then move into structured engagement with participants, using live voting and open discussion to address the following: 1) Appetite and priorities for a Consortium; 2) Feasibility and challenges; 3) Scope and functions; 4) Governance and independence; 5) Data quality, comparability, and methodological standards; 6) Funding and sustainability; 7) Roadmap and next steps.

Anticipated outputs for organizers include: a shared vision of what a Global Consortium on MAiD Policy Oversight could achieve, a concise list of priority areas for further exploration, and a set of guiding principles drawn from participant input. For participants, the workshop will offer a clearer grasp of the potential benefits and risks of a Global Consortium, insight into key design choices and their trade-offs, and an opportunity to help shape whether and how such an initiative should proceed.

The Consortium has the potential to generate high-quality research, education, and evaluation that informs policy, practice, and public dialogue. As MAiD expands globally and existing laws are adapted, a trusted, collaborative, and empirically grounded body could help regulatory systems evolve with transparency, equity, and rigor.

## Voluntary Assisted Dying, Bereavement and Support- Health Professional Perceptions and Educational Needs- A Scoping Study

Ms Hayley Russell<sup>1</sup>, Ms Susan Jury<sup>2</sup>, Dr Naomi Katz<sup>3</sup>, Ms Sarah Meagan<sup>4</sup>, Dr Margaret O'Connor<sup>5</sup>

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**Objective:** This study aims to explore a range of health professionals views on bereavement after voluntary assisted dying including impressions of grief impacts within their professional impact, confidence in personal and health system ability to support grieving families and acceptability of a range of potential educational resources for health professionals.

**Methods:** This scoping study employed both quantitative and free text questions to achieve an overview of health professional opinions and experiences. The survey instrument was distributed via a range of non for profit organisations and health care institutions.

**Results:** The group of 112 providers reported high levels of confidence in individual ability to support grieving families after VAD but lower confidence in general availability of suitable grief support after VAD. A range of proposed educational resources were highly acceptable to respondents. Themes emerging from free text responses included acknowledgement of the individuality of grief experiences and importance of considering risk and protective factors, the need for support both before and after a death and encouragement of equity of services across demographics.

**Conclusions:** Health professionals are likely to take up educational resources in this area if provided and are supportive of enhanced bereavement services for the families they work with.

## Challenges of Legalizing Voluntary Assisted Dying in East Asia: A Comparative Analysis

Dr. Yukio Sakurai<sup>1</sup>

<sup>1</sup>Yokohama National University

This paper examines the current status and challenges of Voluntary Assisted Dying (VAD) legislation in East Asian countries, with comparative reference to European, Australian, and New Zealand systems. While VAD has been legalized and operationalized in jurisdictions such as the Netherlands, Belgium, Canada, and several Australian states, East Asian nations—including Japan, South Korea, Taiwan, Hong Kong, Singapore, and Thailand—continue to classify assisted suicide as a serious criminal offense. Although frameworks for withholding or withdrawing life-sustaining treatment and palliative care exist, active VAD implementation faces multilayered barriers rooted not only in constitutional and statutory frameworks but also in social, cultural, and ethical norms. Confucian family ethics, Buddhist non-harm principles, and collective social values contribute to societal resistance, emphasizing preservation of life and the implications for families and communities. In Japan, legislative and policy deliberations on medical ethics exemplify a distinctive approach, shaped by multi-party consensus, expert advisory committees, and broad societal consultation. This cautious, risk-averse framework emphasizes gradual development over rapid legal reform, allowing the establishment of end-of-life care guidelines that recognize patients' rights to refuse treatment while stopping to discuss active VAD. Similarly, in the legal context, cases are often addressed through mitigation measures rather than definitive judicial rulings, reflecting a broader preference for incremental, consensus-driven solutions that balance ethical and social considerations. Comparative analysis underscores that differences between East Asian and Euro-Australian systems manifest in challenges such as cross-border medical practice, international normative divergence, and "suicide tourism." These gaps highlight the need for context-sensitive policy design that simultaneously respects patient autonomy, prevents abuse, safeguards vulnerable populations, and aligns with prevailing social and ethical norms. By situating VAD within East Asia's distinctive cultural, ethical, and legislative contexts, this study provides a comprehensive perspective for scholars and policymakers navigating the intersections of law, medicine, and ethics in end-of-life decision-making.

## Whose Law Governs Dying? Indigenous jurisdiction and settler-state regulation in VAD-Australia, Aotearoa, Canada & USA

Mrs Jessica Setefano<sup>1</sup>

<sup>1</sup>QUT

Indigenous testimonies in voluntary assisted dying (VAD) reviews highlight a stark truth. Elder François Paulette of the Dene Nation told Canada’s Senate: “You should have had Indigenous people sitting down with government people and designing this legislation” (Senate of Canada, 2021). An Aboriginal participant in Victoria’s review stated: “Imagine asking permission to die from the system that once denied your right to live.” These voices reveal how settler states claim jurisdiction over Indigenous death while inviting Indigenous peoples to respond only after decisions are made. This scoping review analysed 23 sources across Australia, Aotearoa, Canada, and the United States to ask: How are Indigenous peoples represented, or erased, in VAD discourse? Four themes emerged: silence, performative consultation, relational sovereignty, and sovereign-affirming care. Findings show that Indigenous perspectives are excluded or reduced to deficit framings. For end-of-life care to be just, it must be Indigenous-led, affirming sovereignty, kinship, and relational responsibilities.

## End-of-Life Decision-Making: Rethinking Ethical Paradigms Through a Multi-Phasic Lens

Dr Ehsan Shamsi Gooshki<sup>1</sup>

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End-of-life decision-making is among the most challenging areas of clinical ethics and health law, particularly in contexts such as voluntary assisted dying and forgoing life-sustaining interventions. These situations are often sources of disagreement among healthcare providers, patients, and surrogate decision-makers. Cultural and social factors, as well as individual and community belief systems, exert a significant influence, making such decisions even more complex and contested. In this paper, I argue that one of the main sources of disputes, both in academic discourse and in public debates, lies in how the concept of the life span is defined, explained, and communicated. Contemporary practice often relies on a single-phase paradigm of life, which unavoidably results in extending professional and ethical standards designed for stable phases of life to very different phases such as terminal illness and the dying process. This uncritical extension creates confusion and conflict in both ethical reasoning and clinical decision-making.

I propose a shift from this single-phase model toward a multi-phasic conceptualisation of the life cycle, one that distinguishes between different stages such as stable life, terminal illness, and the dying process. Such a nuanced framework allows us to re-define professional standards and ethical norms for each phase separately, creating more appropriate guidance for end-of-life care.

Drawing on insights from the Islamic concept of 'Ihtedhaar' (the final phase of life before death), as an exemplary case, I argue that adopting a multi-phasic approach could help various stakeholders including clinicians, patients, families, and policymakers, better understand and appreciate the justification of different medical interventions and decisions. This paradigm shift would facilitate smoother transitions between therapeutic interventions, palliative care, forgoing life-sustaining treatments, and advance care planning, ultimately reducing conflict and enhancing ethical clarity in end-of-life decision-making.

## When choice meets system design: is euthanasia becoming the default in global assisted dying?

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As assisted dying (AD) becomes a legally regulated practice across an expanding number of jurisdictions, questions are emerging about not only whether AD is permitted, but how it is implemented and experienced in practice. As of May 2025, at least 12 countries have legalised AD nationally or regionally, with more than 200 million people now living in jurisdictions where some form of AD is available. Yet, legal frameworks, terminology, and procedures vary considerably, shaping both public discourse and clinical practice.

Using official national reports and administrative statistics, we analysed recent data from 11 countries where AD is regulated. Across jurisdictions permitting both euthanasia and assisted suicide, a clear trend emerges: euthanasia constitutes the vast majority of assisted deaths. In 2023, assisted suicides represented only 2% of assisted deaths in the Netherlands, 8% in New Zealand, 12% in Luxembourg, and 21% in Australia. Euthanasia is also expanding more rapidly: between 2014 and 2023, annual growth in euthanasia ranged from 5% in the Netherlands to 200% in New Zealand, far outpacing the more modest increases in assisted suicide.

These patterns raise critical questions about the drivers of modality choice. While individual preferences, cultural values, and psychological factors play a role, structural and procedural elements—such as barriers to self-administration, clinical attitudes, place of death, and integration into health systems—might shape these trajectories in important ways. Our findings suggest that euthanasia may be becoming the default form of AD where both options are legally available. This highlights the need for closer attention to institutional design and public health policy to ensure that end-of-life choices remain truly autonomous, equitable, and patient-centred.

## Regulating conscientious objection: the divergent approaches in Assisted Dying and Abortion Law in New Zealand

Dr Jeanne Snelling<sup>1</sup>

<sup>1</sup>University Of Otago

In 2019, New Zealand enacted law partially legalising Assisted dying. The End of Life Choice Act 2019 constitutes one of the most controversial and contested health laws to be enacted in New Zealand in recent decades. Not long after its enactment, New Zealand's Parliament introduced the Abortion Legislation Act 2020, which significantly liberalised existing abortion law. While both legal frameworks incorporate conscientious objection provisions and were introduced almost contemporaneously, the content, scope and effect of the respective provisions vary significantly. While the End of Life Choice Act 2019 provisions are drafted extremely broadly, the comparator provisions in the Abortion Legislation Act 2020 are appreciably narrower, enabling greater capacity for balancing patient rights of access with rights of conscientious objection. This presentation explores the divergent approaches taken in these two regulatory frameworks, including the respective legal challenges to the respective frameworks. It suggests that, while both frameworks govern ethically contested terrain, the degree of divergence cannot be justified and risks contributing to the stigmatisation of assisted dying in New Zealand.

## Psychedelics and End-of-Life Care: Science, Legality and Chaplaincy Pathways

Dr. Leanna Standish<sup>1</sup>, PA-C, Psychiatry Dona Chiechi Elam

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Psychedelic-assisted therapies—including psilocybin, ketamine, lysergic acid diethylamide (LSD), and 3,4-methylenedioxymethamphetamine (MDMA)—have been investigated in the context of end-of-life care for their potential to reduce existential distress, depression, and anxiety associated with terminal illness. Clinical studies demonstrate that these interventions enhance spiritual well-being, strengthen interpersonal connections, and help patients find meaning and purpose in the face of mortality.

A key conclusion of the 2017 University of Washington Conference on Psychedelics in End-of-Life Care was that treatment should ideally begin at the time of diagnosis rather than be delayed until the terminal stage. Nonetheless, nearly a decade later, access to psychedelic therapy in the United States remains restricted to clinical trials. As a result, many patients turn either to underground providers or to psychedelic churches that operate under the framework of religious freedom.

This presentation will provide an overview of the current state of psychedelic science in psychiatry and palliative care, review international clinical trial evidence, and examine the evolving global legal landscape. We will discuss how patients in the U.S. access underground psychedelic therapies and the risks associated with this pathway, while also highlighting the growth of legitimate psychedelic churches offering palliative care practices to patients and families.

Looking forward, we envision a model in which psychedelics are integrated into hospice care through chaplaincy services. In the U.S., hospice remains the only healthcare setting where spiritual care is explicitly reimbursed by insurance. As a case example, we will describe the Sacred Garden Community Church, a multi-sacrament psychedelic community, which illustrates how access to psychedelic end-of-life care may be advanced through a spiritual framework alongside—or as an alternative to—the medicalization model.

## From Choice to Legacy – Integrating Organ Donation into Voluntary Assisted Dying Pathways

Dr Wade Stedman<sup>1</sup>

<sup>1</sup>Royal North Shore Hospital, <sup>2</sup>Winston Churchill Trust

Voluntary Assisted Dying (VAD) is increasingly recognised internationally as a legitimate end-of-life choice for eligible individuals. In Australia, while public support for organ donation exceeds 80%, organ donation following VAD remains rare, with physician and community awareness low and only ~10–15% of VAD patients medically suitable. A key barrier is that organ donation is rarely raised early in the VAD process, leaving patients without the time or opportunity to integrate it into their end-of-life plans.

The 2024 Paul Tys Churchill Fellowship examined established programs in Canada, the Netherlands, Belgium, and Spain, where organ donation after euthanasia/MAiD is a more established part of care. Common principles include: maintaining clear separation between the VAD decision and donation; initiating donation conversations early; structured referral to specialist teams; multidisciplinary planning; and continuous ethical oversight. Successful models—such as home-to-hospital donation pathways in the Netherlands and integration within ALS clinics in Canada—demonstrate that early, transparent engagement can respect autonomy, preserve dignity, and increase donation opportunities.

Successful approaches have common themes: national protocols ensuring consistent, safe practice; training VAD practitioners in how to raise a donation opportunity; accessible written and digital resources; and equitable access across jurisdictions. These measures can be implemented without compromising safeguards against coercion, while importantly aligning with core end-of-life care principles of informed choice, respect, and compassion.

Integrating organ donation into end-of-life care for those choosing VAD offers patients a final opportunity to help others—transforming loss into legacy and enhancing the breadth and quality of choice at life's end.

## Chronic Obstructive Pulmonary Disease Prognostication in Voluntary Assisted Dying: A Case Series and Practitioner Perspectives

Mr Wayne Stevens<sup>1</sup>, Mrs Candice Austin, Mrs Twani Marshall

<sup>1</sup>West Moreton Hospital And Health Service

### Background:

Voluntary Assisted Dying (VAD) legislation in Queensland, effective since January 2023, has introduced new complexities in clinical decision-making, particularly for patients with Chronic Obstructive Pulmonary Disease (COPD). COPD presents a variable and often unpredictable disease trajectory, making prognostication challenging—especially when determining eligibility for VAD, which requires an expected death within 12 months.

### Aim:

To explore the variability and challenges in COPD prognostication within the VAD framework and to understand the perspectives and practices of VAD practitioners across Queensland.

### Methods:

This prospective study includes a case series of three patients with end-stage COPD who accessed VAD, alongside a statewide survey of VAD practitioners. Data sources include IEMR chart reviews, REDCap entries, and practitioner surveys. The study investigates clinical criteria used, respiratory physician input, and practitioner attitudes toward prognostication.

### Results (anticipated):

Preliminary findings suggest significant variability in prognostic approaches and uncertainty among practitioners regarding COPD eligibility for VAD. The study aims to identify barriers to consistent prognostication and highlight the need for standardised tools and guidelines.

### Conclusion:

This research addresses a critical gap in Australian literature regarding COPD and VAD. By examining real-world cases and practitioner insights, the study seeks to inform clinical practice, improve patient communication, and support policy development for clearer prognostic pathways in VAD eligibility assessments.

## The Role of Social Work in VAD

Ms Catherine Stockil<sup>1</sup>

<sup>1</sup>Murrumbidgee Local Health District

Voluntary Assisted Dying (VAD) is a new and emerging field of practice for Social Work, and as such there is very little guidance around what social work practice looks like in VAD, or the ways in which social work can contribute to the VAD process. Catherine has developed a unique social work role within her local VAD team that is not replicated elsewhere across NSW.

This poster will consider different social work theories and frameworks, as well as interventions, that can support VAD clients and their families. It will outline the model of care that Catherine has developed in her role and look at the unique skills social workers can bring to Voluntary Assisted Dying.

It will also consider the need for social work to be an embedded part of the VAD process to ensure that VAD as a healthcare pathway is providing not only excellent quality clinical care but also holistic psychosocial care to our clients.

## Towards a typology of conscientious objection in MAiD: Findings from a qualitative study in Spain

Dr Rosana Triviño-caballero<sup>1</sup>, Dr. David Rodríguez-Arias<sup>2</sup>, Dr. Isabel Roldán-Gómez<sup>1</sup>, Dr. Iris Parra Jounou<sup>3</sup>

<sup>1</sup>Faculty Of Medicine, Universidad Complutense de Madrid, <sup>2</sup>C Y B E - Filolab, University Of Granada, <sup>3</sup>Universitat de Barcelona

**Background:** Conscientious objection (CO) in relation to Medical Assistance in Dying (MAiD) has become one of the most contested ethical and legal issues in contemporary end-of-life care. While CO is often framed as a binary phenomenon—either accepted or rejected—its actual manifestations are far more nuanced, raising questions about consistency, legitimacy, and professional responsibility.

**Objective:** This study aimed to develop a typology of CO in the provision of MAiD by exploring the motivations, modalities, and agents involved in objecting practices in the Spanish context.

**Methods:** A qualitative research design was employed, including semi-structured interviews with healthcare professionals across various disciplines and institutional contexts in Spain. Thematic analysis was applied to identify recurring patterns and divergences in how CO is articulated and practiced.

**Results:** Findings suggest that CO cannot be understood as a single category but rather as a spectrum marked by three interrelated dimensions. First, motivation distinguishes between genuine objectors, whose stance arises from deeply held ethical or religious convictions, and untrue objectors, who invoke CO strategically to avoid workload, stigma, or other pragmatic burdens. Second, mode of practice varies considerably: CO may be declared openly to supervisors or official registries (a legal requirement in Spain), or it may remain hidden; it may be total, rejecting all involvement in MAiD procedures, or partial, limited to specific stages such as administering the lethal substance; it may be absolute, applied consistently, or conditional, depending on patient circumstances. Third, the objecting agent can be the individual healthcare worker, a professional group, or even an institution as a whole.

**Conclusions:** This typology highlights the heterogeneity of CO in MAiD and underscores the need for regulatory frameworks capable of distinguishing between legitimate and illegitimate refusals. Clarifying categories of objection may foster greater transparency, fairness, and respect for both professional integrity and patient rights at EoL.

## New Palliative Care Tool on Horizon: Psychedelic Assisted Therapy

Director Of Advocacy Kathryn Tucker<sup>1</sup>

<sup>1</sup>National Psychedelics Association; Seattle Univ School Of Law

Psychedelic assisted therapy is showing tremendous promise in modern era clinical trials in relieving refractory anxiety and depression, including among those w/terminal illness. A single guided session w/psilocybin brings immediate substantial and sustained relief. Advocacy to open access to those w/life-threatening conditions is progressing in the US, in both federal and state arenas. Tucker has been in leadership of key advocacy efforts, with remarkable progress and momentum. She leads the legal team seeking rescheduling of psilocybin from schedule I of the Controlled Substances Act and to utilize Right to Try law to open access even prior to FDA approval. Learn about the modern research, the potential applications, and these advocacy efforts, where they stand and next steps. Discussion of teaching across various disciplines about these substances and their promise will also be addressed.

## Why am I doing this? Motivations and triggering factors to request Medical Assistance in Dying

Phd Candidate Mar Vallès Poch<sup>1,8</sup>, Dr. Iris Parra Jounou<sup>2</sup>, Prof. Rosana Triviño-Caballero<sup>3</sup>, Dr María Victoria Martínez-López<sup>1</sup>, Prof. Ramón Ortega-Lozano<sup>4</sup>, Prof Janet Delgado<sup>5</sup>, Dr. Maria Isabel Tamayo-Velázquez<sup>6</sup>, MD Silvia M. Sánchez Garrido<sup>7</sup>, Prof. David Rodríguez-Arias<sup>1</sup>

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### Introduction

The international bioethical debate on MAiD rarely incorporates the voices of those requesting it. However, the first-person lived experience of illness and suffering that leads to MAiD is essential to advance this debate. One of the central issues in the discussion is which motivations are considered acceptable to request MAiD.

Since the approval of the Spanish Organic Law 3/2021 regulating euthanasia and until the end of 2023, 1,515 MAiD requests have been registered, of which 697. Nevertheless, little is known about the personal, social, and medical circumstances that motivate such requests.

### Method

In this context, a qualitative study was conducted using semi-structured interviews with 15 individuals who requested MAiD in Spain between November 2022 and May 2024.

### Results

Participants did not identify a single triggering factor for requesting MAiD, but rather a set of unique and personal coexisting elements: awareness of disease progression and the inevitability of suffering, anticipation of a worse future, accumulation of symptoms, exhaustion of therapeutic alternatives, and recognition that their situation also affected their loved ones. The decision was described as the outcome of a reflective balance across multiple vital dimensions—including personal values, principles that give meaning to life, and limits regarding how one wishes to live—and not an impulsive act. Additionally, some participants emphasized that previous experiences accompanying relatives through severe illness and decline influenced their decision. Our findings indicate that the request did not necessarily stem from a desire to die per se, but rather from the experience of an unsustainable life, and participants generally expressed neither doubt nor regret regarding their request. These results are crucial to reevaluate the long requesting periods required by law (around 70 days), as well as to compare patients and healthcare professionals' notion of what is acceptable to request MAiD.

## End-of-life decisions: attitudes of people with advanced illness in 11 countries (the iLIVE project)

Professor Agnes van der Heide<sup>1</sup>, Professor John Ellershaw<sup>2</sup>, Dr Vilma Tripodoro<sup>3</sup>, iLIVE Consortium<sup>1</sup>

<sup>1</sup>Erasmus MC, <sup>2</sup>University of Liverpool, <sup>3</sup>Pallium Latin America

**Introduction:** In the 21st century, most people die after a period of declining health and functioning. Cancer, organ failure and dementia are among the most common causes of death. Care and treatment for people with advanced illness often involves making decisions about whether or not to use potentially life-prolonging treatments. When patients are severely suffering, they may request for intensive alleviation of their symptoms or even the hastening of their death. We investigated the attitudes of people in the last phase of life towards such end-of-life decisions.

**Methods:** Participants were recruited in 11 countries, mainly from Europe but also from Argentina and New Zealand. Patients were eligible if their attending physician 'would not be surprised if they were to die within six months' and if they provided written informed consent to participate. They completed the AEOLI (Attitudes of older people towards End-Of-Life Issues) and ATE (Attitudes Towards Euthanasia) questionnaires, at baseline and four weeks later.

**Results:** 1423 patients participated in the study. On average, 93% wished to be involved in decision making about their care. However, 44% preferred physicians to make decisions about their treatment. Being helpless and dependent was considered worse than death by 72%. The majority thought that physicians should comply with the request of a patient who is severely suffering or dying to refrain from life-prolonging treatment (about 70%) or provide life-ending medication (about 60%). We found no major differences between patients from different countries or patients with different sociodemographic or clinical characteristics.

**Conclusion:** Physicians should explore the decision making preferences of their patients, also when they are in the last phase of life, including their views on the use of potentially life-prolonging treatment or wishes to hasten death, also in countries where physician assistance in dying is not a legal option.

## Uncertain Thresholds: Exploring Psychiatric and Oncology perspectives on Irremediability and Suffering in Canadian MAiD Practice

Dr Parizad Varghaei<sup>1</sup>, Dr Saumil Dholakia<sup>1</sup>

<sup>1</sup>University of Ottawa

### Background

In 2027, Canada will expand eligibility for Medical Assistance in Dying where a Mental Disorder is the Sole Underlying Medical Condition (MAiD MD-SUMC). While other jurisdictions (e.g., the Netherlands, Belgium) have experience in this domain, Canada's expansion is grounded in a commitment to equity and parity—that mental and physical illness-related suffering should be morally and clinically evaluated equally. However, the criteria of irremediability and intolerable suffering remain deeply contested in psychiatric care.

Oncologists, with a longer history of MAiD provision, tend to assess irremediability through clearer clinical trajectories—often associated with loss of autonomy, mobility, meaningful activity, or anticipated decline. In contrast, psychiatry's recovery-oriented model is at odds with definitive declarations of irremediability. The literature identifies three central issues in this debate: uncertainty, hope, and treatment refusal—which complicates psychiatric decision-making.

### Objectives

To compare how psychiatrists and oncology physicians interpret applying the criteria of irremediability and intolerable suffering in the emerging context of MAiD MD-SUMC.

### Methods

We conducted semi-structured interviews with psychiatrists and oncologists at The Ottawa Hospital using purposive sampling. Transcripts were analyzed using Braun and Clarke's reflexive thematic analysis. Researcher reflexivity and peer debriefing supported rigor.

### Expected Results

At the time of presentation, results would highlight key themes: (1) Ambiguity in Irremediability thresholds, (2) Subjectivity of Suffering and Ethical dilemmas and (3) Systemic Tensions including differences in experienced moral distress, professional roles, and perceptions of the healthcare system's readiness for expanded MAiD access. The thematic synthesis draws out implicit differences and similarities in the moral threshold for certainty when navigating intolerable suffering and irremediability in cancer and mental health care.

### Conclusion

This study highlights the epistemic and ethical tensions at the heart of MAiD MD-SUMC. Findings underscore the need for tailored guidance, cross-disciplinary dialogue, and ethically grounded policy to support equitable MAiD access across mental and physical health contexts.

## Family Members' Experiences in the Context of Track 2 MAiD in Canada

Dr. Caroline Variath<sup>1</sup>, Dr. Barbara Pesut<sup>2</sup>, Dr. Sally Thorne<sup>2</sup>, Dr. Helen Sharp<sup>2</sup>, Dr. Glendon Wiebe<sup>2</sup>

<sup>1</sup>Vancouver Island University, <sup>2</sup>University of British Columbia

**Background:** Recent changes to Canada's Medical Assistance in Dying (MAiD) legislation have expanded eligibility to include individuals whose death is not reasonably foreseeable, known as Track 2 MAiD, with the potential for significant impact on families. This expansion allows individuals who may otherwise have lived for many years to access MAiD. Under the original legislation, eligibility was restricted to those whose natural death was reasonably foreseeable (Track 1). Research on Track 1 experiences indicate that family members play complex, multifaceted roles throughout the MAiD process, often experiencing profound and complicated grief. However, the experiences and support needs of families in Track 2 contexts remain underrepresented in the literature. This study explores the experiences and support needs of family members in the context of Track 2 MAiD.

**Methods:** Following harmonized research ethics approval, we recruited family members of people who had MAiD under Track 2 through organizations across Canada that provide MAiD support to applicants and families. Status as a family member was self-defined. To date, eight participants have been interviewed, with a target of 30. Qualitative interviews will be analyzed using an interpretive descriptive approach, and preliminary findings are presented as thematic summaries.

**Preliminary Findings:** Emerging themes include: (1) experiences with the healthcare system, (2) role of family in supporting applicants through MAiD, (3) interpretations of the ninety-day assessment period, (4) the burden of secrecy and acting as family informant, (5) experiences on the day of death, and (6) emotional support for families throughout the process.

**Discussion and Impact:** The moral and philosophical considerations surrounding Track 2 MAiD differ substantially from those of Track 1. This study provides critical insights into the distinct experiences and needs of families in the context of Track 2 MAiD, contributing to evidence-informed policies and care pathways that support families across Canada.

## Bridging Gaps in MAiD Care: A Community-Based Palliative Approach for Patients with Complex Needs

Dr. Caroline Variath<sup>1</sup>

<sup>1</sup>Vancouver Island University

Since the passing of Bill C7 in 2021, Medical Assistance in Dying (MAiD) in Canada has been legislated under two tracks. Track 1 applies to eligible individuals whose natural death is reasonably foreseeable, while Track 2 applies to those whose death is not foreseeable. Although some Track 1 patients and most Track 2 patients have a prognosis exceeding one year, the decision to proceed with MAiD and set a date can mark the beginning of their end-of-life phase. Patients from equity-deserving groups with complex social and health histories who request MAiD often lack access to integrated health, social, and end-of-life supports. For healthcare providers, requests from these patients require significant time and effort, including multiple consultations, assessments, and documentation. This presentation discusses a community-based palliative care approach as a potential solution to better support patients seeking MAiD, their families, and the healthcare providers involved.

Findings from previous studies led by the author will be used to highlight current gaps, which include misinformation and mistrust, inequities in access to health and social supports, insufficient patient and family support, and challenges faced by providers engaged in MAiD-related work. A frequently cited concern from MAiD critics is the legitimacy of requests and the ethical implications of expanding access in the context of adverse social determinants of health, such as homelessness or social isolation. While systemic changes to address these broader inequities may take years in Canada, immediate action is needed to support patients with complex medical and social needs.

A patient-oriented, co-created, community-based peer volunteer navigation program is proposed. This program may help address the multifaceted care needs (physical, psychological, social, and spiritual) of patients and their families in the MAiD program. It also seeks to augment the support provided by healthcare system and to minimize demands placed on healthcare team members.

## Between Law and Loss: Understanding Relatives' Involvement in Austria's Assisted Suicide Process

MSc Tamina-Laetitia Vielgrader<sup>1</sup>, BA Sophie Katharina Zeis, BA Jana Marica Hluch, Priv. Doz. Dr. Elisabeth Lucia Zeilinger, Priv. Doz. Dr. Maria Kletecka-Pulker

<sup>1</sup>Institute for Ethics and Law in Medicine, University of Vienna

On January 1st, 2022, Austria legalised assisted suicide through the introduction of the Dying Decree Law. The law established a structured procedure requiring the person wishing to die to undergo two separate consultations with physicians. Only 12 weeks later can they establish a dying decree with a notary or a patient lawyer. When establishing a dying decree, the person who wishes to die can name an assisting person, who is legally allowed to aid with tasks, such as picking up the lethal supplement from the pharmacy. As of now, there is only limited research on assisted suicide in Austria, none of which centers on those most involved- the relatives who are present until the very end and often named as assisting persons.

To discern what roles relatives play throughout the process of arranging an assisted suicide, we have conducted semi-structured interviews with relatives of individuals who wish to, are currently or have already established a dying decree. The study explores the barriers they faced, the function they assume, and the emotional complexity they experienced in the pre- and postmortem phases. We will present our findings at the conference. Early analysis reveals key themes including situational altruism, anticipatory grief and patterns in bereavement reaction.

By focusing on a group that is essential in social care at the end of life, as seen in theory and practice, this study offers an important insight into how relatives of people who turn to assisted suicide in Austria navigate legally coordinated death. This study aims to inform future policy developments, give a clearer understanding of what legal immunity is in providing aid in the lead-up to assisted suicide, and highlight the invisible labour of relatives at the end of their loved ones' lives.

## Amendments to Australian model VAD laws to permit access despite loss of capacity

Mr Stephen Walker<sup>1</sup>

<sup>1</sup>Dying With Dignity Western Australia Inc.

Since the passage of VAD laws in Australian jurisdictions, the issue most commonly raised with advocacy groups is the inability of those with dementia to qualify.

Many do not understand that under the Australian model laws, people whose capacity does not endure until death – whether as a result of dementia or another cause – cannot access an assisted death. This applies even if they have stated a wish for VAD in a lawful advance health directive; and even if they have been approved for an assisted death but are deprived of that choice by a later loss of capacity.

Those who discover these facts are often nonplussed and deeply distressed by this feature of VAD and advance care planning laws.

This paper seeks to identify the amendments to Australian model VAD laws that are necessary to remove a fundamental gap between the rhetoric of autonomy, dignity and compassion, and the harsh reality facing those who seek VAD but are denied the choice because of a loss of capacity. There is no single or simple amendment to Australian model VAD laws that would achieve access by those who lose capacity prior to death. Contrary to a view advanced by some, for example, the simple removal of the time to death requirement would not have that result. Rather, a carefully crafted set of interlocking additional amendments also will be necessary.

This paper sets out to identify some feasible additional amendments. They include:

- Permitting eligibility based on execution of a particular form of advance health directive, using the Quebec model;
- Removing the requirement that the condition be advanced, or, alternatively, inserting an appropriate definition of that term;
- Substituting for the time to death requirement a criterion that death be reasonably foreseeable; and
- Improving the definition of unbearable suffering.

## Online training to improve Queensland healthcare workers' knowledge of voluntary assisted dying: a cross-sectional survey

Ms Katherine Waller<sup>1</sup>

<sup>1</sup>Queensland University Of Technology (qut)

### Background

In Australia, eligible practitioners (doctors, and nurses in some jurisdictions) must undertake mandatory training to become an authorised VAD practitioner. While VAD laws impose significant obligations on authorised VAD practitioners, other healthcare workers must also comply with some legal requirements and play an essential role providing VAD related services. However, healthcare workers do not generally have access to the mandatory training, and the availability of education and resources on VAD varies between jurisdictions.

### Aim

This study reports on the evaluation of a short, online training initiative for healthcare workers, implemented by Queensland Health three months before the state's VAD law became operational.

### Methods

After completing the online training, participants were invited to complete an evaluation survey. Quantitative and qualitative analyses of the data provided by 1,619 participants were undertaken.

### Results

Most participants completed the training within 30-60 minutes (68%). The most common reasons for completing the training included participants wanting to know more about VAD (61%) and being requested to complete the training by their organisation/employer (54%).

Almost all participants found the training helpful or very helpful (98%) and somewhat, or very, relevant to their role (94%). While most participants indicated no change in their likelihood to participate in VAD, 47% of respondents noted that following the training, they were more likely to participate. Participants often cited increased knowledge and confidence, and the belief that participating in VAD is the right thing to do, as reasons why they are more likely to participate.

### Conclusion

Readily accessible VAD training for a wide group of healthcare workers can be an effective tool for improving healthcare workers' knowledge about, and willingness to, support patients with VAD. This in turn may lead to enhanced access for patients, reduced stigma around VAD participation, and greater VAD literacy and compliance within the VAD workforce.

## "He Wouldn't Want This": Minimal Comfort Feeding for Patients with Advanced Dementia

Dr. Hope Wechkin<sup>1</sup>, Dr. Thaddeus Pope<sup>1</sup>

<sup>1</sup>EvergreenHealth

**Background.** As ICEL5 participants are aware, voluntary assisted dying (VAD) / medical aid in dying (MAiD) is available in an increasing number of jurisdictions. And for patients with decisional capacity who cannot qualify for VAD/MAiD, voluntarily stopping eating and drinking (VSED) is an alternative option to hasten death. But many patients seeking to avoid living with advanced dementia cannot take either approach.

**Problem.** In response, growing numbers of individuals prepare advance directives that instruct caregivers to cease providing all nutrition and hydration once dementia is advanced. But while often compliant with relevant statutes, such directives may not be followed, particularly in institutional settings. After all, these directives impose a significant ethical burden on caregivers and administrators who feel obligated to provide some measure of comfort in the form of nutrition and/or hydration to patients who lack capacity to refuse food and drink when offered.

**Solution.** Minimal Comfort Feeding (MCF) offers a compromise that both honors patients' goals and addresses clinicians' concerns. Introduced in the United States in 2025, MCF is a new approach to providing nutrition and hydration to people with advanced dementia who previously indicated a desire not to continue living once dementia is advanced. The current standard of care, Comfort Feeding Only, entails careful, scheduled handfeeding. But this prolongs living with advanced dementia, often for many months or years. In contrast, MCF entails providing nutrition and hydration only in response to signs of hunger and thirst, and only after employing alternative means to promote comfort. Thus, MCF offers a "third path" between indefinite, life-prolonging handfeeding (CFO) and the complete cessation of all food and fluids (VSED).

**Conclusion.** This session explores ethical, clinical, legal, and institutional considerations surrounding MCF. And it reports on current efforts both to provide and to study MCF in the United States.

## “Death with Dignity” in the U.S. – and in Germany

Prof. Dr. Bettina Weisser<sup>1</sup>

<sup>1</sup>University Of Cologne, Institute For Comparative Criminal Law

One thing that liberal U.S. jurisdictions that have introduced Death-with-Dignity provisions and the German criminal law have in common is that neither permits so-called active euthanasia. As a consequence, a person wishing to end their life must carry out the decisive terminating act with their own hands. While legal regulations allow for mere assistance in autonomous suicides, killing on request remains a crime – even if the “victim” is physically unable to kill themselves. Other countries – like for example the Netherlands – do not make this distinction, but instead subject assistance in suicide and active euthanasia to the same legal requirements. The first part of the presentation will highlight the reasons for the prohibition of active euthanasia in the U.S. and in Germany.

Apart from the common feature of criminalizing active euthanasia, a stark contrast exists between Death-with-Dignity provisions in U.S. constituent states and the German criminal law on assistance in suicide: Since the German legislator has repeatedly failed to create a legal framework governing assistance in suicide, the only legal requirement is that the person who wishes to end their life has made this decision autonomously. By contrast, U.S. Death-with-Dignity states tie legitimate assistance in suicide to a second prerequisite besides autonomy: Assisted suicide is only lawful if the person ending their life suffers from a certain irreversible medical condition. In Germany, however, such a legal restriction has been largely ruled out by a landmark judgment of the Federal Constitutional Court in 2020. The Court explicitly stated that a sane, self-determined individual does not have to justify their desire to end their life to the state. This discrepancy between the compared legal orders will serve as a starting point for the second part of the comparative discussion which will focus on the rationales behind the respective regulations.

## Experiences of family and loved ones supporting voluntary assisted death: A qualitative systematic literature review

Ms Sarah White<sup>1</sup>, Associate Professor Eyal Gringart<sup>1</sup>, Dr Aaron Alejandro<sup>1</sup>, Professor Davina Porock<sup>1</sup>

<sup>1</sup>Edith Cowan University

**Background:** Voluntary assisted death (VAD) has been available in an increasing number of countries for over 20 years, and in Western Australia since July 2021. Families have a significant role in supporting and facilitating access to assisted dying with their loved ones, however little is known about how families experience their role in this process and the type of supports they may need.

**Aim:** To systematically review the literature relating to the experiences of family members and loved ones who are supporting people choosing VAD.

**Design:** JBI qualitative systematic review using meta-aggregation.

**Method:** Medline, CINAHL, PsychINFO and Scopus were systematically searched (January 1997-April 2025). Primary studies with qualitative findings examining family member experiences in regions where VAD is legal were included. JBI SUMARI tool was used for data extraction and meta-aggregation of findings.

**Results:** Twenty-nine articles from six countries met the inclusion criteria, with semi-structured interviews and thematic analysis being used. Meta-aggregation resulted in three synthesized findings – (1) accessible and responsive support requirements; (2) the need for ceremony and ritual to assist with emotional aspects; and (3) the uniqueness of the VAD end of life journey requiring increased awareness and understanding.

**Conclusion:** The findings showed consistent experiences among family members supporting loved ones through voluntary assisted dying across international settings. They highlight the complex interplay of family dynamics, cultural and social context, relationships, and available support from health professionals and the community.

Despite these complexities, many well-supported relatives report positive experiences and identify areas where systems and policies could better support patients and families. As VAD has only recently become available in Australia, it is timely to examine how support can be tailored to families within Australia's legislative, geographical, and healthcare systems.

## Willow: A peer-to-peer support group for people whose loved ones have chosen voluntary assisted dying.

Ms Sarah White<sup>1</sup>

<sup>1</sup>Lived experience

Voluntary assisted dying is a new and often unfamiliar experience for families supporting a loved one at the end of their life. In 2022, less than a year after legislation came into effect in Western Australia, my father chose this path for the end of his life's journey. Throughout supporting him, I searched for others who had walked a similar road, hoping to share feelings and gain support.

At that time, no available supportive space existed for people in Western Australia whose loved ones have chosen voluntary assisted dying. Recognising this gap, myself and another family member, whose mother had also passed with voluntary assisted dying, established Willow, a peer-to-peer support group. Willow's vision is to walk alongside others, foster connections, reduce isolation, and create a compassionate space for sharing stories and experiences of voluntary assisted dying.

Willow provides both a publicly accessible social media page and a closed members-only page for those with lived experience who are currently, or have previously, supported someone choosing voluntary assisted dying. In addition, we hold monthly in-person meet-ups in a central metropolitan location, offering members the chance to connect, share personal journeys, and build a community of support.

Importantly, Willow is not a therapeutic grief or bereavement service. Instead, it offers peer-to-peer connection, grounded in the mutual understanding that comes from lived experience.

Since its inception, Willow has grown to over 50 members in two years, demonstrating both the need and the power of peer connection in navigating voluntary assisted dying, reducing isolation, and fostering compassion through lived experience.

## Withdrawing Life-Sustaining Treatment in Sri Lanka: A Critical Appraisal of Criminal Law and Comparative Perspectives

Ms Udani Wijayarathna<sup>1</sup>, Professor Sanath Wijesinghe<sup>2</sup>

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The withdrawal of life-sustaining treatment (LST) raises ethical and legal challenges in Sri Lanka, where the absence of statutory authority or judicial precedent has left clinicians navigating end-of-life decisions amid significant legal uncertainty. While professional guidelines encourage best interests decision making, these instruments lack binding force, and the discontinuation of treatment risks being construed as homicide under existing criminal law. Consequently, the act of withdrawing LST is often perceived, socially and legally as 'Playing God,' intensifying clinician moral distress and family uncertainty. This research critically examines how Sri Lankan criminal law conceptualises the withdrawal of LST and explores lessons from comparative jurisdictions. Employing a doctrinal and comparative methodology, it evaluates Sri Lanka's reliance on non-binding professional guidance against recent legal developments in India and Australia. In India, the landmark Common Cause (2018) judgment constitutionalised the right to die with dignity and sanctioned passive euthanasia through advance directives, with subsequent reforms simplifying the execution of living wills, digitising registration, and reducing judicial oversight. By 2025, Karnataka became the first state to operationalise these reforms through hospital review boards and standardised directive formats, offering procedural clarity in a culturally and religiously diverse context. In contrast, Australia has long established a settled framework: advance care directives are binding, courts uphold the autonomy of competent adults to refuse treatment, and clinicians are shielded from liability when treatment is withdrawn with valid consent or medical futility. Moreover, voluntary assisted dying is now available in all Australian states under strict statutory safeguards, distinguished in law from the withdrawal of LST. By situating Sri Lanka's ambiguous position alongside these comparative models, this research underscores the need for a rights-based and culturally sensitive framework that clarifies legal authority, protects clinicians, and safeguards patient autonomy, contributing a Global South perspective to international debates on assisted dying and end-of-life law.

## Reforming Assisted Dying Laws in Sri Lanka: Comparative Insights from Australia and New Zealand

Prof Sanath Wijesinghe<sup>1</sup>, Dr Upeka Silva<sup>2</sup>

<sup>1</sup>The Open University Of Sri Lanka, <sup>2</sup>The Nawaloka Hospital PLC

This research examines the legal framework governing assisted dying in Sri Lanka and undertakes a focused comparative analysis with Australia and New Zealand, two jurisdictions that have developed structured, rights-based regulatory models for voluntary assisted dying (VAD). In Sri Lanka, all forms of assisted dying, including voluntary euthanasia and physician-assisted suicide remain expressly prohibited under the Penal Code. Aiding or abetting suicide attracts criminal liability, and intentional termination of life is treated as murder. Despite this strict legal stance, emerging studies suggest that many Sri Lankan medical practitioners recognise the need for legal clarity in end-of-life decision-making, particularly for patients suffering from irreversible, painful, or terminal illnesses. This disconnect between legal prohibition and medical–ethical realities underscores the urgency for informed debate and evidence-based reform.

Australia provides particularly rich comparative insights. Since Victoria’s Voluntary Assisted Dying Act 2017, multiple Australian states, including Western Australia, Tasmania, Queensland, South Australia, and New South Wales have enacted VAD legislation with rigorous safeguards. These frameworks emphasise terminal illness criteria, voluntary and well-informed patient consent, multiple clinical assessments, cooling-off periods, and independent oversight boards. New Zealand’s End of Life Choice Act 2019 similarly incorporates stringent eligibility requirements and transparent review mechanisms. Together, these jurisdictions illustrate how high-quality safeguards, accountability systems, and ethical medical practices can coexist with end-of-life autonomy.

Through this comparative lens, the research argues that Sri Lanka’s legal and socio-cultural context may favour a gradual and cautious reform trajectory. A pragmatic starting point could involve formalising the legal permissibility of withdrawing futile life-sustaining treatment under defined conditions, thereby improving clarity for medical professionals and families. Lessons from comparative jurisdictions demonstrate that well-designed and balanced legislative models can protect vulnerable individuals while respecting human dignity. The research concludes with context-sensitive recommendations for legal reform, capacity-building, and public dialogue to strengthen VAD regulation in Sri Lanka.

## Nurse-Led End-of-Life Care During Ventilator Withdrawal in the Oncology Ward: A Case Report

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**Background :** Mechanical ventilation is often used to manage respiratory failure in oncology patients with advanced disease. However, decisions regarding withdrawal at the end of life present ethical, emotional, and clinical challenges for healthcare teams and families. Nurse-led involvement is pivotal in guiding families through decision-making and ensuring compassionate end-of-life care.

**Case & Methods :** We report a 49-year-old woman with stage IV breast cancer and leptomeningeal metastases, emergently intubated in the emergency department due to brain death. After confirming the irreversible condition, the team facilitated ventilator withdrawal through shared decision-making. During the nursing care process, the nurse noticed the patient's mother often standing alone by the window, quietly weeping. She expressed feelings of guilt, sorrow, and helplessness as other family members firmly insisted on ventilator withdrawal.

**Results :** Through nurse-led end-of-life care, the nurse identified the family's ethical dilemma and navigated multidisciplinary collaboration to provide holistic support. (1) Initiated a family meeting and served as the mother's advocate to facilitate emotional communication and family consensus. (2) Arranged a private room to conduct a religious ritual before ventilator withdrawal. (3) Guided the mother to perform a culture-based Taiwanese end-of-life practice known as the "Four Expressions" — gratitude, apology, love, and farewell. (4) Accompanied the family during ventilator withdrawal and encouraged their participation in body care. (5) Referred the family to a social worker for bereavement counseling. (6) Engaged the medical team in ethical reflection following the case.

**Conclusion :** Nurse-led end-of-life care enhances the quality of dying while supporting families and healthcare teams. Culturally sensitive, structured training programs are essential to prepare providers for the ethical and emotional challenges of palliative ventilator withdrawal.

## What does an equitable assisted dying service look like?

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Equity is the inclusiveness for all communities and access to end-of-life care that prioritises needs, preferences, and values. Given the evidence of bias within healthcare and its impact on structurally disadvantaged groups, as well as concerns about vulnerable populations, considering equity in the context of assisted dying is imperative.

Our talk reports on a national study of assisted dying in Aotearoa New Zealand. We used semi-structured online interviews and face-to-face hui (meetings). We interviewed 96 adults from the following groups: eligible/ineligible service users; eligible/ineligible service users with impairments; families of service users; assisted dying providers; non-providers (providers who objected to assisted dying as well as others who, although not opposed in principle, were not directly involved in providing AD); health service leaders; and Māori community members.

We used a 4D appreciative inquiry to co-envision with participants what an ideal assisted dying service could look like. A whole team coding exercise produced the coding framework with further analysis to explore equity within participants' experiences and envisioning. We identified what's working well (discovery), what could be (dream), what needs improving (design) and how to achieve what should be (destiny) if the system could work at its best.

We propose a working model of equitable facilitators and barriers to Aotearoa's assisted dying service. We explore how this model could be translated into assisted dying law and praxis. Improvements are needed regarding equity-driven data collection, palliative care funding, and health and death literacy.

## Insights into patient interest for Voluntary Assisted Dying: a metropolitan health service audit

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**Background:** Voluntary Assisted Dying (VAD) has been in effect in Victoria, Australia since June 2019. It has established itself as an evolving end of life option for patients with a life limiting illness. However, the patient cohort that expresses interest in VAD but does not progress to assessment by a VAD-trained doctor remains poorly defined and is not well reflected in the current literature or statewide database.

**Aim:** Firstly, to identify patients who have expressed interest in VAD and explore why they have not progressed to doctor assessment. Secondly, to compare key benchmarks of the VAD process at a metropolitan health service (Eastern Health) in comparison to state average.

**Methods:** We conducted a retrospective audit of a prospectively maintained database of VAD outcomes at Eastern Health between May 2023 to April 2025. Outcomes were stratified according to stage of VAD process, from first enquiry, first assessment, second assessment, successful permit, drug delivery, time from first enquiry to death and final outcome.

**Results:** A total of 211 patients expressed interest in VAD at Eastern Health between May 2023 and April 2025. Of these, 101 patients who expressed interest in VAD did not undergo first assessment, with 25.7% (26/101) dying within 14 days of first inquiry or first referral. 110 patients underwent first assessment with a doctor, with 80.0% (88/110) progressing to second assessment, 59.1% (65/110) having permits issued and 33.6% (37/110) dying through VAD.

**Conclusion:** Within our inner metropolitan health service, there is a high interest in VAD amongst terminally ill patients that is not clearly reflected in the current literature. Our results support the notion that a significant proportion of patients are requesting VAD too late in their disease. Further study is required to elucidate underlying patient reasons for withdrawal from VAD process and improve future policy and practice.

## Expanding Nurse Practitioner Roles in Voluntary Assisted Dying: Insights from Western Australia's Implementation Experience

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**Background:** Voluntary Assisted Dying (VAD) legislation in Western Australia (WA) came into effect in July 2021, introducing a regulated framework for end-of-life choice. While medical practitioners have traditionally been central to VAD provision, nurse practitioners (NPs) have emerged as critical contributors, particularly in regional and rural areas with limited access to medical practitioners. However, evidence on NP-led VAD interventions and their impact on service accessibility remains limited.

**Aim:** This study examines the role of NP in VAD implementation in WA, focusing on their participation as administering practitioners, enablers and barriers to their involvement, and implications for equitable access to VAD services.

**Method:** A descriptive analysis of WA VAD Board annual reports (2021–2024) was conducted, supplemented by a review of legislative guidelines and workforce recommendations.

**Results:** Since VAD's implementation in WA, eleven NPs have completed state-approved VAD training—seven in 2022–2023 and four in 2023–2024. The number of NPs acting as Administering Practitioners increased from one in 2021 to three in 2024, demonstrating a steady and meaningful rise in their engagement. The WA VAD Board noted that NPs accounted for 12.3% of all practitioner administrations in 2023–2024.

NP-led administrations mainly occur in patients' homes, with growing involvement in hospices and palliative care units. Enablers include the Regional Access Support Scheme, the Statewide Care Navigator services, and peer support. Barriers include limited opportunity to build early patient relationships, inability to certify death, pay disparities with medical practitioners, and burnout risks from workforce shortages. The Board recommends expanding NP roles, improving remuneration, and clarifying legislative authority to support sustainability.

**Conclusions:** NP plays an essential role in expanding equitable access to VAD, particularly in rural regions. Supporting NP training, role expansion, and sustainable funding is essential to ensuring the timely, ethical, and equitable delivery of VAD services.

**Keywords:** Care access, Nurse Practitioner, Voluntary Assisted Dying

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