



THE OFFICIAL NEWSLETTER OF DYING WITH DIGNITY CANADA

VOICE FOR CHOICE



insights that empower us in our mission to tear down the unfair barriers to access that are rampant in the healthcare system.

For Jan, it was the death of her father, 84-year-old Ian Shearer, that prompted her to raise her voice. Dying from kidney failure and sepsis, and in writhing pain from spinal stenosis, Ian requested an assisted death this summer while at Vancouver's St. Paul's Hospital. Citing its religious affiliation, the hospital refused to allow him to die with the help of a physician while in its care.

Like other dying Canadians who've found themselves in a public healthcare facility that refuses to allow assisted dying on-site, Ian faced a choice: stay at St. Paul's and endure the pain, uncertainty and possible indignity that his "natural" death had in store; or ask to be transferred to another hospital in order to exercise his *Charter* right to a peaceful passing. He chose to move hospitals.

The ensuing transfer would have been hard for anyone at end of life, but for Ian, it was excruciating. He "yelled out in agony" as he was lifted from his bed at St. Paul's into a stretcher, Jan said. During the ambulance ride to Vancouver General Hospital, he "cried out going over every single bump."

The horrors Ian endured in his final days led Jan to approach the *National Post* to tell her father's story.

"Dad's last day with us, his last hours of life, could have been so peaceful and loving for him and for those of us by his side," she told DWDC, speaking about her motivation to go public.

"Now, I live with this haunting memory.

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After requesting an assisted death in a hospital that prohibits it, Vancouver's Ian Shearer had to be transferred to another facility in order to get his wish. (Courtesy of Jan Lackie)

The power of personal stories

By sharing their individual experiences, two courageous Westerners have exposed one of the biggest obstacles facing Canadians who want to exercise their right to a peaceful death.

One is a birth doula and children's hospital volunteer in Calgary, Alta., the other a family physician in B.C.'s sleepy Comox Valley.

Both have seen up close the human cost of unjust policies on assisted dying. Both refused to stay silent about what they observed.

By sharing their experiences publicly,

Jan Lackie and Dr. Jonathan Reggler have ignited a national dialogue about one of the most troubling obstacles facing dying Canadians who want to exercise their right to an assisted death. In the process, they have furnished Dying With Dignity Canada with invaluable intelligence on the ongoing implementation of legal assisted dying after the passage of Bill C-14 — key

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Dying With Dignity Canada is a member of the World Federation of Right to Die Societies.

MESSAGE FROM THE CEO

Looking to our North Star

As DWDC's work becomes broader and more complex, we rely on the personal stories of our supporters to keep us on course, writes DWDC CEO Shanaaz Gokool.

While I was in Alberta in September, our Edmonton and Calgary chapters each hosted community panel discussions on assisted dying. They invited Ministry of Health officials, representatives from Alberta Health Services and, of course, DWDC supporters to participate.

These wouldn't have been DWDC events without hearing moving personal stories. I was humbled listening to Lisa Peters-Schmidt speak about her late sister, Lee-Anne, who had Huntington's disease. Lee-Anne was around 30 when she ended her own life — after repeated attempts and with the knowledge that she wouldn't qualify for an assisted death in Canada. I was also struck by Evie Wallace's account of her husband Hugh's assisted death in April. And I met Mary Valentich, who had accompanied her dear friend Hanne Schafer from Calgary to Vancouver, where Schafer received the first court-authorized assisted death in Canadian history.

Speaking with Lisa, Evie and Mary reminded me of a fundamental principle in human rights work: the individual — their words and their stories — must always inform the advocacy work, never the other way around. And through their powerful stories and their support of DWDC, these strong women continue to help build the legacy of their loved ones as we fight for better access to medical assistance in dying (MAID) in Canada.

But what exactly does "fighting for better access" mean, and how do we approach achieving that goal? For decades, DWDC was almost singularly focused on winning comprehensive legislation that would ensure assisted dying is allowed in Canada. However, the passage of Bill C-14 has presented our movement with a cornucopia of complex new challenges. A single-minded, one-size-fits-all approach to solving them just won't do.

Our work is changing accordingly. Identifying gaps and barriers facing

individuals who want access to the country's new assisted dying law has emerged as a vital part of our day-to-day. We have been on the lookout for instances of healthcare practitioners who refuse to provide an effective referral and policies that force residents to leave their local hospital in order to access MAID, to give some examples. These are critical roadblocks for many of the most vulnerable and physically compromised patients who want access to an assisted death under Bill C-14.

In addition, we continue to educate Canadians about patient rights and the importance of advance care planning, and our Personal Support Program remains a rock for people navigating their end-of-life options. These are areas of our work that have now expanded to include healthcare practitioners who are providers of, or assessors for, MAID.

But don't think for a second that we've given up on pushing for assisted dying rules that respect the *Charter* and the Supreme Court's decision in *Carter v. Canada*. We emphatically support the *Lamb v. Canada* court challenge against the overly restrictive, unconstitutional eligibility criteria in Bill C-14. We will continue to speak out loudly on how the new law infringes upon the rights of Canadians, and plan to participate in future legal challenges and consultations on these issues.

Yes, each of these endeavours requires its own tailor-made strategy, but they all serve a single overarching objective: ensuring Canadians have a full range of compassionate end-of-life options and empowering them, through education and personal support, to see their final wishes through. Fundamentally, that's who we've been, it's who we are, and it's where we're going. I thank Lisa, Evie and Mary — and indeed all DWDC supporters who've shared an intimate personal story with me — for showing us the way.



Shanaaz Gokool is DWDC's CEO.

Exposing major barriers to access

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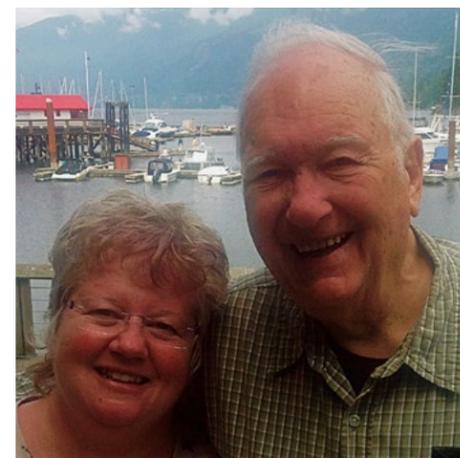
"What Dad had to go through to exercise his legal right to die is something no one should ever have to experience."

The article sparked an outpouring of outrage and sympathy nationwide because it was the first news story to truly illustrate how much harm hospital bans on assisted dying can inflict upon Canadians at end of life. With its vivid detail, Jan's account forced readers to stop and think to themselves, *how would I feel if I had been in Ian's or even Jan's shoes?* Her story put a human face on what had been, up until then, a hidden problem.

Dr. Reggler's decision to speak out came not from a place of personal grief but instead from a sense of professional duty. A general practitioner on Vancouver Island, he served until recently as a member of the ethics committee at St. Joseph's General Hospital, another publicly funded healthcare institution whose board of directors voted against allowing assisted dying on-site.

The policy is particularly egregious, Dr. Reggler said, because St. Joseph's is the only acute-care hospital in the Comox Valley. As a result, residents who want an assisted death either have to go home or suffer a 45-minute ambulance ride to the nearest hospital.

"We've started having cases where people [who want an assisted death] are having to go home when they are too sick



Jan Lackie (left) with her late father, Ian Shearer. (Courtesy of Jan Lackie)

to go home," he told DWDC in November. "Or they have to go to a hospital where they will have doctors they haven't met before and that is far away from where their families live. It's unnecessary except for the hospital's policy."

In the fall, Dr. Reggler decided enough was enough: he could not in good conscience continue to sit on the ethics committee of a publicly funded hospital that — despite his protestations and those of some colleagues — continued to obstruct patients' rights. And in an Oct. 18 letter to St. Joseph's President and CEO Jane Murphy, he announced his resignation from the committee.

"This is the cruelest hospital policy that I have ever encountered in over thirty years of medical practice," he wrote, after laying out in detail the reasons for his decision. "St. Joseph's motto 'Care with Compassion' rings hollow now."

Dr. Reggler's resignation attracted media attention on Vancouver Island and across Canada. He spoke with reporters from *The Globe and Mail*, the CBC, the *Victoria Times Colonist* and two community papers in the Comox Valley, becoming the first doctor with privileges at a faith-based but tax-funded hospital to speak out publicly against the facility's ban on medical assistance in dying. He also implored other physicians to follow his lead, a call we at DWDC hope will reverberate across Canada.

"The message I want to give colleagues is that we as a profession have always challenged unethical and immoral stances taken by organizations that affect our patients," explained Reggler, a member of DWDC's Physicians Advisory Council.

"When the organizations we're working within are acting unethically towards the people we care for, we should be saying it, challenging it and stopping it."

Impact on DWDC's work

By raising their voices about unfair

hospital policies, Jan and Dr. Reggler have helped inform DWDC of the scope and scale of the challenges we face in working for fair access to assisted dying across Canada.

Jan's story prompted the organization to issue a statement calling on the provinces

and territories to ensure that all publicly funded hospitals, hospices and long-term care facilities permit assisted dying on their premises. We have also launched a series of digital advocacy tools to help our supporters put pressure on their provincial leaders.

"We are incredibly grateful to Jan and Jonathan for having the courage to speak out against the injustices they've observed," said DWDC CEO Shanaaz Gokool.

"Without their actions, Canadians might still be in the dark about the injustice of allowing hospitals that use public funds — and have a duty to provide public healthcare in their communities — to impede rightful access to assisted dying." These human rights violations are not limited to faith-based-but-publicly-funded healthcare institutions, Gokool stressed. In Ontario, for example, *any* public hospital can opt out of the provision of assisted dying. In addition, many dozens of hospices and long-term care homes that care for dying individuals have bans on assisted dying, arguing that the practice is not compatible with the principles of good palliative care.

"We must act now to make sure that Canadians aren't stuck with a healthcare system where assisted dying is only available to people who live in particular communities or have the financial resources and the family support to die comfortably at home," said Gokool.

"Unless we make ourselves heard now, while the dust is still settling on Bill C-14," she added, "barriers to access that should only be temporary may become set in stone."

—Cory Ruf

New guidelines allow DWDC volunteers to serve as independent witnesses for assisted dying

Developed with the help of our Victoria chapter, the policy addresses an unexpected barrier to access facing Canadians who want to exercise their right to assisted dying.

In the wake of the passage of Bill C-14, harmful barriers to assisted dying access continue to present themselves. While some barriers were expected, one in particular caught us by surprise.

Under the new law, an individual applying for an assisted death must have two independent witnesses sign their request form. But because the rigid criteria for who can qualify as an independent witness exclude anyone who stands to benefit financially from the applicant's death, it often disqualifies people a dying individual would typically turn to, like one's children or spouse. To add to that, healthcare practitioners who are involved with the individual's care can't serve as witnesses either. This requirement has led to unnecessary delays, exposing dying individuals to additional unwanted suffering and further complicating the already tense and complex process of requesting medical assistance in dying.

This summer, Dying With Dignity Canada began to hear from doctors and patients who, without any viable independent witnesses, were unable to proceed with requests. Uniquely positioned to address this surprising barrier to access, DWDC jumped into action by developing a policy that would allow our volunteers to act as independent witnesses in cases where the applicant has no other options.

Turning to the expertise of our supporters

To ensure volunteers know what to expect when they witness, DWDC sought to produce a how-to guide that would clearly define their role in the process.



Jeffrey Brooks was instrumental in the creation of DWDC's new independent witness policy. (Courtesy of Jeffrey Brooks)

"Since it's such a new role that some of our people are taking on, we wanted to provide them with guidance and things to consider when doing this sort of work," said Kelsey Goforth, DWDC's national volunteer and events coordinator.

"The guide outlines things from a process perspective — making sure volunteers know what the steps are — and from an emotional perspective, ensuring they know how to deal with this situation."

DWDC turned to the expertise of Jeffrey Brooks and Ellen Agger, co-chairs of our Victoria chapter, to develop the guide, which has been distributed to all of our chapters. Brooks, a long-time palliative care volunteer, said he wanted to introduce protocols and procedures that would give volunteers straightforward guidance on how to serve as an independent witness.

Brooks said he and Agger, along with fellow Victoria chapter leaders Dr. Adrian Fine and John Priddle, felt motivated to lay the framework for the new volunteer policy after receiving panicked phone calls from healthcare providers who needed an independent witness — and fast.

"When [Bill C-14] became law, we turned our focus on everything to do with

access," Brooks said. "As a chapter, we asked, 'How do we support the doctors in being able to provide assisted dying with as little fanfare and as few problems for them?'"

So far, 29 volunteers across Canada have expressed a willingness to serve as independent witnesses. Of those volunteers, 10 have actually acted as independent witnesses in a total of 23 cases. In most cases, DWDC volunteers were the sole independent witnesses involved in a request.

A flawed requirement

Though DWDC CEO Shanaaz Gokool is glad the organization has developed the independent witness policy, she hopes it won't be needed in the future. That's because the independent witness requirement is, in the eyes of DWDC, unnecessary and puts Canadians' right to privacy at risk.

"This was intended as a safeguard, but having someone drop by to sign a piece of paper does little to ensure that a request for assisted dying is legitimate," said Gokool. "It does, however, expose people's most private healthcare matters — sometimes to complete strangers — at perhaps the most delicate moment in their lives."

She said healthcare institutions can help ease the burden on patients in the short term by allowing employees — those who are not involved in an assisted dying applicant's treatment or personal care — to serve as independent witnesses.

"But ultimately, we urge federal leaders to re-visit this requirement and respond accordingly."

—Rachel Phan

Personal stories drive assisted dying documentary 'Road to Mercy'

DWDC supporters and staff make cameos in the film, which debuted on CBC TV in October.

It was an opportunity we just couldn't pass up.

In 2015, Dying With Dignity Canada received a message from a group of filmmakers looking to create a documentary that would challenge viewers to think more deeply about assisted dying. Led by award-winning director Nadine Pequenezza, the team sought to produce a film that would examine the coming legalization of assisted dying in Canada by focusing on the individuals most desperate for choice.

"They asked me whether DWDC could put them in touch with Canadians who were waiting for change and were willing to share their plight with the rest of the country," said Cory Ruf, DWDC's communications coordinator. "Sensing a genuine desire to go deep and get the story right, I knew in an instant that I would want to help them out however I could."

The resulting documentary, *Road to Mercy*, premiered on *CBC Firsthand* in early October. The film offers a compassionate take on the issue of assisted dying, ultimately treating the end-of-life option as a merciful act while also suggesting that the practice represents Canada's "journey into the furthest ethical frontier."

While a number of documentaries have covered the right-to-die movement in Canada, *Road to Mercy* is the first to take a deep dive into the recent debate over this country's new federal assisted dying legislation. To fuel the discussion, the film features the stories of individuals who want access to assisted dying, but for very different reasons. One participant was Amy De Schutter, a 29-year-old



At the DWDC-premiere of *Road to Mercy*, director Nadine Pequenezza poses, bouquet in hand, alongside assisted dying advocates who appeared in her film. (Cory Ruf)

woman from Belgium who has suffered from mental illness for more than half her life. Another was the late John Tuckwell, a long-time Alberta government spokesperson who had ALS and who died before the release of the film.

"In these very early days, we know that the way assisted dying is talked about and explained in the mainstream will have a significant impact on how accessible and available it is moving forward," Ruf said. "If people see the very real trials and tribulations that some Canadians have to face when weighing their end-of-

life options, they might take a different perspective on who should ultimately be able to access this right."

DWDC CEO Shanaaz Gokool and Personal Support Manager Nino Sekopet appear in the full 83-minute director's cut of the documentary. They — along with Jack Brown, an Ontario man grappling with early-onset Alzheimer's, and his wife Riemke — speak passionately about why Canadians should be allowed to make advance requests for assisted dying. However, most of this narrative was cut from the CBC broadcast, as the film had to be edited down to fit *Firsthand's* one-hour timeslot.

To celebrate the launch of the film, DWDC hosted a special screening of *Road to Mercy* on

Oct. 5, the day before its television debut. More than 100 Toronto-area supporters came out to a downtown theatre to watch the film. They were then treated to a live Q&A discussion with director Pequenezza and five people who appeared in the documentary. Gokool, Sekopet,

patient rights advocate Maureen Taylor, and John Tuckwell's sister, Cathy, were in attendance, as was De Schutter, who had flown in from Belgium to help promote *Road to Mercy's* release.

"Having all those people together in one room was just unbelievable. That's something that will never happen again," Ruf said.

"It was an incredible experience to be involved in a project in a small way at its genesis and then to celebrate its release with the people who made it and the people whose stories brought it to life."

—Rachel Phan



Barriers to assisted dying access are rampant across Canada, from coast to coast, in communities large and small. We know that. But until we have a clear picture of the scope and scale of these problems, we are powerless to root them out of our public healthcare system.

Exposing these injustices is a mammoth undertaking. We simply do not have enough staff members or a big enough budget to do it on our own. But we do have you, the legions of Canadians who support assisted dying and believe fair, timely access should be available to every eligible Canadian, no matter where they live.

That's why we're excited to announce the launch of our Shine a Light Campaign. It's an opportunity for our supporters to bring abuses to Canadians' end-of-life rights out of the shadows, for all to see.

Introducing the Shine a Light Campaign

How you can participate:

1

HELP MAP OUT BARRIERS TO ACCESS

Desperately ill individuals across the country want information about the choice of a peaceful death, but don't know where it's available or whom to ask for help. They need a map. And with your help, DWDC is going to build one for them.

Right now, we are mobilizing our supporters to call every hospital, hospice and long-term care home in their respective communities, to find out their policies on medical assistance in dying. The intelligence we gather will be plugged into an interactive online map showing which facilities allow assisted dying, which ones forbid it and which ones have no formal policy whatsoever.

Plotting out these disparities will not only help dying Canadians and their families more easily navigate the healthcare system; it will also put heat on institutions and practitioners who refuse to respect patients' rights.

2

SPREAD THE WORD ONLINE

The Shine a Light Campaign is about more than just scoping out unfair barriers to access. It's also about bringing them to the attention of the general public and taking a stand in defense of Canadians' rights. As a result, we are launching a series of Shine a Light digital actions to help you spread the word. Some will centre on asking powerful decision-makers to remove unfair barriers to access for assisted dying. Others will aid you in mobilizing your online social network to join the campaign. The first of these tools are already active on our Shine a Light webpage, and more will go live in the weeks to come.

3

SUBMIT A TIP

Are you an employee or a volunteer at a healthcare institution that is impeding patient access to assisted dying? Let us know by sending an email to shinealight@dyingwithdignity.ca or by submitting a tip on our Shine a Light campaign website. If appropriate, we will follow up with the facility directly, without identifying you as the source of the lead.

Individuals and families who themselves are encountering barriers to access are encouraged to contact DWDC's Personal Support Program. Nino Sekopet, the program's manager, provides information and emotional support to Canadians who are exploring their end-of-life options, and he can answer your questions about your rights as a patient. To contact Nino, email him at nino@dyingwithdignity.ca or call him toll-free at 1-844-395-3640. Your information will be kept strictly confidential.

4

SHARE YOUR STORY

Not a day goes by without us marveling at the passion and pluck of our roster of dedicated volunteers. It is truly infectious. And we hope that by profiling their contributions to breaking down barriers to assisted dying access, it'll inspire others to pitch in. Volunteers who wish to share personal stories on our website about their involvement with the Shine a Light Campaign should contact DWDC Communications Coordinator Cory Ruf at cory@dyingwithdignity.ca.

For more information on how you can take part, go to Dyingwithdignity.ca/shinealight.

Examples of unfair barriers to access:



Hospitals that don't allow assisted dying on their premises.



Long-term care homes and hospices that don't have formal policies on assisted dying.



Medical practitioners who won't discuss a full range of end-of-life options.



Physicians who refuse to provide referrals for assisted dying.

A Good Death is a good read

Journalist Sandra Martin's new book is a thorough, engaging take on the rise of the right-to-die movement in Canada, writes retired Lethbridge, Alta. doctor David Amies.

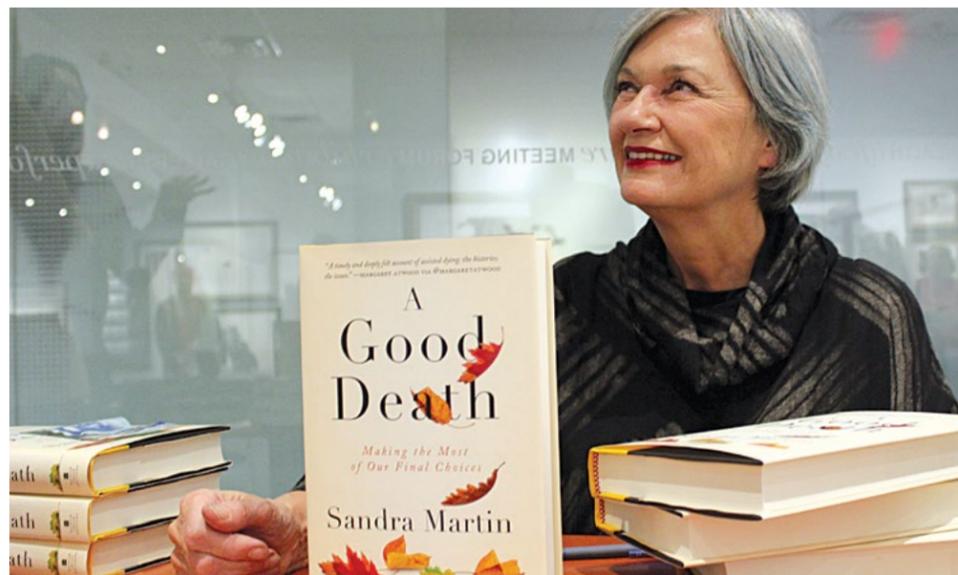
In her new book, *A Good Death: Making the Most of Our Final Choices*, journalist and author Sandra Martin writes an excellent and comprehensive account of the story about medical aid in dying, as it is has come to be known in Canada, or physician-assisted suicide, the term more widely used elsewhere.

Martin traces the story from its origin in Switzerland in 1942 right up to the introduction of federal legislation in Canada earlier this year. Her account outlines the arrangements now in place in Belgium; the Netherlands; and the American states of California, Washington and Oregon; and she even finds space

'As the tale unfolds, the book introduces us to the heroes, heroines and even the villains who have played their parts in bringing medical aid in dying out of the shadows as a subject that can now be discussed freely and openly throughout the Western world.'

to mention the short-lived legislation in Australia's Northern Territory.

As the tale unfolds, the book introduces us to the heroes, heroines and even the villains who have played their parts in bringing medical aid in dying out of the shadows as a subject that can now be discussed freely and openly throughout the Western world. Martin introduces us to Derek Humphry, author of *Final Exit* and founder of the Hemlock Society; Elizabeth Kübler-Ross, Swiss-born psychiatrist; Cicely Saunders, founder of the hospice movement in the United Kingdom; Véronique Hivon, lawyer and member of Québec's



Journalist and author Sandra Martin promotes her new book at a DWDC-organized event in Toronto on Nov. 2, 2016. (Cory Ruf)

National Assembly, whose efforts were instrumental in getting right-to-die legislation passed in the province; Sue Rodriguez, victim of Lou Gehrig's disease, whose Supreme Court challenge to the then-existing assisted suicide laws narrowly failed in 1993; and Kay

Carter, whose successful application to the Supreme Court in 2015 led to the introduction of right-to-die legislation in Canada. These larger-than-life players in the story of assisted dying are joined by many other noteworthy patients, politicians and physicians in Martin's tremendously comprehensive book. The villains, on the other hand, could be said to include the Catholic Church; bioethicist Margaret Somerville; and Dr. Jack Kevorkian.

I was especially interested when Martin drew parallels between what's currently happening with assisted dying and the evolution of the laws surrounding

therapeutic abortion. She mentions that it was once deemed unacceptable for a woman to have the right to exert control over her own fertility. Similarly, right-to-die advocates now fight for suffering individuals to have the right to exercise control over their own deaths. Equally noteworthy is the fact that the same organizations who now argue strenuously against right-to-die laws are the same ones that oppose legal abortion.

Not an academic treatise

A Good Death — which was released in April, only days before the federal Liberals tabled their assisted dying bill in Parliament — comes with an extensive bibliography containing more than 70 references to books and articles, and more than 20 legal case citations. Martin's writing style is crisp, clear and unemotional. This book is not an academic treatise; it is not meant to be. In spite of that, it would be an admirable resource for candidates for master's or doctorate degrees in the fields of public health, social science, anthropology or law who have chosen to carry out research into some aspect of medical aid in dying. Within its pages they would find an admirable and complete record of the story to date.

In summary, I strongly recommend this book and wish to thank Sandra Martin for her hard work in publishing it.

Why the 'fight for Hanne' must continue

Last winter, Hanne Schafer became the first Canadian outside Quebec to access a legal assisted death in her home country. She died wanting her story to be told, so it could be used to help others looking to make the same choice, writes her friend Mary Valentich.

On Feb. 29, my friend Hanne Schafer became the first person outside Quebec to end her life with a physician's help, after obtaining a court exemption to do so. In April, a judge lifted a publication ban on her case, allowing her story to be told.

Hanne and I met 38 years ago when we lived in the same townhouse complex in Calgary. She was bright, articulate, loved discussing issues, and enjoyed music and films. She was a psychologist; I was a social worker, as was my late partner. With much in common, a great friendship grew.

Three years ago, Hanne was diagnosed with ALS. We knew the grim reality facing her. Valiantly, she and her beloved husband, Daniel Laurin, embarked on living life even more fully — ballroom dancing, hiking, camping, travels to Europe, the United States, Mexico. But nothing could offset the dreaded scenario. By June 2015, she had made her decision to seek a physician-assisted death, but Daniel was not yet ready. She waited.

In late August, Hanne informed her sister and other family members in her native Germany of her decision. She took the lead and included all of us, to the extent that we wished, in her search for resources. We found that only Switzerland offered physician-assisted death to non-residents. We applied to Dignitas and Life Circle; both were ready to proceed. But after learning of the possibility of a court-approved exemption in Canada, and knowing how

difficult it would be for her to travel, we moved in this direction.

Overcoming obstacles

The frustrations were many: finding a willing physician, a lawyer, a funeral company; court postponements; the



Calgary's Hanne Schafer died with the help of a physician on Feb. 29 in Vancouver. (Courtesy of Mary Valentich)

actual court hearing; the logistics of travel arrangements; the physicians in Vancouver being blocked at the last moment in getting the requested medication. If there was an obstacle, we met it. But we laughed, too: When it was discovered that a worn-out cord was

causing my computer troubles, Hanne opined that "maybe the cord had ALS." And when I was trying to reassure an anxious funeral director that I really was not plotting a murder on Feb. 29, she typed that our conversation sounded "like a Monty Python skit."

In her last two years, Hanne was speechless, in her wheelchair, wearing a neck brace, eating and drinking by tube. But she maintained enough strength to type, with one hand, on her iPad. She was steadfast in her support of Daniel, friends and caregivers. Daniel and I promised that we would make her situation known so that others might have a more straightforward path to an assisted death.

In the week before she died, at the age of 66, she laboriously typed out details of a dream in which she was a "young, vibrant lawyer, fighting for Hanne" and

'Daniel and I promised that we would make her situation known so that others might have a more straightforward path to an assisted death.'

then, horribly, was transformed again into "frozen Hanne, in bed, unable to move, and feeling pain everywhere." We marvelled at her strength and her determination not to be stopped. When we assured her that we would continue to "fight for Hanne," she would raise her thumb in response, as she did on her final journey to Vancouver whenever we asked if she had changed her mind, if she wanted to go back to Calgary. She would glance at us lovingly, with a half smile, and raise her thumb.

We love and miss Hanne and value her inspirational leadership in seeking a physician-assisted death and working, through us, to promote educational and legislative changes so that those who qualify can gain timely access to it. We can see the thumbs-up sign.

A version of this op-ed appeared in the May 12, 2016 edition of The Globe and Mail. Used with permission.

When passion and persistence pay off

After years of struggling to be heard, DWDC's Calgary chapter is attracting attention in a big way.

Since dying is part of living, why then have Calgarians seemed hesitant to speak about it? This was one of several frustrations that led to the creation of Dying With Dignity Canada's now-thriving Calgary chapter.

Trish Remmers and Sigrid Wili founded the chapter after participating in an inspiring and well-attended presentation by Wanda Morris, DWDC's CEO at the time. We wanted to raise awareness about the prospect of legalizing medical assistance in dying (MAID).

For the first few years, however, some video presentations, book studies, advance care planning workshops and a number of discussion evenings drew a variety of attendees but it

never really gelled into a large body of committed members. From 2012 to 2014, many ideas were generated at our chapter meetings, but were proving difficult to implement. However, all was not lost!

In 2013 and 2014, Trish, Sigrid and Shelly Hunter began working earnestly to raise awareness through a few workshops, panel discussions and presentations. Arranging to have Wanda return to Calgary for another event generated media attention. We also set up booths at local seniors' expositions, which drew in a large number of interested people, and we continued to write letters to our government representatives. More DWDC supporters also began to show interest in helping with these events. Our chapter's "core" team expanded

to include June Churchill, Judy Hunt, Alexandra McKinnon, Jenn Leclaire and Doone Watson.

It wasn't until the Supreme Court ruling in 2015 that public interest started to rise. We began to receive invitations to



From left to right: DWDC Calgary chapter members Kerrie Hale, Evie Wallace and Trish Remmers. (Courtesy of Sigrid Wili)

speak. As a result, our activities increased as did the number of new supporters — 281 for that year alone. This brought the total number of supporters in the Calgary area to nearly 1,000.

'Going forward, we anticipate sharing ideas with other DWDC chapters and learning from their efforts and experiences.'

With the passage of Bill C-14, the reality of MAID seems to have finally struck a chord with Calgarians and the media. People are much more aware of the subject of assisted dying and our chapter is now getting requests to speak at community centres and churches to

promote awareness of how MAID is being implemented in Alberta. The media is now using DWDC's Calgary chapter as a resource.

An expanding, evolving role

Over the last year, the core team has grown even further. There are also several supporters who are happily willing to help out at events. With this fresh energy, our panel discussion event, Medical Assistance in Dying: An Alberta Perspective, was our greatest achievement this year. Extremely well-attended and media-covered, it was held on September 17 to coincide with DWDC CEO Shanaaz Gokool's trip to Alberta. Our event featured not only Shanaaz, but also Dr. James Silvius, lead for MAID preparedness for Alberta Health Services, and Evie Wallace, whose husband was granted the first legal assisted death in the province of Alberta after the passing of Bill C-14.

Going forward, we anticipate sharing ideas with other DWDC chapters and learning from their efforts and experiences. The Calgary chapter will continue to educate people about their choices at end of life through presentations and events. We are considering making ourselves available to work with patients and doctors within allowable parameters, should they request it.

In addition, we are looking at how we might reach out to university and college students.

As the world of MAID continues to evolve, so will our Calgary chapter role.

—Sigrid Wili and Judy Hunt

Getting an 'A' in activism: Q & A with University of Ottawa student Tammy Pham

The founder of DWDC's only on-campus chapter opens up about what drew her to get involved and the challenges she faces in trying to get other university students talking about death and dying.

How did you first hear about Dying With Dignity Canada?

The first time I heard about Dying With Dignity Canada was just by looking up physician-assisted dying online, and that was one of the first things that popped up. Coincidentally, when I was looking into this, it was when the main Ottawa chapter was just starting. They were going to hold their first meeting, so I thought it would be a fantastic opportunity for me to come out and learn more about the movement.

Was there a personal experience that motivated you to want to get involved?

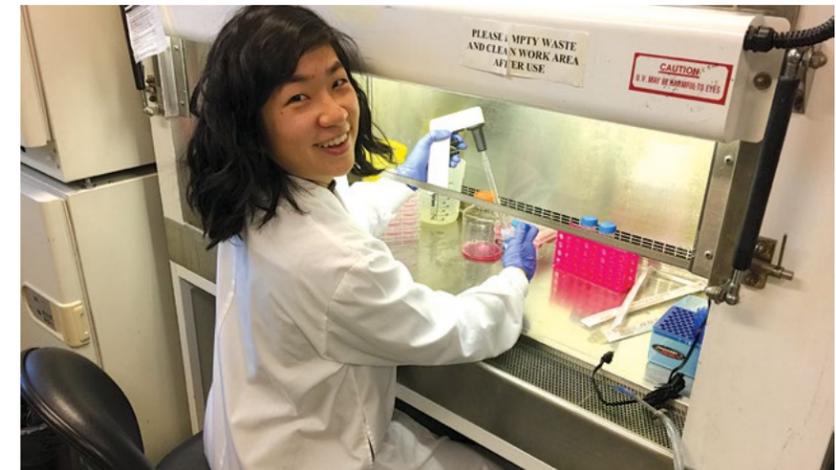
I come from a Vietnamese family. Growing up, death was never talked about in a direct way.

I remember when I was around 13, before my grandpa passed away from cancer, my parents wouldn't let me go see him. They thought it was something that would be too traumatic for me. But at the time, I thought that was something I was ready to see, and I wanted to say goodbye to my grandpa.

Now that I'm older and we're going through different experiences caring for my grandmothers, who are in nursing homes for different reasons, I'm mature enough to open up that discussion with my parents and say, "What would you want if you were in a certain situation?"

Young people don't have a reputation for spending a lot of time discussing issues around death and dying. What type of response have you been getting from your peer group at the University of Ottawa?

The response has been really positive. They feel that, by me being a part of



Tammy Pham is a graduate cellular and molecular biology student at the University of Ottawa. (Courtesy of Tammy Pham)

this movement, it's very different, very unique, and it makes a huge difference. They're very impressed with it, and they're excited to learn more about what I'm doing with the cause at the University of Ottawa and about the organization in general.

What challenges have you faced in getting your message across?

Some students who come to our meetings are interested in the issue in kind of an

academic sense. They're interested in learning about the societal change, but unless they've had specific experiences relating to death, they don't really think of assisted dying in terms of their own lives and their own families and as something to talk about with their families. That's something I'd like to be able to do with the club — to be able to bring that awareness to campus life in the future.

What's it like to collaborate with DWDC volunteers who are decades older than you are and have such a broad array of life experiences?

For me, that was an attractive thing about being able to participate in events at Dying With Dignity Canada. I wanted to do something that was different from my bubble on campus, which has a very

"student" demographic.

Assisted dying relates to issues faced by an older demographic. It also incorporates so many different fields — such as law, policy, philosophy, medicine and ethics — that I wanted to learn about outside of my education at the university, which is very much focused on science.

Finally, what role do you, as a university student, see young people taking on in our movement as the Canadian population grows, on average, older and greyer?

These students I'm talking to, they're going to become the lawyers, the politicians in Parliament and the doctors entering the field. It's important to expose them early, to have them think about assisted dying and how important it is for Canadians right now. To have that before they enter the field will, I think, contribute to a more general open-mindedness about assisted dying.

This interview has been edited for length and clarity.

A love story and its lasting impact

Married for 56 years, Christie and Will Bentham spawned a legacy of giving that continues on in their wake.

When Margaret Bentham closes her eyes and thinks of her parents, she sees them sailing away on their beloved boat, Spree. She pictures them having a peaceful moment together at the end of lives well-lived.

For Christie and Will, living well meant so much more than just an undeniable commitment to each other; they also lived to serve and empower others. So committed were they to improving the lives — and the deaths — of those less fortunate, the Benthams left a legacy of overflowing kindness that has outlived the two of them and promises to endure long into the future.

True to form, Christie and Will met while helping others. Will, after suffering a boyhood episode of severe pain, decided to become a doctor. He soon became the anesthetist-of-choice for other doctors, nurses and their families. And while interning at Hamilton General Hospital, he met Christie, one of the first speech pathologists in Ontario. Six months later, they were married.

The duo became proud and devoted parents to six children, adopted at different ages and from a number of countries around the world. Margaret was the first child to join the family. She says her father used to joke that he was reluctant to drive by the Children's Aid Society in case Christie insisted on "dropping in."

Championing choice

Christie and Will joined DWDC in 2012. Shortly after, Will was diagnosed with Parkinson's disease. For the Benthams,

dying with dignity was not about politics. It was about having the ability to plan ahead for end of life and having the choice to die on their own terms.

As Will's condition worsened, he turned to his wife of 56 years to support him in his decision to end his life. That summer, they invited loved ones to the couple's favourite place in the world, their cottage on Stony Lake in Ontario, to say goodbye.

After Will died, Christie carried a great weight on her shoulders. She deeply regretted that her husband had to end his life earlier than he might have wanted,



Christie and Will Bentham became DWDC members in 2012, the year before Will was diagnosed with Parkinson's disease. (Paul Orenstein)

since he could not rely on others for help. She felt strongly that the system needed to change.

That change started when the Supreme Court of Canada announced its landmark *Carter* ruling in February 2015. When it happened, Christie was at DWDC's head office with her granddaughter Genevieve. Christie taught her grandchildren that in order to be interesting, you needed to be interested. And Genevieve felt incredibly grateful to share her granny's interests on such a momentous day, celebrating compassion, choice and change.

However, Christie was not able to

see this change realized in her lifetime. She suffered a devastating stroke last December. When it was clear that she would not recover, her family had her advance care plan ready and honoured Christie's wishes for no more medical intervention. While hers might not have been the gentlest of deaths, Christie's family was grateful because they knew their mother's wishes were being respected.

Christie's parting gift

The Benthams' commitment to the choice of a dignified death did not end with their own. When Christie died, she left DWDC a legacy gift in her will, which we received in the spring. Hers was the single largest donation we had received all year.

Christie's donation couldn't have come at a more critical time. It helped us make a difference while Bill C-14 was being fiercely debated in the House of Commons and the Senate. We were directly involved in blocking the passage of a Senate amendment that would have required desperately ill Canadians to apply to a judge for permission to have an assisted death. Had we not been prepared to mobilize our resources quickly

and efficiently, we wouldn't have been successful in convincing key members of the Senate to quash this disastrous proposal. Simply put, Christie's gift was instrumental in our small but hugely consequential victory.

In sum, the Benthams set a powerful example not only for their 14 grandchildren and 10 great-grandchildren, but also for the team at DWDC and thousands of Canadians who support the right to a dignified death. May their loving, generous spirit be felt by Canadians for many decades to come.

—Laura Satin Levin