

The World of Champions tells the stories of the parents, siblings, activists, doctors, supporters, volunteers who are working to make dying with dignity possible from all the corners of the earth; a testimony of their struggle and the complexities they face in championing the right to die with dignity. [www.wfrtds.org](http://www.wfrtds.org)



# World Right to Die Day 2022: World of Champions

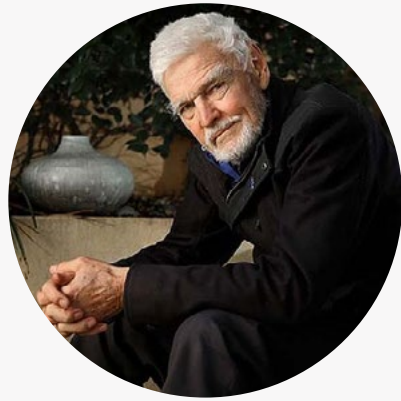
## Introduction

There are many forces that differentiate us in the world: politics, religion, beliefs to name only a few. One thing that unites us is the desire to die with dignity. As a result of these forces not all of us have the opportunity to do so, yet a great many 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 this 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.

The World of Champions tells the stories of the parents, siblings, activists, doctors, supporters and volunteers who are working to make dying with dignity possible from all the corners of the earth; a testimony of their struggle and the complexities they face in championing the right to die with dignity.

There are 58 World Federation Right to Die Societies spread throughout 30 countries across six continents. This map is a testament to the unity and commitment of “the Champions” worldwide.





## *Dr. Rodney Syme (1935-2021)*

### Compassionate, caring and kind to his fellow human beings.

Dr. Rodney Syme was a third-generation surgeon. In 1974 he encountered a patient with excruciating suffering which doctors were unable to relieve. He recognised that that the approach to pain relief for terminally ill patients needed to change. This eventually set him on his path to advocate for a law enabling voluntary assisted dying. However, law reform to allow VAD was very slow in coming. Syme, at considerable personal risk, provided free counselling to thousands of people suffering at end of life, as he developed expertise in the subject. He also provided some people with medication which they could use to end their lives, though this was against the law. Unable to get traction with law reform, Syme went public about these activities, in an effort to bring the matter before the courts, for a common-law ruling.

But the authorities had no interest in challenging him in this way. For decades Syme was president and vice-president of Dying with Dignity Victoria (DWDV), the law-reform and advocacy organisation advancing the VAD cause in Victoria, Australia. He made a significant contribution to DWDV's submission to the Victorian government's Inquiry into End-of-life Choices in 2015 and also appeared as a witness before the inquiry. Rodney Syme was 2017 Australian Humanist of the Year and received the WFRtDS Health Professional Award for 2014. He was tireless in the application of his keen mind to his advocacy, counselling and teaching activities, courageous in his actions and above all, compassionate, caring and kind to his fellow human beings.

Victoria





*Ian Wood*

## Giving a voice to those of faith who support VAD.

### Australia

It is with honour that I write this testimonial on behalf of a truly inspirational gentleman: Ian Wood, co-founder of Christians Supporting Choice for Voluntary Assisted Dying (based in New South Wales), Australia. All of the six Australian states that have now passed Voluntary Assisted Dying legislation, and many lobby groups outside of Australia, recognise and appreciate the incredible contribution made by Ian (now 81 years of age!) for his Herculean contribution to the voluntary assisted dying movement over many years. VAD advocates, globally, recognise the negative impact religion plays through fear-mongering arguments, when it comes to progressing the voluntary assisted dying movement. Ian has successfully made it his mission to ensure the many voices of those of faith, who support voluntary assisted dying, contin-

ue to be heard and shared with our key decision-makers. Ian is to be commended for his gentle but incredibly influential and powerful knowledge when it comes to biblical reference and support for the cause. His voice has proved to be crucial and balanced over and over again in key parliamentary settings. Whether it be out amongst the public, campaigning, distributing information by hand, or spending hours preparing information packages and posting to reach those who do not have access to technology, his efforts are simply admirable. He has also demonstrated courage in the public arena, with counter-arguments to the divisive and negative opinions voiced by some of the most senior representatives of opposing religious groups. Ian has truly earned his place in the World of Champions.







## *Dr Cameron McLaren*

### **An unwavering commitment and selfless dedication to his patients.**

#### **Victoria**

Dr McLaren is a Medical Oncologist from Victoria, Australia. He signed up to provide VAD assessments to Victorians from the day it became legally available. In Victoria, one of the doctors assessing eligibility must be a specialist in the area of disease that the patient has. Due to the low uptake by his colleagues, Dr McLaren began to be asked if he would assist other doctors' patients to access VAD, and his answer has never been "no". In the three years of operation of VAD in Victoria, Dr McLaren has been involved in over 200 cases of application, often attending in support of his patients and their families if the patients choose to take their VAD medicines. He has championed the right of patients to access this option, and is dedicated to sharing his craft, and encouraging other doctors to answer their patients' pleas.

Dr McLaren is a Board member of Dying with Dignity Victoria (DWDV), one of the Clinical Moderators of the Victorian VAD Community of Practice, and is the Founding Director of VADANZ (Voluntary Assisted Dying, Australia and New Zealand). He has been involved in sharing his experience and contributing to legislative development and implementation of VAD in Western Australia, Tasmania, South Australia, Queensland, New South Wales, New Zealand, and in the United Kingdom.





## *Dinny Laurence*

**Worked ceaselessly and with utmost dedication to get assisted dying legislation passed.**

### Australia

Dinny Laurence is the unsung hero of the Australian voluntary assisted dying (VAD) campaign. Joining the committee of Dying with Dignity WA at a critical point for the organisation, Dinny stepped forward and took on the role of campaign manager. For four years she worked ceaselessly and with the utmost dedication, intelligence and determination to get assisted dying legislation passed in Western Australia. These campaigns are never easy, and Dinny faced many challenges. There was little money to run an effective campaign, so she had to organise fundraising events, not a task that came naturally to her. She had to deal with personalities – power-mongers, egomaniacs, and religious right fanatics. She worked long hours, with a remarkable attention to detail and a warmth and humility that is rare.

But what really took its toll was dealing with literally hundreds of people with heartbreaking stories about their terrible experiences of watching a loved one die an agonising death. Committed to the cause and involved in every aspect of the campaign, Dinny was steadfast in doing what she needed to do. It goes without saying that this work was voluntary, and it continued after the passage of the legislation when she conducted a series of workshops during the Act's implementation phase. Dinny is the epitome of the totally committed and hard-working quiet achiever.





*Hon. Mike Gaffney* MLC, Member for Mersey

**A natural champion to bring us all together.**

## Tasmania

When you first meet Mike, you're struck by the warmth of his greeting; backed up with bright-eyed energy, genuine enthusiasm, a firm handshake and a winning smile – it's like bumping into an old friend that you haven't seen in years. It's these qualities that were the catalyst in bringing our community together for what was the fourth, and now successful effort in bringing voluntary-assisted-dying legislation to Tasmania. Looking back at the Bill's evolution, it's mindful to note that it took two-years of widespread input and consultation, with the active support of the Office of Parliamentary Counsel to draft the proposed legislation and the subsequent refinements. As part of this process, Mike led 115 community and stakeholder forums, across Tasmania, to consider and incorporate community feedback with a genuinely impartial approach

and an open-door policy for all sides to actively engage with him. These elements in the process were crucial in garnering community understanding and confidence in the Bill, and for Members of the Legislative Council, Tasmania's Upper House, who voted unanimously for the Bill; the first time this has ever happened in the passage of VAD legislation. Mike always gratefully acknowledges the enduring advocacy of so many individuals and community groups, together with the assistance from national and international experts, organisations, governments, academia, law and medical specialists; all have worked tirelessly to support this legislative process. However, without Mike there wouldn't have been a natural champion to bring us all together, and for this Tasmanians will be forever in his debt.





## Shayne Higson

### Optimism in the face of bleak prospects.

#### New South Wales

Like so many advocates, Shayne Higson's involvement in the campaign to legalise Voluntary Assisted Dying began after she witnessed the traumatic death of her beloved mother from an aggressive brain cancer in 2012. Shayne began her advocacy by sharing her mum's story on ABC news to coincide with the introduction of the 2013 VAD Bill in NSW Parliament. Since then she has devoted her life to this cause, as Vice President of Dying with Dignity NSW; by running as the lead candidate for the Voluntary Euthanasia Party in five elections – state and federal; and by supporting the campaigns of other Dying with Dignity organisations around Australia. Shayne faced devastating disappointment seeing two bills fail in NSW in 2013 and again in 2017. But what distinguishes Shayne Higson's advocacy is her “never give up”

attitude, her optimism in the face of bleak prospects and her belief in the power of respectful conversations. While other advocates left the so-called ‘no’ votes alone, Shayne persisted, with patience and respect, always believing that there was some hope that those opposing MPs might one day come to understand the need for law reform, if they heard her story, or the heartbreaking stories of so many other families. She didn't convince every opponent, but she helped secure enough votes to see NSW become the last state to pass assisted dying laws in May 2022. Shayne is highly respected within the dying with dignity community for her endless compassion, kindness and her steadfast and selfless commitment. Her mum would be extremely proud.







*Tanya Battel (1963-2022)*

## A passionate, dedicated, articulate and vocal advocate.

### Queensland

Driven by the traumatic experience of nursing parents through harrowing suffering (from incurable disease) in her younger years, her own breast cancer diagnosis at age 32, again at age 37, and then a terminal metastatic breast cancer diagnosis at age 52, Tanya Battel has made an indelible mark in the Voluntary Assisted Dying space, not only as “the face of the Queensland campaign” but by her ongoing support to other Australian states and overseas groups. Passionate, dedicated, articulate and a vocal advocate, Tanya has demonstrated her ability to take on the most fierce of opponents, whether that be through media, media interviews, well-written responses to media articles or submissions to parliamentary bodies ensuring that confronting information, often glossed over, is brought into discussion with key decision makers.

Her “Voices for Change” campaign assisted in the Queensland Parliament holding its first Voluntary

Assisted Dying Parliamentary Inquiry; her social media platform “VALE: Voluntary Assisted Life Ending” followed and has provided a “go to” information vault for all things relating to Voluntary Assisted Dying, providing a compassionate platform for those sharing their experiences and reasoning in support of legislation. Tanya’s tireless campaigning over many years has seen her form valuable networks with diverse groups/individuals to gather support required to drive the progress of voluntary assisted dying. Her “The People’s Petition” – Why you should support Voluntary Assisted Dying – gathered 115,000 signatures and was received/tabled by the Deputy Premier of Queensland at the commencement of the Queensland Parliament VAD debate.

*Unfortunately Tanya was unable to access an assisted death in her home state of Queensland and it was necessary for her to travel to Switzerland.*





## Angie Miller

### A gentle, thoughtful and caring approach gaining the confidence of people to share their stories.

#### South Australia

Angie Miller's dad, Dusty Miller, was a Vietnam Veteran and founder of the iconic Birdsville Bakery in the isolated centre of Australia. Dusty died a difficult death in 2018 from cancer. Angie supported her father after his diagnosis, initially with regular visits from her home 2000 kms away, and then every day in his last months. Being part of her father's harrowing last months, Angie became a powerful advocate for voluntary assisted dying in the successful 2021 campaign in South Australia. In 2020 Angie established a facebook page, A Peaceful End, creating a community of interest with people across the state, sharing their stories and generating momentum for a VAD law. Angie travelled all over South Australia to address meetings, knowing there was widespread but silent regional support for VAD, and that Members

of Parliament who had previously opposed VAD held regional seats. Social media enabled contact with people who previous campaigns had not reached. Angie spent hours every day communicating with and supporting people through her facebook page. People sharing stories of unnecessary suffering of loved ones at the end of their life. Angie's gentle, thoughtful and caring approach was instrumental in gaining the confidence of people to share their stories and join the campaign, many taking new leadership roles in their local community. Angie's passion was relentless. All while managing paid employment and a young family. Angie knew that if a Voluntary Assisted Dying law had existed, her father's suffering could have been avoided.





## *Dr. Libby Smales*

### Swimming against the tide is hard, especially as a health professional at odds with many of your colleagues.

#### New Zealand

Swimming against the tide is hard, especially when you're a health professional putting yourself out there at odds with many of your colleagues. Enter Dr Libby Smales CNZM FChPM, palliative care consultant and former hospice director. Libby was an early adopter of the right to die with dignity and despite the discomfort of being offside with professional colleagues, has never stopped her speaking her mind. It has been a long battle, particularly intense during New Zealand's referendum year (November 2019 – November 2020) when Libby consistently unpicked the unrealistic claims made on behalf of palliative care. Wealthy right-to-die opponents mounted disinformation and misinformation campaigns; much money was spent on portraying palliative care as the answer and assisted dying as unnecessary.

Libby allowed herself to be co-opted by neutral and biased TV programmes on national and regional channels, staring down official palliative care spokespersons and an Opus Dei lawyer with that most uncomfortable weapon: the truth. The public learned that palliative care, though in many ways wonderful, is neither infallible nor sufficient in all circumstances. They also heard what we all inherently know – that being approved for assisted dying can be in and of itself palliative for some. Importantly, these messages came to them directly from the mouth of a credentialled palliative care practitioner and were convincing by virtue of their realism. While some criticism came from Libby's own inner circle, the public and other like-minded medical professionals rallied around her. The referendum was won by a 65.2% majority.





## Esther Richards

### Changed hearts and minds through her public championship of assisted dying rights.

#### New Zealand

Esther Richards fought for assisted dying legalisation in New Zealand from 2013 when she was diagnosed with brain cancer. On 22nd April this year, she achieved her final wish; an assisted death with her beloved son Alex and her closest friends beside her. But it was her life, rather than her death, that made Esther so remarkable. Her absolute commitment to law change meant that, despite increased suffering, she continued to organise meetings across the country and wrote daily to multiple news outlets so that the public had full information before voting in the critical New Zealand referendum on assisted dying. She was published often.

Esther also ran a Facebook site, the Medically Assisted Dying Information Group where she ensured that New Zealanders were aware of

international events as well as sharing her own personal journey with terminal illness. Even this was not enough for Esther. During the last increasingly difficult months of her life, she permitted a documentary film crew to follow her so that the resulting current affairs programme would help others feel comfortable to follow her lead. She was determined that people should know that avoiding a painful and drawn-out death was a valid option. On TV she said, *“I don’t want to die as someone other than me”*. She remained Esther to her last breath.

So, who was Esther? She was loud, she was funny, a loving mother and a deeply committed Christian. She changed hearts and minds through her public championship of assisted dying rights.







## Adrienne Germain

### My last bold act would be to end my life at a high point of satisfaction and joy.

#### North America

*“In recent years, I’ve reflected deeply on my life, my contributions and shortfalls, as well as the people I cherish. My life has been rich, satisfying and, I’ve concluded, complete.”*

So begins Adrienne Germain’s final letter to the world she had so fiercely dedicated her career to improving.

Germain fought tirelessly to promote the sexual, reproductive, and economic rights of women, serving as the Ford Foundation’s representative in Bangladesh and co-founding the International Women’s Health Coalition. She was an early proponent of expanding development programs for women beyond simply handing out contraceptives or providing sterilization, arguing that reproductive health did not exist in a vacuum, and that education for girls and credit for women

to pursue business opportunities were critical to advancing women’s reproductive freedom.

In May 2022, at the age of 75, Germain chose to end her life using inert gas. She was neither terminally ill nor suffering irremediably, but, she wrote, the *“loss of physical health and stamina curtails my independence and my ability to enjoy life as fully as I wish.”*

She concludes her final statement with, *“My one frustration is that laws, social norms, and the medical establishment have prevented me from talking with loved ones in advance, and have also severely restricted my choice of a peaceful means and a secure place to end my life. I fervently hope that these restrictions will ease ...”*





## Rachelle Chapman

**This law is not coming for us.  
This law is including us.**

### North America

I believe everyone has the right to die with dignity if they have the unfortunate prognosis of being terminally ill. There are some advocacy groups who believe that this is some huge conspiracy to get rid of people with disabilities, like it's targeting them. In fact, this is not denying rights – it's expanding rights. I have a spinal cord injury and am paralyzed from the chest down. Therefore, I have a disability as well and I have something to say to them. You are fighting the wrong fight. There are so many other issues out there that include affordable housing and affordable healthcare – those are worthy causes, and I will stand with you on that. But when it comes to dignity in dying, it is not a disability-rights issue.

Anyone with a disability who has a problem with the right to die – for all people – makes no sense to me. There are a lot of things that people with disabilities don't have access to. We are discriminated against, and I'm all about fighting those things – but the right to die is not one of those issues.

If I were talking to a group of people with disabilities about medical aid in dying, I would tell them: *“This law is not coming for us. This law is including us.”*





## Cheryl Romaine

**I remain approved for MAID, and choose to keep that for when I make the decision to use it.**

### Canada

I became sick just over four years ago and the decline in my physical ability was rapid, brutal and, unfortunately, largely irreversible. Within a few months I went from having health and independence to being unable to walk up and down the stairs in my own home without assistance. I'm living with adhesive arachnoiditis and axial spondyloarthritis – both autoimmune-triggered inflammatory spine diseases – as well as numerous related conditions, all of which cause many neurological symptoms, the loudest of which is intractable pain.

I requested medical assistance in dying (MAID) for the first time in June 2019 but was denied because I didn't have a reasonably foreseeable natural death.

After Bill C-7 passed in Canada, I requested MAID for the second time and was approved. I remain approved for MAID, and I choose to keep that approval for when I make the very difficult decision to use it. I have shared my lived experience with the media, including a documentary on MAID in Canada. I do this to bring awareness to assisted dying and to help shine a light on areas of the MAID process that still need improvement.





*Ernest Frederiksen*

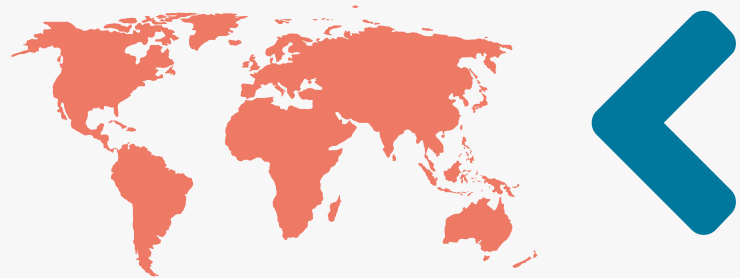
**MAID at its core is about choice and the ability to exert control over your own life and death.**

Medical assistance in dying (MAID) isn't about groups of people. It's about individuals. Individuals who are going through the most horrendous pain and are forced to choose between prolonged suffering and ending their life.

MAID isn't a matter of whether or not we die; it's a matter of how we die. Some people may choose to stay alive as long as possible based upon their beliefs and values.

I respect that point of view. Others, like myself, feel we have suffered enough, and wish to end the suffering we feel, even at the cost of our lives. Deciding to request MAID can be an extremely difficult decision, particularly for those like myself who are in intolerable pain, but who could live for many years or decades before dying of natural causes. MAID, at its core, is about choice, and the ability to exert control over your own life and death.

Canada







*John Scully*

**The mentally ill must be treated as equal to the physically ill. We suffer terrible and real pain.**

Canada

I am a former journalist who has incurable depression, general anxiety disorder, and PTSD from covering and filming wars around the world for over thirty-five years. I have explored many different forms of treatment and I have attempted suicide twice. It was discriminatory to exclude people with mental illness from their constitutional right to medical assistance in dying (MAID), and I support the Canadian government's decision to broaden access to assisted dying legislation to those of us who suffer from a mental illness in March 2023. The mentally ill must be treated as equal to the physically ill. We suffer terrible and real pain.

Canada must improve its support and services for people who suffer from mental illness but for some of us, modern psychiatric medicine has few or no answers. I share my lived experience publicly because, for too long, mental illness has been avoided, stigmatized and misunderstood.





*Marta Olynyk*

**Unlike the traumatic decades of chronic pain, my daughter's death at home was peaceful and painless.**

Quebec

When my daughter was diagnosed with an invisible genetic disease called Ehlers-Danlos Syndrome-Hypermobility Type in October 2015, she did deep research into this multisystemic syndrome caused by a defect in the collagen gene, learning that one day she might be wheelchair-bound, fed through a stomach tube, and blind. She instantly announced her desire to die with dignity, even though the existing law governing MAID in Canada only applied to people whose deaths were foreseeable. My daughter had zero quality of life, and was wracked with unmanageable pain, unable to sleep, or to eat adequately.

When the amendment to the MAID law passed in April 2021, I wondered if my daughter would be granted the right to die with dignity. I shuddered to think of the disastrous impact on her life in the event of a refusal.

I was horrified at the prospect of her taking matters into her own hands. The Canadian Association of MAiD Assessors and Providers (CAMAP), based in Victoria, B.C., gave me the name of a Quebec physician, who visited our home twice, in between consulting with a doctor familiar with EDS-HT. After a second MAID assessor's visit, my daughter was granted MAID. Unlike the traumatic decades of chronic, unmanageable pain, sleeplessness, malnutrition, and other medical horrors, my daughter's death at home by a heart-stopping injection was peaceful and painless. Thus ended the short life of my beautiful, multi-talented, funny, altruistic, and brave daughter (38) who, as I wrote in her obituary, "gave more than she received."





*Faith Sommerfield* (1940-2022)

## Choice is the vital underpinning of all fundamental human rights.

### North America

At any given moment of my life, can I experience joy, see beauty in a grain of sand, ambulate safely, engage in meaningful social interaction? Some might want to live until actually overcome by death; others, knowing the likely progression of their disease, might choose to view their life as complete before arriving at the precipice of “existence” where suffering, even if controlled, never ends and still others feel their lives have been completed in the absence of disease or terminal diagnoses.

In the words of St. Paul, “the best is yet to come.” Like many of life’s great unanswered questions, meaning is found through open discussion. Choice is the vital underpinning of all fundamental human rights, which protect all free people from political, legal, social, or medical abuse.

We are given free will at birth and should therefore absolutely possess the right to self-determination at the end of life.

The Completed Life Initiative seeks to empower every human being to exercise this choice through self-determination, by making the personal choices they want when convinced, absolutely, that their lives are complete. It is my hope that, in founding this initiative, we will expand our national policies within the United States and elsewhere to include compassionate and legally-protected approaches towards mortality.





## *Liza Passade*

### **I will keep sharing my father's story and honor his legacy.**

My father, Stephen Dunn, fiercely believed everyone has the right to control their own destiny and joined the Death with Dignity Board in 2016 to help pass medical aid in dying laws.

He not only had a passion for increasing autonomy for patients making end-of-life decisions, but also for life. His enthusiasm for living and enjoying all moments, big and small, spread to those around him.

In June 2019, MRI scans showed lesions on his spine. Subsequent scans quickly revealed metastatic lung cancer, which had spread to his spinal column, brain, and liver.

He went from cane to walker to wheelchair in a few weeks. Lesions spread from spine to hip.

He could no longer lie down in bed and resorted to sleeping in his wheelchair. Chemotherapy caused too much pain to be continued.

Toward the end, my father's quality of life was awful. His suffering was extreme. My dad died on October 16th, 2019, at only 79.

My dad had one last lesson to teach me in his dying days and upon his death: this cause is worthy. Death with Dignity needs to pass in New York right now – and everywhere else, too. We cannot keep expecting people to suffer needlessly at the end of life. I will keep sharing my father's story and honor his legacy as a valued board member of Death with Dignity, until all patients with terminal illness have the vital right that he never got.

**New York**







*Tamra Allred*

## Carrying on Kylie's fight for death with dignity.

Utah

My daughter, Kylie, was such a bright light from the beginning. If she wanted to accomplish something, she made it happen. Her fighting spirit persisted on the worst day of our lives up to that point. At only 25, Kylie was diagnosed with a very aggressive type of ALS.

Kylie was determined to keep fighting. She underwent every treatment offered. It was too much for someone her age, and I would have done anything to be in her place.

Kylie was a strong advocate for Death with Dignity way before her ALS diagnosis. So, I was not surprised that she brought up this option as she got sicker. If Utah allowed it, Kylie could have had a drastically different and better death in her home, surrounded by family.

She could have focused energy on the positive, knowing this option was there if needed. Instead, her energy was spent on sleepless nights, loss of bodily autonomy, and constant pain. I had to bathe her, brush her teeth, and watch her lose control over her body. Can you imagine going through this at such a young age? I can't.

My daughter died at only 27. My head is still in a fog. Every day is so hard. But I know Kylie would want me to continue fighting for Death with Dignity in Utah and all other states where patients who are going to die can't make this choice. And I am.





*Dinah Magnante* (Lawyer)

**A daily fight so that laws are sanctioned to expand the right to die with dignity.**

I fight daily so that in Argentina and Latin America laws are sanctioned to expand the right to die with dignity, and so that patients' autonomy and sense of dignity are respected. I help spread this topic to professionals and citizens, and I advise legislators so that these rights materialize in the country and are respected by the health system.

**Argentina**





*Camila Jaramillo* (Lawyer)

**Accompanying people in their autonomous decision has been the utmost experience of my life.**

As lawyer, I never thought that one of my professional purposes would be so full of life. Advising and accompanying people in their free and autonomous decision to die as they believe is a dignified death has been by far the utmost experience of my life. I am grateful and proud of the advocacy we do at DescLAB and how far we have come in advancing this affair in Colombia.

Dying with dignity is a human right, and that is why my efforts to defend it worldwide will continue. With certainty, I believe someday we will be sure that forcing someone to live is a form of torture. And we will be staggered by the fact that nowadays in most of the countries on this planet, it is illegal to support and aid someone who wants to end their life.

Colombia





*Josefina Miro Quesada Gayoso* (Lawyer)

**I fight so that dignified death is not taboo in Peru.**

Peru

I fight so that dignified death is not taboo in Peru. That freedom to decide on our lives and bodies is a guaranteed right. That what is an expression of dignity is not a crime and that the secular State becomes a reality in a profoundly Catholic country. I defend and accompany Ana Estrada, the first Peruvian to demand before a court her right to decide how, when, and where to die, according to her idea of dignity. I defend that there is no one more authorized than her to choose how much she has to suffer and how she has to live.







**Andrea Caballero** (Lawyer)

**I fight so that people find empathetic listening and never judgment.**

I fight so that people who have considered this option find empathetic listening and never judgment. I fight so that during the time of the intervention there is absolute respect for each person's concept of life and death with dignity. I fight so that this person, who is making one of the most complex decisions that someone can make, finds a safe place where he can talk about his most intimate fears, finding relief from his suffering at least for a few minutes.

**Colombia**





*Lucas Correia*

## Tackling the barriers people face when it comes to medical assistance in dying.

I fight every day to make the right to die broad and deep all over Colombia and Latin America. I believe every person can decide how and when to die, according to their idea of dignity. I work to tackle the barriers people face everyday when it comes to medical assistance in dying and for health systems to transform themselves into systems that care and support autonomous decisions along the life-course.

Colombia





**Elisa Lisnofsky** (Creator/Administrator of the Facebook Page “Euthanasia Rights and End of Life”)

**I dream and work so that sovereignty over our lives is never taken away from us.**

I am a mother who, three years ago, lost her daughter to cancer. At the end of her life, she requested an end to her suffering, but she turned out to be a victim of therapeutic cruelty. Her agony, cruel and useless, sealed my conviction to fight for the right to die with dignity in Argentina. As a result, a citizen organization was born that has more than three thousand wills from every corner of the country and other countries of the world. With them, I dream and work so that sovereignty over our lives is never again taken away from us. We are transforming personal pain into a collective struggle, as our Mothers and Grandmothers from *Plaza de Mayo* taught us.

Argentina





**Martha Peña Preciado** (neurologist at the ALS Clinical Care Center, Roosevelt Institute)

**So that patients can decide freely and have their definition of dignity and suffering.**

Every week for the last 17 years, I have been treating people with Amyotrophic Lateral Sclerosis-ALS. As a neurologist, I must confirm the diagnosis and that they will die. And not that death that is pictured far away, but instead the one that forces one to say goodbye quickly. I talk to them and their families. I see them crying and feeling fear and hatred. I read the movement of his eyes. I accompany them to make good and bad decisions, to get tired and, sooner or later, die or get trapped in their body supported by a ventilator. The struggle is to accompany them, to communicate the best possible information so that they can decide freely and have their definition of dignity and suffering.

Colombia







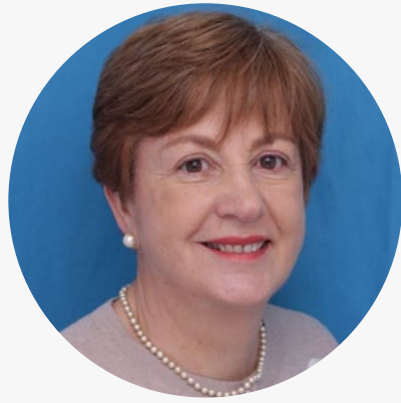
**Florencia Salgueiro** *(member of Empatía Uruguay)*

**I spread information so that the debate does not fall into misinformation and myths.**

I am part of a civil society organization working for the legalization of euthanasia in Uruguay. I spread information and evidence about why dying with dignity should be a right so that the debate on euthanasia does not fall into misinformation and myths. On a daily basis, I face campaigns based on fear and confusion, which seek to keep individuals silent. I dream of a future where people feel they have control over their lives until the last moment, where their will is not ignored, and where everyone has guarantees for a freer life and death.

**Uruguay**





## *Carmenza Ochoa*

### **I have had the privilege to accompany people who want this end-of-life option.**

#### **Colombia**

Witnessing the undignified death of people who could not accept their end and could not talk about it with their families or their doctors led me to work for a dignified death.

I lived very closely with a friend who had breast cancer with lung metastases. The doctor told her she could get better if she worked hard and avoided people with bad energy. Since she had adopted a child and I saw that she was not going to recover, I suggested that she write him a letter explaining why she had adopted him despite her illness. She got upset saying I had bad energy. She was in agony before she died. Her end of life should have been otherwise. I thought there had to be a way that people could die with dignity and accepting their end.

I discovered that possibility when I met the Foundation for the Right to Die with Dignity (DMD Colombia) where people could talk about death with their family, their doctors and their friends. They could learn about advance directives and their options at the end of life, including euthanasia that is allowed in Colombia. Working there I have had the privilege to accompany people who want this end-of-life option. Together with them, I go through the process that guarantees their right to die with dignity through help in dying when this is what they choose.





**Ana Estrada** *(Feminist activist)*

**I am free and my life and body now belong fully to me.**

I am a 45-year-old woman from Peru. I live with a generative disease. In 2019 I started writing a blog about my daily life. After a while, many people identified with my thoughts about the right to decide upon my body and life. Today, I am the first woman in Peru who has requested euthanasia. The procedure is not legal in my country but it was ordered by the judicial power. In the legal fight, I received the assistance of the Ombudsman Office. Since the judicial decision I am no longer afraid; I am free, and my life and body now belong fully to me.

Peru





## Dieter Harck

**My biggest fear is that when my love of life reaches the stage of fearing life, I will not be able to die.**

### South Africa

Dieter Harck, 72, was diagnosed in 2013 with a motor neuron disease which changed his life from being an ultra-marathon runner to barely being able to communicate, tie his shoe laces or button his shirt. Harck, together with Dr. Suzanne Walter, a palliative care specialist, is fighting in the High Court of South Africa for the right to assisted death.

In his evidence, he said, “my biggest fear is that when my love of life reaches the stage of fearing life, I will not be able to die.”

Harck’s condition is progressive; his muscles are weakening and eventually his diaphragm will stop working, so that he is unable to breathe.

Dieter Harck’s court case began earlier this year when his testimony and evidence was heard. The opposing side will be presenting its case towards the end of this year, followed by the court’s judgement. In court Dieter Harck presented his personal story to back up his legal claim to be allowed to choose how and when to die and for consenting medical practitioners to assist him.

Together with Walter, Harck set up a trust to fund any project or cause which seeks to develop the South African laws to allow both physician assisted suicide and physician assisted euthanasia. If the high court does not grant Dieter Harck an assisted death, Dignity South Africa will challenge the ruling in the Constitutional Court.





## Sean Davison

### I am not a murderer.

## South Africa

In a landmark case in South Africa, in 2019, the high court found Professor Sean Davison guilty of assisting three men to die. All three men had repeatedly begged Davison to relieve them of their suffering.

In a plea bargain agreement Davison only received three years' house arrest. This was far lighter than the mandatory life imprisonment he faced, and this became the first time in South African legal history that a person convicted of pre-meditated murder did not receive a jail sentence. This lenient outcome, was a consequence of Davison admitting in the plea bargain that he was guilty of murder as charged.

In June 2022, immediately after his house-arrest sentence finished, Davison declared, on the steps of the very high court that had convicted

him, that he had not committed any crime and was not a murderer. This statement showed brazen contempt for the court since his plea bargain was based on his admission to committing three counts of murder. Groups opposing euthanasia immediately called for his re-arrest.

The explanation for both Davison's apparent double-speak and his relatively light sentence is to be found in an untenable contradiction in the laws regarding assisted dying.

Although Davison's three-year house arrest sentence finished in June this year, his story continues to reverberate in media and legal circles in South Africa. Judging from the news media and social medias response to Davison's release, there is significant public support for assisted suicide in South Africa.







## Nikola Göttling

### Would you want this for yourself?

#### Austria

December 11, 2020 was a day of joy and accomplishment for Niki Göttling (52), a Vienna-based psychologist. On this day, the Austrian Constitutional Court lifted the ban on assisted suicide, ruling that the prohibition violated an individual's right of self-determination. The decision came after four affected stakeholders had filed a constitutional lawsuit, requesting removal of the provision. Niki's compelling plea in the courtroom contributed to this outcome.

Niki suffers from a progressive form of multiple sclerosis and depends on a wheelchair. Her physical abilities are steadily declining and she is in constant pain. Her outlook, she told the court, is bleak. At some point, when her arms become too weak and her hands lose their grip, she will need full care. Someone will have

to feed her and change her diapers. "That might go on for another 30 years... would you want that for yourself?" she asked the judges.

Niki wants to decide for herself when it is enough. "Knowing that I can end my life is an incredible relief, it is my back door out of an unbearable situation." And it may prolong her life since she doesn't have to seek help abroad before she becomes too incapacitated to travel.

When she became involved in the lawsuit, Niki joined the Austrian Right to Die Society ÖGHL, one of the driving forces behind the initiative. As a member of the Advisory Board, she is a convincing advocate for voluntary assisted dying and will continue to lobby as her energy allows.





## Staffan Bergström

### Not even world-class palliative care can alleviate all suffering.

#### Sweden

Staffan Bergström, a Swedish medical doctor, is chairperson of the Swedish RTVD (Right to Die with Dignity) association. In July 2020 he publicly carried out the first medical assistance in dying to a terminally ill ALS patient in Sweden destined to end his life at Dignitas in Switzerland. Due to the pandemic the patient was denied access to the flight. Bergström decided to help the patient to end his life by handing over to him drugs that the patient himself ingested. Bergström then notified the police of his action but was acquitted one year later.

Bergström now waits for a “disciplinary” verdict as to whether he will be punished by losing his license to practice medicine. He has hitherto 52 years of impeccable work as a licensed medical doctor. There are two possible outcomes: loss of his license to practice medicine (which will lead to his appeal – if necessary – to the Supreme Administrative Courts and to the European Court of Justice) or his acquittal (which will lead to the acceptance of medical doctors performing medical assistance in dying under defined circumstances). Both outcomes will lead to continued intense public debate in Sweden and possibly abroad on the need to fully legalise medical assistance in dying.





*Ingrid Kuhlman*

## A person's last hours should not be at the mercy of the doctor's morals.

My father, who lived in the Netherlands, was granted euthanasia in 2002, only a few days after the law came into effect. Since then, I have campaigned for the right to assisted dying in Iceland. Witnessing my father's unbearable suffering during the last stages of his terminal illness evolved and strengthened my support for assisted dying.

I firmly believe that people should have the choice over their body and life and that the way a person spends his last hours should not be at the mercy of the doctor's morals. People should be allowed to self-govern their dying with dignity; their autonomy should be respected.

I was one of the founders of the Right to Die Society in Iceland in 2017 and have been the chairman since. The purpose of our society is to create awareness and bring forward discussion and education about assisted dying. I have shown unwavering commitment to bringing a law in Iceland that allows medical aid in dying by pushing politicians to discuss the matter. I have also actively worked on mobilising public opinion by writing numerous articles advocating for aid in dying. Currently, 77.7% of Icelanders support the practice of assisted dying.

Iceland





## *Mina Welby*

### **I will continue to commit civil disobedience until Parliament passes a law.**

Italy

If I hadn't met Piergiorgio Welby, my story would be different. We married in 1980. He was suffering from muscular dystrophy. We worked in his atelier as an art photographer and painter. He told me that he did not want to be tracheostomized.

In July 1997, he had respiratory failure and against his will I took him to the emergency room where he was tracheostomized. In 2002 we met Luca Coscioni, suffering from ALS, who founded the Luca Coscioni Association. Welby's health was deteriorating, but he had a dream: euthanasia! It became a forum, where news was published about world developments. Though he requested a living will from parliament, Italian politics was still backwards and civil society did not want to talk about the end of life.

Piergiorgio Welby died of sedation administered by Dr. Mario Riccio, accused of murder of the consenting. My testimony in court acquitted the doctor. After my husband's death I testified in public debates on issues such as the self-determination of the person, the choices of life and end of life, as well as adequate assistance to sick people and the independent life of the disabled person.

In 2017, Marco Cappato and I committed civil disobedience by accompanying Davide Trentini, suffering from multiple sclerosis, to Switzerland, where he obtained assisted suicide.

We were charged with incitement and aid to suicide, punishable with a sentence between 5 to 12 years. The court acquitted us. After the judges' ruling, I said I would continue to commit civil disobedience until Parliament passes a law that protects and regulates the end of life.





## *Jérôme Sobel*

### Sought to change perspectives concerning the rights of patients to determine their end of life.

#### Zwitzerland

Jérôme Sobel took over the presidency of EXIT ADMD French-Switzerland in 2000. He had been a member since 1986 believing that the fight echoed his personal views. Convinced that doctors have the confidence of the courts and that the latter enjoy authority in areas that go far beyond the limits of medical practice, he sought to change perspectives concerning the rights of patients to be able to self-determine their end of life. Having witnessed during his presidency many achievements reducing the limitations to carry out assisted suicide, he left his position as president in 2018. Approaching his own end of life, he sent the association the prescription for pentobarbital for which he himself signed, to facilitate, if necessary, setting up support for his own end of life.

During his tenure, Jérôme Sobel achieved tremendous inroads and assisted suicide in French-speaking Switzerland would not have received the social recognition it has without his commitment.







## Michael Irwin

### Being able to help others in these situations is a great privilege.

At 91 years, Michael Irwin has begun to contemplate his life and death, “It is natural that I should be considering how my life could possibly end. I have had a wonderful life – fortunately with few regrets – and now I am planning my own departure.”

Michael worked as a physician for United Nations system for thirty-two years, of which ten years as Medical Director of the United Nations in New York. After retiring in 1990 back to the UK he became highly involved in campaigning for legalized doctor-assisted dying. From 1996 to 1999 and again 2001-2003, Michael was the Chairman of the Voluntary Euthanasia Society (now known as Dignity in Dying). In 2009 he founded the Society for Old Age Rational Suicide (renamed My Death My Decision in 2019).

Internationally, he was very involved with the World Federation of Right-to-Die Societies, serving as Vice-President from 2000 to 2002 and then President for the next two years.

Between August 2005 and February 2016, Michael Irwin accompanied five seriously-ill individuals from the UK to Switzerland, “Being able to help others in these situations is a great privilege and this will certainly be an option for myself.”

UK





## *Claudette Pierret*

### Who will have the courage to stop the hypocrisy in France?

Living close to Belgium, where euthanasia has been possible since 2002, Claudette has helped many French patients over the years to cross the border to access this serene and chosen death that is still illegal in France. She also sometimes refers patients to a Swiss association. Luckily, these two neighbouring countries allow people to end their lives according to their own wishes and without being forced to wait for the terminal phase of an incurable disease or to live with handicaps that are too heavy to bear.

She does not agree with the supposed “experts” (mostly well-meaning) who denigrate the laws of the countries that decriminalize euthanasia or assisted suicide and want to decide for others. Some years ago, her father died in poor conditions while in home palliative care.

With great humility, Claudette listens to the sick, helps them build their case and sometimes accompanies them until the last minute.

Recently, she wrote: *Who will have the courage, in 2022, to pass a law that will legalize euthanasia and make death a little more humane by stopping the current hypocrisy in France?*

Claudette Pierret is a member of *Le Choix-Citoyens pour une mort choisie* Honor committee.

France





## Nicolas Bonnemaïson

### A man wrongly condemned.

#### France

Nicolas Bonnemaïson (b.1961) was the first doctor to pass the University Diploma of Palliative Care in the year of its creation at the Faculty of Bordeaux (early 1990s). He became an ER doctor after setting up the Mobile Palliative Care Unit (UMSP) project and was also in charge for the organ and tissue harvesting unit for several years. Nicolas was Chief of Emergency Services and EMS, then Chief of “Pôle Urgences-Réanimation”. This enabled him to create the short-term hospitalization unit (UHCD) at the Bayonne hospital.

It was within this unit that he was arrested on August 10, 2011 and immediately taken into custody for murder, after helping a very elderly patient with massive brain hemorrhage to die. He was banned from practising medicine and stood trial at the Assizes in Pau in June 2014 (acquitted) and then on appeal in Angers in October 2015 (two years suspended sentence).

Although acquitted in the first instance, and despite the disciplinary chamber of the Nouvelle-Aquitaine Regional College of Physicians twice requested his reinstatement, seven years after Nicolas Bonnemaïson is still prohibited from exercising his profession by the National Council of the College of Physicians.





*Phil Newby*

## When is the right time to die?

UK

Phil Newby, who suffers from Motor Neurone Disease, has for many years been at the forefront of the campaign for a compassionate assisted dying law for the UK.

He crowdfunded a case asking High Court judges to review and balance expert evidence for and against assisted dying, but the English courts (both in Phil's case and others) have made it clear that Parliament must address this, not the courts.

Phil always wanted the chance to have this discussion in UK courts. While he has yet to get the chance, he has spoken regularly in public and to the media on the subject as well as creating his own podcast series called Kill Phil: Debating Assisted Dying without the Sh\*t Flinging <https://shows.acast.com/kill-phil>. This podcast follows Phil's journey living with an incurable and life-ending illness, and he unpacks some of the key debates around assisted dying with some help from experts and campaigners.

Through this medium, he is keen to foster dialogue with opponents, most recently with one of the most vocal disability campaigners in the UK.





## Ramón Sampredo

### For whom thousands incriminated themselves in his self-deliverance

Spain

In August, 1968, Ramón Sampredo, a 25 years old sailor, jumped into the sea near his home in Xuño, Galicia. He miscalculated the depth of the waters and broke his neck against the sea floor. He was paralyzed, bedridden. As he said frequently, his accident made him “a living head glued to a corpse”. He became the first person in Spain to make his will to die public, and the legalization of euthanasia a public debate.

Because of his quadriplegia, Ramón Sampredo couldn't take his own life. In 1993, already 50 years old, he took his case to justice. He requested a way for his doctor to provide him with the means to end his life. His petition was rejected. He wrote two books, “Letters from Hell” and “When I fall”, with letters and poems, all revolving around the same idea: his wish to a freely decided death.

In 1998, he took his own life by drinking a glass of water mixed with potassium cyanide. He recorded a video of his agony and death, and made sure it reached the public. When the judge investigating his death indicted his close friend Ramona Maneiro, thousands of citizens incriminated themselves as coparticipants in his self-deliverance. The case was dismissed for lack of evidence and nobody was convicted. Once the statute of limitations expired, Maneiro acknowledged her involvement. She did it “for love”.







*David M. Hoffman*

**I wish that all patients may enjoy life fully until prolonging it is no longer a joy.**

**New York**

Justice Cardozo proclaimed in 1914, “every human being of adult years and sound mind has a right to determine what shall be done with [her] own body.” To be a proponent of the right-to-die is to be a guide to those whose moral, legal, and medical convictions regarding an end of life experience ought to remain solely the choice of any individual whose life has been lived and which they deem to be completed.

Much academic and clinical debate centers upon the point at which one’s life is completed – or complete enough. In my decades-long devotion to clinical bioethics, intersecting law, medicine, and ethics, the equal protection of all patients is foremost in my mind. Canada

sees no distinction between self-administered and clinician-administered aid-in-dying; yet the United States naively embraces that distinction, restricting self-administration, which precludes many patients who suffer from debilitating neurodegenerative diseases such as ALS, and pushes them toward early intervention. I fervently wish that all patients, within the United States and beyond, have access to support by advocates such as myself and the organizers of the Completed Life Initiative, to see life as a precious and scarce resource – to be enjoyed fully, until prolonging life is no longer a benefit or joy.





*Pepe Valencia*

## What I consider a real act of love is practicing euthanasia.

Mexico

The most important right we have is the one over our own death. When I started my practice, more than 49 years ago, it was difficult to me to accept that there's a moment when the medicine must stop and allow the patient's nature to take their life reins. Usually, I fought to keep him alive no matter how.

I was 28 and was in charge of the ICU in a general hospital, one night, I wondered if all my 10 patients were alive or just breathing and their heart pumping because of the medical procedures. Hours later I asked to practice an EEG (electroencephalogram) to all of them. Three of them showed brain death! Then I spent days, months thinking it would be correct to disconnect a patient (human being with special needs) in this situation. Hundreds of patients whispered: – “Please doctor stop this, it's not life!”

The only one who must decide in these cases is the patient; usually everyone decides instead. When the human being in that bed at a hospital or at home (home is the best place to die) says, “no more!” is exerting the most important right and must be respected. What's next are expressions of love and compassion which will lead the patient to die, stopping medical support, using palliative sedation, but what I consider a real act of love is practicing euthanasia. It is so gratifying see their face resting peacefully, with no expression of pain and vibrating at the rhythm of the second most important event of their lives.

