

**World Federation of Right to Die Societies  
General Assembly and Conference  
November 2-5, 2022  
Toronto, Canada**

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# 1. World of Champions

Wednesday November 2 was 'World Right to Die Day'. Those attending the World Federation of Right to Die Societies (WFRtDS) biennial conference in Toronto were invited to an evening reception where we were warmly welcomed by WFRtDS President, Asunción Alvarez.

It was wonderful to be among so many inspiring and like-minded people, some of whom we have frequently communicated with by email but never met in person. Within minutes we were deeply engaged in conversation with others, describing their VAD legislation, or in some cases, lack of choice.

The highlight of the evening was the launch of the World of Champions. The World of Champions was displayed on a five by three metre world map, showing assisted dying champions identified by WFRtDS member organisations. The names and photos of the 40 champions were placed in their country, with a brief description of the person's contribution. Below the map was the following

*"Around the globe, many people fight to make a death with dignity possible for themselves and those they love. It is these people that we would like to put in the spotlight for World Right to Die Day 2022; the Champions, who through their support, activism, fighting, writing, willpower, vision and strength, are advocating to make right to die legislation possible all over the world."*

Eight Australians and two New Zealanders were nominated from the Oceania region. This proved to be an extremely challenging project as there were so many truly worthy recipients. Congratulations to all champions all over the world. Our regional champions are:

1. **Victoria**, Dr Cam McLaren - *"An unwavering commitment and selfless dedication to his patients"*
2. **Tasmania**, Hon Michael Gaffney, MLC – *"A natural champion to bring us all together"*
3. **South Australia**, Angie Miller – *"A gentle, thoughtful and caring approach gaining the confidence of people to share their stories"*
4. **Western Australia**, Dinny Laurence - *"Worked ceaselessly and with utmost dedication to get assisted dying passed"*
5. **New South Wales**, Shayne Higson – *"Optimism in the face of bleak prospects"*
6. **Queensland**, the late Tanya Battel – *"A passionate, dedicated, articulate and vocal advocate"*
7. **Australia**, Ian Wood, Convenor of Christians supporting choice for VAD – *"Giving a voice to those of faith who support VAD"*
8. **Victoria and Australia**, the late Dr Rodney Syme – *"Compassionate caring and kind to his fellow human beings."*
9. **New Zealand**, Dr Libby Smales – *"Swimming against the tide is hard, especially as a health professional at odds with many of your colleagues"*
10. **New Zealand**, the late Esther Richards – *"Changed hearts and minds through her public championship of assisted dying"*

The nine organisations from our region who are members of the WFRtDS were provided with an interactive digital version of the map prior to the launch. This has been placed on websites and Facebook pages. The interactive map allows you to click on each person and read a longer statement about the person's contribution to the campaign for Voluntary Assisted Dying.

## 2. WFRtDS General Assembly

November 3, 2022

Participants were welcomed by Asunción Alvarez, President, and Rob Jonquière, Executive Director, WFRtDS.

### 2.1 New WFRtDS members

We were informed that during the year, three new Societies had been accepted for membership:

1. Denmark Ret til at dø
2. The Netherlands De Vredige Pil
3. South Korea

### 2.2 Lobbying rights at the UN

WFRtDS has submitted an application to the UN for registration as an NGO. This would provide lobbying rights at the UN.

### 2.3 Terminology

The WFRtDS Committee proposed that 'assisted dying' be used as the term to describe the work of the World Federation. It could be preceded by 'voluntary' or 'medical'.

- The use of the term 'assisted suicide' by the WFRtDS to describe its work, and defining the legislation in member organisation countries with the same terminology, was raised at the 2021 GA by delegates from Australia, requesting that more appropriate terminology be used, such as voluntary assisted dying
- Following a June 2022 webinar held with WFRtDS members, the term 'assisted dying' was proposed as the more appropriate term, and accepted by the GA; the item generated more discussion from the floor than any other item on the agenda
- During the debate several points of note:
  - Victorian Palliative Care Physician, Greg Mewett, stated that the term voluntary assisted dying makes the procedure more 'patient centric' and non-medicalises it.
  - 'Terminal Comfort Care' was suggested by a US doctor (Ed Toorey) who reasoned that as 38% of those deemed eligible for an assisted death don't use the medication, but they, and every other citizen, are comforted knowing the option is available
  - 35 states in USA where assisting a suicide is a crime, plus all states in Australia and NZ
  - Germany's Constitutional Court has ruled invalid the law which states that it is a crime to professionally assist someone to die (suicide); so Germany is back to where the law was 150 years ago

### 2.4 Election for World Federation of Right to Die Committee member

- One vacancy on the five person Committee (Board) following the resignation of Masahiro Nomoto from Japan
- Three nominations: Nathalie Andrews, Le Choix, France; Dr Jürgen Dankwort, Exit International, Canada; Dr Yoshikiro Kitamura, nominated by the Japan Society for DWD
- Jane voted as a DWDV representative and was proxy for NSW, the NT and ACT; Anne voted as a VADSA member and proxy for Christians Supporting Choice for VAD, WA and Queensland.
- Dr Kitamura was elected with an overwhelming majority (Anne Bunning the Returning Officer)
- The Japan Society for DWD was founded in 1976 and has 120,000 members across Japan

- Dr Kitamura is a virologist and now works as a physician with older patients, as a Professor at Nippon Medical School and has spent the last 42 years informing the public about assisted dying

The Committee membership is now:

**President** – Ascunciön Alvarez, Mexico

**Treasurer** – Jean-Jacques Bise, Switzerland

**Secretary** – Anne Bunning, South Australia

**Committee member** - Sten Niklasson, Sweden

**Committee member** – Yoshihiro Kitamura, Japan

## 2.5 Future General Assembly and Biennial Conferences

End of Life Ireland, Belgium (RWS) and Scotland (FATE) had shown interest in hosting the 2024 Conference. A fabulous presentation from Janie Lazar, Director EofLI, and Justin McKenna of End of Life Ireland, easily managed to convince the Committee that Dublin would host the next conference.

- 2024 Conference will be in Ireland
- 2026 Conference to be in Japan

## 2.6 Assisted Dying Around the World

### 2.6.1 Canada

- MAiD is federal legislation, but implemented by each province using different policies and procedures depending on the priorities of the province
- Mainly practitioner administration (90% doctor, 10% nurse) because provinces have not established easily accessible policies and procedures for self administration, including funding; when MAiD first enacted sodium pentobarbital was not available in Canada
- Initial criteria stated ‘death is reasonably foreseeable’ (now called Track 1)
- Track 1 available since commencement in 2016; ‘death being reasonably foreseeable’, interpreted to mean a person with a diagnosis of a disease or illness which will cause death (see Julia Lamb case, S 3.20.3); MAiD practitioners refer to a ‘five to seven year’ timeframe; dementia always been a criteria for MAiD because a diagnosis of dementia means death is reasonably foreseeable
- Two tracks for MAiD since March 2021: Track 1 death is reasonably foreseeable or Track 2 death is not reasonably foreseeable
- Track 2 came into effect in March 2021 as a result of the 2019 Truchon case and allows MAiD when ‘death is not reasonably foreseeable’
- Track 2 includes additional procedural safeguards, such as a 90 day waiting period between first assessment and MAiD
- Mental illness excluded under Track 2 for 24 months while an Expert Panel considered the matter; Expert Panel has reported however some doubt that the March 2023 deadline will be met
- Individuals on Track 2 reported
  - Grief often accompanies loneliness, frustration, fear, anger or rage
  - Administrative delays prolong the grief as the process takes longer
  - Often lack informal (and formal) supports so navigate the process alone
  - Support networks stop engaging in conversation or try to dissuade the individual from choosing an assisted death
- Considerations for a person supporting someone choosing MAiD
  - Anticipatory grief and the ‘Grief-Bereavement’ experience

- Intense emotions knowing that the time together until the day of the procedure was so precious
- Ambiguous and hidden grief experienced by individuals whose loved one wants to keep their MAiD private
- Challenge and guilt of agreeing and supporting the decision, yet wanting the person to continue living
- Difficulty with having to continue with daily life, knowing that MAiD was a constant fixture in an individual's life and an influence on their future decisions
  - “Knowing that others understand and have experienced these unique experiences of death: anticipatory grief around setting the date; the internal conflict of supporting your loved one's decision and holding back your feelings from them to give them peace (personal sacrifice); the counter intuitive process of advocating for the peaceful death of your loved one in some circumstances.”
- Individual grieving
  - MAiD has been described as being ‘beautifully traumatic and traumatically beautiful’
  - Witnessing moment of death, especially if it does not go to plan
  - Experience of disenfranchised grief as a result of norms associated with VAD in our society
  - Becomes a barrier to an individual's grief journey as it is assumed that because someone died by choice, grief will be diminished
  - Feelings of guilt, resentment, anger at the thought of having a role in supporting someone in their decision to die
- Peer Support
  - Benefits of peer support; the genuine understanding, the connection to the unique experience, and the compassion. I find we all have to help others shift through the messy feelings around grief and MAiD”*
  - three benefits of peer support
    1. Seeing different versions of my experience with MAiD really helped me validate my own feelings
    2. Having a place where MAiD was talked about openly, and a place where I could safely share my experience really helped me be more open with others
    3. Being able to share my experience and feelings about it to support others.
- Participant Experience
  - Need for appreciation of the experience from others and to have their grief witness – validation, comradery, community
  - Trauma associated with the experience – the time leading up to, the moments of, and events after, death
  - Expectations of what the day of the MAiD death would look like and be like vs reality
  - Juxtaposition of feeling like not being enough or doing enough, yet feeling nothing more could have been done
  - Stigma from others and pressure to ‘get over it’ more quickly because death was planned
  - Not knowing how to talk about MAiD with family and friends as MAiD is still a new procedure and misunderstood by many

#### 2.6.2 Iceland Society: founded in 2017 has 190 members

- LIFSVIROING President (Ingrid) - father used euthanasia in Netherlands in 2002
- Use assisted dying as the term
- Excellent speaker – grew up in the Netherlands
- Two supportive MPs giving consideration to tabling a Bill

- Been talking about assisted dying in Iceland since 2004
- Mercy killing and mercy murder - terms used in media
- Iceland survey of doctors and nurses: 54% physicians and 71% of nurses supportive; was 18% and 20% in 2010; more GPs supportive than specialists; 18% against
- Society survey: 82% would want assisted dying available for themselves

### 2.6.3 France

- President Macron appears supportive of an assisted dying bill
- Announced citizens' convention with 150 randomly chosen individuals
- Powerpoint to be provided

### 2.6.4 Italy

- Johannes Agterberg, Member of the Council of the Association Luca Coscioni
- Luca Coscioni Association for the Freedom of Research, freedom to have abortion, have children, an assisted death
- Coalition of RTD groups collected over a million signatures, when only 500,000 needed to secure a national referendum
- Constitutional Court said the referendum question was inadmissible
- March 2022, MPs tabled a new law that would legalise a "voluntary assisted medical death"
- Still under consideration in Upper House
- In May 2022 a man with paralysis became Italy's first case of 'assisted suicide'

### 2.6.5 South Korea

- 2009 first case where court upheld right to remove ventilator
- 6% of deaths in hospice and palliative care
- 2022 poll says 80% support
- Bill tabled May 2022
- Called 'voluntary death with dignity' because suicide and euthanasia have negative response
- Termination of life sustaining treatment can be stated in an ACD
- S Korea: 33% each Catholic, Buddhist, Christian; Catholics and Buddhists not so conservative
- Major opposition to assisted dying from medical community
- Being an economic burden to the family is a major cultural issue in S Korea; but assisted dying advocates' position is that the medical system should be fixed and be more accessible so people don't feel a burden; should not be used as an excuse not to proceed with assisted dying

### 2.6.6 New Zealand

Dr Gary Payinda, NZ emergency and helicopter rescue doctor

- NZ Medical Association has now folded; during debate four years ago NZMA said NZ doctors were against VAD, based on no evidence as they had not surveyed members
- NZ End of Life Choice Act commenced in 2021; after passing through Parliament required support from a public referendum at the time of the national election, and received 65% support
- Doctors and nurse practitioners can support the person
- 6-month time frame
- Grievous or irremediable illness
- Not available for dementia or mental illness
- Takes at least three weeks to complete the many steps

- “We hassle and harry patients for no other procedure like we do for VAD. I can talk to patients: do you want dialysis, do you want a blood transfusion, and you can decide straight away. I decide whether to intubate a patient after a massive burn and I do it instantly. But for VAD it takes three weeks of interviews.”
- Have ‘gag law’ similar to Vic and SA; what if I couldn’t mention chemo to a patient with cancer; people would be outraged
- Also have problems with citizenship and permanent residency criteria
- Salaried doctor can provide service for free
- “End of Life Choice Act not made with the best interests of patients or doctors in mind; lawyers are happy with it”
- Not allowed in a hospice - person has to be moved to somewhere else
- Palliative care in NZ has been totally opposed
- Greg Mewett (Australia) commented that there has been movement in Australia in the palliative care sector, on show at the recent national conference where there was positive discussion. He is also observing this in the new generation of PC specialists

#### 2.6.7 Scandinavian Countries

- No legislation and little public interest

##### **Norway**

- Norwegian psychologist and anthropologist stated that all MPs and the medical association oppose assisted dying

##### **Denmark**

- Denmark - doctors have obligation to prevent suicide or to rescue
- Volunteer transports people to the airport in a small van so they can go to Switzerland; does not take any payment; liable for four years in gaol
- Switzerland costs 10,000 euros for the procedure

#### 2.6.8 Switzerland

- Not legalised
- VAD prohibited if it is seen as providing a personal benefit to the provider or there is personal exploitation
- See further information, Erika Preisig, Lifecircle (S3.8.4)

# 3. WFRtDS Conference

## WORLD FEDERATION of RIGHT TO DIE SOCIETIES - CONFERENCE 2022

### Global Perspectives on End-of-Life Choice Toronto, Canada, November 4-5, 2022 Hosted by Dying with Dignity CANADA

Note that many presentations held concurrently so we were unable to attend all sessions. The Conference Program and Speaker Bios are attached.

#### 3.1 MAiD in Eastern Canada

Dr Aaron McKim, Medical Director for MAiD, Eastern Health, based in Newfoundland (replacing Dr Jeff Myers who was unable to attend - due to fog in Toronto)

- based in Newfoundland, in the east
- 95% of palliative care physicians still opposed to MAiD
- Some PC doctors do support MAiD but do not want MAiD performed in the PC unit
- Others will act as assessors but not providers
- Talked about the first case in Newfoundland
- No-one would talk to the person about MAiD, so he asked a lawyer friend to go on radio and ask - 'can someone help me'
- Was in a palliative care unit and they would not allow MAiD in their facility
- Dr McKim responded to the radio request and visited the person
- (Dr McKim was a juggler in his earlier life!)
- At end of life people are more afraid of the suffering than the death - MAiD gives them peace of mind and control
- Newfoundland document lists MAiD and all EOL options
- Many families furious that they were not made aware of MAiD as an option earlier in the person's illness
- Cases of litigation by family because doctor did not provide MAiD as an option

#### Comment from Ontario doctor

- Story of the elderly woman, in tears and awful pain when he arrived
- When he left, a big smile as they now had a plan
- She spent two weeks saying goodbye, laughing, having a big party
- 40 people there at the end when he arrived
- Jokes, fun as the first medication given
- No sadness and tears

#### More questions with following responses from the speaker:

- Many health services and staff are still opposed and resistant to MAiD
- Some now allowing assessments - but not the death
- People are having to be moved - transferred elsewhere for their death
- Patients being transferred to another facility often causes great pain and many reluctant to be given pain relief as scared they will lose capacity
- One patient in a nursing home run by the Catholic Church – the institution sent the decision to a local Bishops forum; they sent it to a national group; they sent it to Rome; Rome said

they would shut the nursing home if MAiD was administered in St Patrick's; that would mean 250 people would be on the street

- Dr McKim: I will continue to push the system to incorporate MAiD, patient by patient

### **David Robinson Vancouver Island 2016 Medical Director**

- In the past PC was seen as a way out for doctors who had given up on a patient's care
- Charter provides a right to access MAiD
- Health authority has obligation to make MAiD available
- 10% MAiD is carried out in hospitals
- Nurses in 2017 covered for discussing MAiD
- Vancouver Island - population 900,000; 2/3 of the physicians, (60 practitioners), have completed a MAiD assessment and the results of these assessments are made available through electronic records, similar to My Health Record

## 3.2 Terminology

Susan Desjardins, Vice President DWD Canada and Anne Bunning, Vice President VADSA

- "Language frames the debate."
- Presentation on the development of the language in Canada and the eventual adoption of Medical Assistance in Dying
- Anne's powerpoint slides showed articles from South Australia's The Advertiser, where a front page referred to mobile scooter killer murdering his own wife; the inside story was more compassionate; the slides had a very powerful effect on the audience
- Examples of the confusion when words like euthanasia and suicide continue to be used in the media and by academics
- Analysis from Australia's media watch over two months in 2017 compared with same two months in 2022 shows some progress; overall there is a small increase in the proportion of headlines using 'assisted dying'; however 'suicide' is used significantly more frequently in 2022 than in 2017; 'euthanasia' is being used less frequently
- Detail of why suicide is the wrong term – offensive, wrong, and misrepresents VAD
- Discussion of how language develops, particularly the English language, with new dictionary words each year
- European intransigence on use of 'suicide' perhaps partly attributed to not recognising the development in the English language
- Need to keep contacting media when they use suicide or euthanasia and explain why assisted dying is the correct term
- Recognition that World Federation has adopted 'assisted dying' as the terminology to describe the focus of our activity
- 50 participants formed into small groups for discussion of guided questions; extremely successful (says Jane) and resulted in a lot of 'interesting' views as to how we should refer to 'Assisted Dying'. Everyone thoroughly enjoyed this.

## 3.3 MAiD House in Toronto

Dr Chantal Perrot and Tekla Hendrickson

- See notes from visit to MAiD House (S3.17)

## 3.4 Bridge C 14

Lauren Clark, Alicia Freeborn

## Lauren

- Bridge4You 1:1 peer support
- Psychosocial support for people going through MAiD, supporting someone going through MAiD or who has witnessed MAiD
- Provide a 10-week structured group writing workshop with Facebook groups
- Have supported over 200 people this year
- Volunteer network – all trained
- Person is contacted within 72 hours of contacting Bridge
- Have found more males join an 8 week group therapy course
- Age range 28-83
- 140 1:1 peer supports since launch in April 2021
- 20 volunteers
- No government funding
- <https://www.bridgec14.org>

## Alicia

- Unstructured, ad hoc support, connect people through podcasts and facebook groups
- Peer Support, drop-in, use structured workshop format to open up the conversation
- Provide group guidelines
- Structured 8-10 week group, use grief readings, participants provide feedback. Look at someone supporting someone using MAiD, anticipatory grief and grief bereavement
- Look for ambiguous, hidden grief.

**Bridge 4 You:** A support group which works collaboratively with Bridge C-14 – Signy Novak

## 3.5 Hanne's story

Dr Mary Valentich (PhD)

- Hanne was Mary's friend and was diagnosed with MND; lived in Alberta
- 'Fighting for Hanne' documents Hanne's story, based on emails between Hanne and Dr Valentich
- Before MAiD law passed, but after 'Carter' court ruling; went to court for an exemption
- Took ages finding a lawyer, doctors - finally a Netherlands doctor suggested a doctor in Canada
- Thurs Feb 25 exemption approved by the court
- Set date for procedure Monday Feb 29, 2016
- Travel to Vancouver for procedure as there was no supportive doctor in Alberta
- Difficult finding a funeral director
- Had rooms at Fairmont Hotel (a famous institution in Vancouver)
- Hanne typed 'This sounds like a Monty python sketch' during Mary's telephone conversation with a funeral director; trying to organise for the body to be collected in three days; funeral director thought Mary was planning a murder
- Hanne did not want to die a choking death
- \$13000 to go to court
- \$4000 to get a publication ban lifted to allow Mary to talk about the death
- Transfers of dying people from publicly funded Catholic hospitals is outrageous
- Catholics run all long term care in rural Alberta – impossible to use MAiD on premises
- Two streams in Canada: death is reasonably foreseeable and death is not reasonably foreseeable, second category has lots more hoops to jump through

### 3.6 An Alzheimer's Odyssey – Coming Full Circle - Moving Forward Towards Healing

Julie Briese. Vancouver Island BC

- Husband suffered from Alzheimer's, husband had MAiD death January 6, 2022
- Book Richard Wagamese 'Embers missing someone'
- Great emphasis on the benefits of nature throughout
- Had three monthly meetings for three years with doctor
- Healing power of telling one's story
- "A story is a promise of a conversation"
- Husband equated Alzheimer's to a snowdome or a blackboard eraser and blank board
- Bill C-7 from July provided capacity to waive the final request if the person had capacity at time of assessments
- Husband signed waiver September 22, 2021
- His choice to set the date, difficult to know when, husband chose December 2, 2021 – then deferred to January
- Doctor says "Your subconscious knows" when you must set the date
- "MAiD is the gift of life for the carer"

### 3.7 Expert panel on mental health

Rose Carter

- Expert Panel commissioned to consider MAiD rights of patients for whom mental illness is the sole underlying condition
- March 17 2023: intended start date for new changes related to mental health being eligible
- Reasonably foreseeable or not reasonably foreseeable are the two MAiD pathways; mental health cases will be part of the 'not reasonably foreseeable' path (also called Track 2)
- Still require a definition of "reasonably foreseeable"
- Accessibility and waiting times will be barriers for patients to access MAiD
- Problem with access to treatment records (similar to My Health Record) not everyone can access government health records
- Assumes shared understanding of suffering, impact of treatment options between requestor and assessor - unlikely with power imbalance
- 90-day cooling period; but it will take at least that to get through all the steps
- Medical people not good at saying 'we're at the end of what we can do for you; instead, they say you haven't tried this pill yet'
- Most people who access MAiD in higher socio-economic bracket
- Comment during questions re Catholic hospitals: three patients were certified because they asked about MAiD; there was no evidence of mental illness observed by their regular treating doctors
- Alberta story of a man requesting MAiD in a Catholic aged care facility:

After the assessments were complete the MAiD provider (doctor) informed the pharmacist at the facility of his prescription and the date; a 2.5 hour drive from Edmonton; came back on day; pharmacist said there was a complaint so the drug could not be supplied; doctor drove back 2.5 hrs to Edmonton, gets drugs, drives back; hospital has circulated whole hospital that MAiD planned for patient (name provided on circular) on this day; a breach of confidentiality; doctor told can't do MAiD here; there's a building out there they use for vaccinations and you can use that; doctor puts patient on gurney and pushes him outside to the building; created a makeshift curtain, administered MAiD; waits outside in the cold with the now deceased patient for three hours for the Coroner.

- Disability rep on Expert Panel, Ellen, resigned and then told fake story to Global News (major respected paper in Canada) about poor treatment on the panel; exit interviews with Chair and Deputy did not raise any concerns.

### 3.8 Assisted Dying around the world: Canada, Victoria, New Zealand, Switzerland

#### 3.8.1 Canada

Dr Derryck Smith

- former member World Federation Committee
- Great data slides on Canada – to be provided by DWDC
- 50% of psychiatrists think mental illness should not qualify for MAiD
- Have relied on courts to push MPs to deliver legislation - go to court all the time
- Eg conservatives tried to remove charity status from DWD Canada
- See notes on Canada from GA (S2.6.1)

#### 3.8.2 Victoria: VAD Sweeps a Continent

Jane Morris

- six states have now passed VAD legislation in five years
- Advantages of staggered legislation, other states can observe what is good and bad about implementation process and operation of VAD
- A few problems with the original Victorian legislation – other states have addressed many of these over time
- Main issues are gag clause, Institutional Conscientious Objection for health care facilities, requirement for one of the two doctors to be a specialist and the ban on using Telehealth due to federal legislation.

#### 3.8.3 New Zealand

Dr Gary Payinda – See presentation during General Assembly (S2.6.6)

#### 3.8.4 Switzerland

Dr Erica Preisig

- Worked for Dignitas 2006-2008 and then founded Lifecircle with her brother Ruedi Habegger
- 2011 Habegger left Lifecircle and later established Pegasos (see S3.20.2)
- Erika was charged in 2019 with mishandling medication involved in the death of a depressed woman; fined 20,000 dollars and given a 15-month suspended gaol sentence
- Before, during, and after the death, the needs of the relatives and interprofessional care and support team must also be taken into consideration
- Required support is to be given and must be documented
- They accept concept of ‘a completed life’ as the person usually has co-morbidities
- Have assisted couples to die together
- Doctor must not make money from performing assisted dying, just normal fees
- Unbearable suffering
- Lifecircle is no longer accepting members ie it is closing down
- Need to improve conditions in Switzerland, pessimistic about what is happening

Swiss rules have tightened up:

- In May 2022, the Swiss Medical Association (FMH) agreed on the revised guidelines for the ‘Management of Dying and Death’ proposed by the Swiss Academy of Medical Sciences (SAMS)

- The physician must – other than in justified exceptional cases – conduct at least two detailed discussions with the patient separated by an interval of at least two weeks
- The symptoms of the illness and/or functional impairment must be unbearable, the severity of which is to be substantiated by a legitimate diagnosis and prognosis
- Assisted dying for healthy persons is not medically or ethically justifiable.

#### **Thaddeus Pope**

- MAiD gets attention from policymakers, academics and advocates, but even in countries with broad eligibility requirements, not all patients can qualify
- Important to better clarify other alternative EOL options such as voluntarily stopping eating and drinking, a lesser known but widely available end of life option

### 3.9 Keynote Address: Canada Bill S-248

#### Senator Pamela Wallin

- Impressive bio, including as a journalist
- Bill S-248 seeks an exemption to the Criminal code of Canada to allow for advance request for MAiD for Canadians diagnosed with a serious or incurable disease, illness or disability
- The bill would allow Canadians to waive requirement for final consent when receiving MAiD if they lose capacity and will allow provinces and territories to legally create advance request frameworks
- Bill S-248 aims to allow a MAiD request due to dementia to be nominated in an ACD
- 500,000 people in Canada have dementia
- Needs both state and Federal law to achieve the outcome
- Wallin Bill covers the federal law; federal government could charge a doctor who followed provincial law allowing MAiD in an ACD
- Aim is that after diagnosis, person could request MAiD in an ACD
- Would stop it being a criminal offence to request MAiD in an ACD
- ACD request for MAiD can't be more than five years old
- Would require two witnesses to the ACD
- Would mean person has to first be assessed as eligible for MAiD - just waves final request if person's condition has deteriorated
- Third annual report on MAiD released in July
- Most common MAiD recipient: cancer patient, in 70s, died at home
- As an MP 'It's our job to take on tough issues'
- Re the Parliamentary Committee on MAiD workings (Wallin a member): much of the time has been spent relitigating MAiD - much misinformation - wasting time when should be addressing other issues
- Mother had dementia, father cancer - both had difficult deaths

#### 3.9.1 Waiver v Advanced Directive

##### **Waiver of final consent**

- Person must have been assessed as eligible for MAiD (including having decision making capacity at the time of assessments) and have 'capacity' at the time the waiver is signed
- An agreement between provider and patient
- Not used to refuse treatment
- Must set a date for MAiD
- Delegated decision maker not involved

##### **Advance Directive**

- Can be written when a person is well and not with a serious illness

- Not specific to one clinician
- Is used only for refusing care
- No specific date or time frame
- Delegated decision maker involved

**“HAPPINESS IS A SYMPTOM OF DEMENTIA NOT A STATE OF MIND”**

### 3.10 Colombia: Using the Media in the campaign

Camila Salazar (via zoom)

- Two cases used in media campaign, both had ALS
- Court approved an assisted death for both people
- Court ruled that it is not a crime - but there is no law to support it
- Most people don't know it's not a crime - including health authorities
- They created online resources, press releases
- Constitutional court created constitutional right to assisted death
- Need a face and a strong person to create a story
- The two women had strong families, lives beyond their illness, were strong themselves - one a Catholic who said 'believes god would not want her to suffer'
- Need to connect with the public - the two women in the media stories were excellent speakers
- Need to be loud
- Focus of campaign was on rights and autonomy
- Got prime time TV to run their stories - Sunday night 7 pm
- Catholic woman was younger, had a son, was laughing in the story - generated much discussion after the TV ran the story (Sun night 7pm)
- Media engagement last year raised awareness about assisted dying and the court ruling in the community; media campaign has pushed MPs to address the matter and stop ignoring it
- expect a law in the next year
- Worked with feminist groups and media; made new contacts in this campaign for her - not just doctors and lawyers
- Got abortion law in Columbia this year; feminist groups had not considered VAD before
- Question: England Trevor - do you challenge the misinformation and give it airtime or ignore it (AB had long discussion with Trevor afterwards about rephrasing the misinformation and promoting the opposite argument; not giving their argument airtime, but giving the real and opposite story airtime eg 'you kill people' becomes emphasising that VAD is voluntary, there are many steps to achieve a VAD death)
- Answer: pick your fights; they don't debate religious opposition; however, if opponents say there is no right to VAD because there is no law, they counter that and provide correct information; if opponents say 'doctors will kill patients' they find medical allies and patients to speak out

### 3.11 First dementia patient to use MAiD

Dr Konia Trouton

- Patient lived on Vancouver Island, which appears to be an incredibly progressive community of about 900,000 people to the west of Vancouver; Vancouver Island has the highest MAiD rate in Canada
- A predominantly retired and older population
- MAiD providers on Vancouver Island self identified on line; 60 MAiD providers on the island
- Mary asked GP for referral for MAiD in 2017

- Mary had three degrees, was well motivated and well informed; Dr Trouton did second assessment and said she had capacity; first assessor was then advised that if the review afterwards said they got it wrong, the licence to practice would be at risk; first assessor subsequently pulled out, worried about the professional risk of being associated with the first dementia case for MAiD
- “So now I am lead assessor and likely provider. I checked with my family that they’re OK if that happens”.
- Neurologist had put in writing that the prognosis was 5-7 years, which was consistent with Canada’s ‘reasonably foreseeable’ criteria
- Canada’s ‘reasonably foreseeable’ criteria provides the flexibility for dementia to be a criterion for MAiD providing there is a prognosis
- two years between Mary’s diagnosis in 2014 and MAiD request in early 2017; she set MAiD date for October 2017
- Specialist neurologist was prepared to put in writing that her capacity had not changed
- In 2017 all MAiD deaths had to be reported to the Coroner; after death, Dr Trouton reported Mary’s death to the Coroner and heard nothing
- Three months after Mary’s death Dr Trouton’s Professional College requested information, giving her 14 days to respond; she engaged a lawyer; her College sat on it for months
- Finally, a response; all positive; no regulatory problems
- The process after death took one year and caused considerable professional and personal anxiety
- Key learning: keep your paperwork in one place
- As a patient: make sure your family doctor documents over and over that you are interested in MAiD - an ‘assisted death’; make sure your specialist documents your prognosis and that you are interested in an assisted death
- Written documentation of patient’s prognosis and patient’s view on MAiD is really really helpful for assessor’s
- Alzheimer Society invited Dr Trouton to speak about MAiD
- 1% of MAiD deaths are people with dementia
- Waiver of final consent is an agreement between provider and person about setting a date; it is not binding
- The four elements the clinician requires from the patient requesting MAiD:
  1. Proof or evidence you want MAiD, tell everyone, record a video of your intention re MAiD to make sure there is no doubt (a personal multimedia campaign)
  2. Insist that your Primary Care Provider documents your request
  3. Ensure a recognised specialist writes down your request and documents your prognosis
  4. Talk to your family and loved ones to make sure they will respect your wishes
- Re nursing home behaviour: reframe to ‘where would you like to die’ because no one wants to die with hostility around them
- Dr Trouton has provided continuous education and training at institutions with all staff, including cleaners, kitchen staff, about MAiD; what it is, why, what can be expected
- Must be citizen or permanent resident of Canada to be eligible for MAiD
- Dementia is a neurological disease, not a mental health issue

Book: MAiD in Dementia – Dirk Coetsee

### 3.12 Dementia in Japan

- Life expectancy 82-88 years
- 74% of people die in hospital, 14% in their own home
- Highest number of hospital beds in the world per capita
- In 1976 established Japan Society for Dying with Dignity (JSDD)

- 120,000 members
- 1 in 6 people > 65 have dementia
- Japanese cultural norms mean that people avoid any discussion of death and leave decisions about death to the family
- Very few ACDs made
- High levels of medical intervention, PEGs, N/G tubes, tracheostomies
- Too early to talk about assisted dying in Japan
- Japan provides universal health insurance; high ratio of hospital beds; cheap to stay in hospital
- Most individuals diagnosed with dementia are institutionalized and receive life prolonging interventions during late stages of dementia.

### 3.13 MAiD in prisons

Dr Jessica Shaw (PhD)

- Presentation title summarises research findings: Dying with a smile, just knowing that someone's listened to me: End of life care and MAiD in Canadian prisons
- Research project between Calgary University and Canada Research Council
- Correctional Services Canada published MAiD guideline in 2017; speaker believes they are the only correctional jurisdiction in the world to do so
- 4% of prisoner admissions are for life, but lifers represent 26% of prison population; 60% are indigenous
- 11 people have applied for MAiD and three were granted
- USA: Specifically excludes assisted dying for prisoners in each state where it is legal
- Case 1: transported for death in restraints, handcuffed during assessments
- Case 3: guards present at time of death
- 11 prisoners interviewed during the study; three were caregivers in the palliative care program
- Some prisoners with terminal illness not granted parole so just stay in prison to die
- Some respondents said let us die; save taxpayer dollars because we will never get out
- Are prisons about punishment or rehabilitation
- Need to look at principle of 'Equivalent Care'

### 3.14 Digital storytelling

Kathy Kortés-Miller and Keri-Lyn Durant

- Excellent initiative with universally positive outcomes
- Participants document their experience supporting someone through MAiD using video
- Clearly had incredibly positive impact on the participants who told their story
- Story tellers were nervous about their ability to tell a story well or make a video
- Program staff provided good technical advice on how to present the story
- Three stories presented:
  - Story 1 about Jack's death; Celia has put it on her website so it's public (and excellent)
  - Story 2 about a mother's death in aged care, the mother was born in Austria
  - Story 3 had beautiful music playing; Rufus Wainwright's Hallelujah and Joni Mitchell singing Blue
- All stories are owned by the person - researchers only have access if they ask
- Both speakers happy to be contacted and provide more information
- A compelling initiative and good to follow up
- Contact details: [kkortesm@lakeheadu.ca](mailto:kkortesm@lakeheadu.ca); [kdurant@lakeheadu.ca](mailto:kdurant@lakeheadu.ca)

### 3.15 VAD and discrimination

Silvan Luley - lawyer

- Provided a handout and the presentation will be on the Dignitas website
- Silvan is a lawyer and has been with Dignitas for 18 years
- Dignitas founder turns 90 on Dec 5
- Referred to one patient, a quadriplegic from a rugby injury at age 17; by 23 had tried suicide twice; got support with Dignitas
- Sodium pentobarbital used in Switzerland
- Collection of old age ailments provide eligibility – people with co-morbidities
- Argued that suicide was the right legal word, and we should explain it better
- Court of public opinion v law court in achieving law reform

### 3.16 Assisted Dying around the world: Netherlands, Italy, France

Netherlands

- No residence requirement
- Need relationship with family doctor
- 20 dementia cases

Speakers from Italy and France spoke previously.

### 3.17 MAiD House

Visit on Sunday November 6, 2022

- No government funding but can't survive on donations
- Location not publicised
- No charge to MAiD user
- Two comfortable, carpeted rooms, set up with couches (one converts to a bed), chairs, large table, plus a kitchen-office; French doors between the two rooms can be open or closed
- Chair lift for the stairs
- One procedure a day and the family has the space for 24 hours
- Community nurse sets up IV first, then MAiD provider (doctor) arrives
- No paperwork at MAiD House – all completed beforehand by MAiD provider
- In current location since April 2022 – previously used a temporary room in a church
- 16 procedures since April; two were hospital transfers, both in great pain caused by the transfer, scared to ask for pain relief as it may affect 'capacity'
- Supporters arrive 45 mins before MAiD provider, so the environment is calm and relaxed
- Not all supporters understand what is going to happen
- Ambulance staff don't necessarily know they are transferring a patient for MAiD
- Roster of 28 MAiD providers registered to work at MAiD House; people can only use these doctors at MAiD House; all have been carefully vetted to ensure they are thoughtful and caring; a review committee of three clinicians review each provider before accreditation; four of the 28 have so far used MAiD House
- Each MAiD provider has completed three procedures before accreditation at MAiD House; most have done 10; sign an access and equity policy (one refused, so not accredited)
- Coroner has to be advised and give permission to release the body
- Every province has different MAiD rules
- Pharmacy in same street - MAiD provider can send script and Tekla can collect it
- Would prefer a house with a garden, accessible garden at back for hearse, but landlords have not been willing to rent to them
- Had considered a caravan so that people could choose where they would like to die
- Mona chairs the Board and volunteers at MAiD House - works 20 hours/week
- Have a dedicated parking space for clinician

- Support research around MAiD
- Developing a grieving program
- Not all MAiD providers are created equal - some are not as sensitive
- First year provided space for six people; now providing for three times more, but not receiving three times in donations
- Tekla works full time
- Took 18 months to find these premises

### 3.18 Conference Dinner and Awards

What a wonderful few days we shared with so many others at the WFRtDS Conference., 2022. Not only did we finally get to meet so many wonderful individuals, many of whom we regularly communicate with, but we were also able to forge new friendships. Of course, the conference was not all just work and the Australian team, of Anne Bunning, Greg Mewett, Mike Gaffney and Jane Morris, certainly made time for fun as well. We especially enjoyed the company of the Irish, English and Scottish representatives who seemed to always want to join us for a bit of fun!

At dinner that night, President of the WFRtDS, Asunción Alvarez, delivered several awards. We were all so very happy and excited to learn that Shayne Higson, CEO DWDNSW, received the Marilynne Seguin award. This award is given, ***“For the person who has achieved much in their country for their national right to die movement.”*** Shayne was a truly deserved recipient. She has so generously, over the years, shared her time, knowledge, and skills with all the DWD organisations all around Australia, to ensure the successful passage of VAD. Shayne’s advocacy work began following the horrendous death of her mother from brain cancer in 2012. Her mother would be so proud of her, as are we.

It was also wonderful to see the Medical Specialist award presented to Dr Jack Havill from New Zealand, a retired intensive medicine specialist. Dr Havill was instrumental in the advocacy for end of life choice in New Zealand, with relentless evidence based advocacy in the medical profession, as past President of End of Life Choice New Zealand, and in providing drafting instructions for the first Bill tabled in the New Zealand Parliament in 2012. He remains an active member of the Australia-NZ doctor’s groups.

Australians have certainly cemented our position on the map that indicates the places in the world that provide a compassionate and empowering end of life choice for the terminally ill. We left Toronto extremely proud Australians and as an even prouder South Australian and Victorian.

An experience never to be forgotten.

Thank you to the WFRtDS and DWD Canada for hosting such a successful conference. We are definitely looking forward to Ireland in 2024.

### 3.19 Suggestions for future World Federation Conferences

- Ramps or railings to reach stage, not just stairs
- PA check: someone allocated to check whether each speaker can be heard; moderator to know to check with the PA person
- Moderator to check microphone positioning for each person – helpful if a sound check done with each speaker in the break before they speak; makes speaker aware it could be an issue as well as increasing the possibility that each speaker will be heard
- Cost conscious accommodation to increase participation – positive reference to Australia providing accommodation in university student colleges
- Prior agreement to sharing contact details to enable a list of delegates, organisation, email and phone number to be provided at registration
- Prior agreement with speakers for sharing PowerPoint or speeches

## 3.20 Miscellaneous

### 3.20.1 Sean Davison joins Exit International

- [Professor Sean Davison joins Exit International](#) in November 2022 as an Executive Director
- Sean was previously Professor of Molecular Biology and DNA Forensics at the University of the Western Cape, Cape Town South Africa
- Sean Davison is the Founder of Dignity South Africa
- From 2016 to 2021, he was President of the World Federation of Right to Die Societies
- At Exit International, Sean will be part of the daily management team of the organisation. His first major task is the implementation of the Sarco project in Switzerland where it is expected to be used in 2023.

### 3.20.2 Compassion and Choices

(pers con) Barbara Toeppen-Sprigg, Ohio family doctor, former Professor, retired to Florida

- Compassion and Choices: the USA organisation which provides umbrella support for assisted dying advocacy across the US; have field officers in many states; excellent website <https://www.compassionandchoices.org>
- Likely the go to organisation for USA organisations lobbying for assisted dying, rather than the WFRtDS (WFRtDS has eight financial members from the USA, same as Australia)
- Assists people directly through their network of field officers
- Focus on self administration
- Lobbying for ACD for dementia and VAD
- Barbara is a C&C field officer as well as an agent for Pegasos (Switzerland) which was established in 2019; Pegasos has broader criteria; website uses 'assisted dying'
- Barbara's husband used Dignitas

### 3.20.3 Julia Lamb case

- Significant legal case in Canada: instrumental in providing clarity for doctors undertaking MAiD assessments on the definition of 'reasonably foreseeable'
- Julia Lamb had spinal muscular atrophy and took the case in 2016 soon after the MAiD law was enacted, arguing that 'reasonably foreseeable' would be interpreted by cautious doctors as death being imminent, which would deny her access to MAiD
- The case was withdrawn after a government witness said Lamb met the 'reasonably foreseeable' criteria, because if Lamb stopped using her nighttime ventilator and developed a chest infection, her natural death was reasonably foreseeable
- Dr Stefanie Green, from the Canadian Association of MAiD Assessors and Providers, commented at the time:  
"The government's evidence suggests that anyone requiring personal care such as regular turning in bed, being fed, requiring regular dressing changes or in-dwelling catheters, would meet the eligibility requirement for a reasonably foreseeable death if they decide to refuse that care. And mercifully, they are not required to actually do so in order to qualify."
- Message: court action is often required to interpret VAD laws, especially if they are being interpreted to the disadvantage of people who wish to request VAD.

### 3.20.4 Oregon

Oregon removed the residency requirement in March 2022.

**Jane Morris, Dying With Dignity Victoria**

**Anne Bunning, Voluntary Assisted Dying South Australia**

**November 22, 2022**