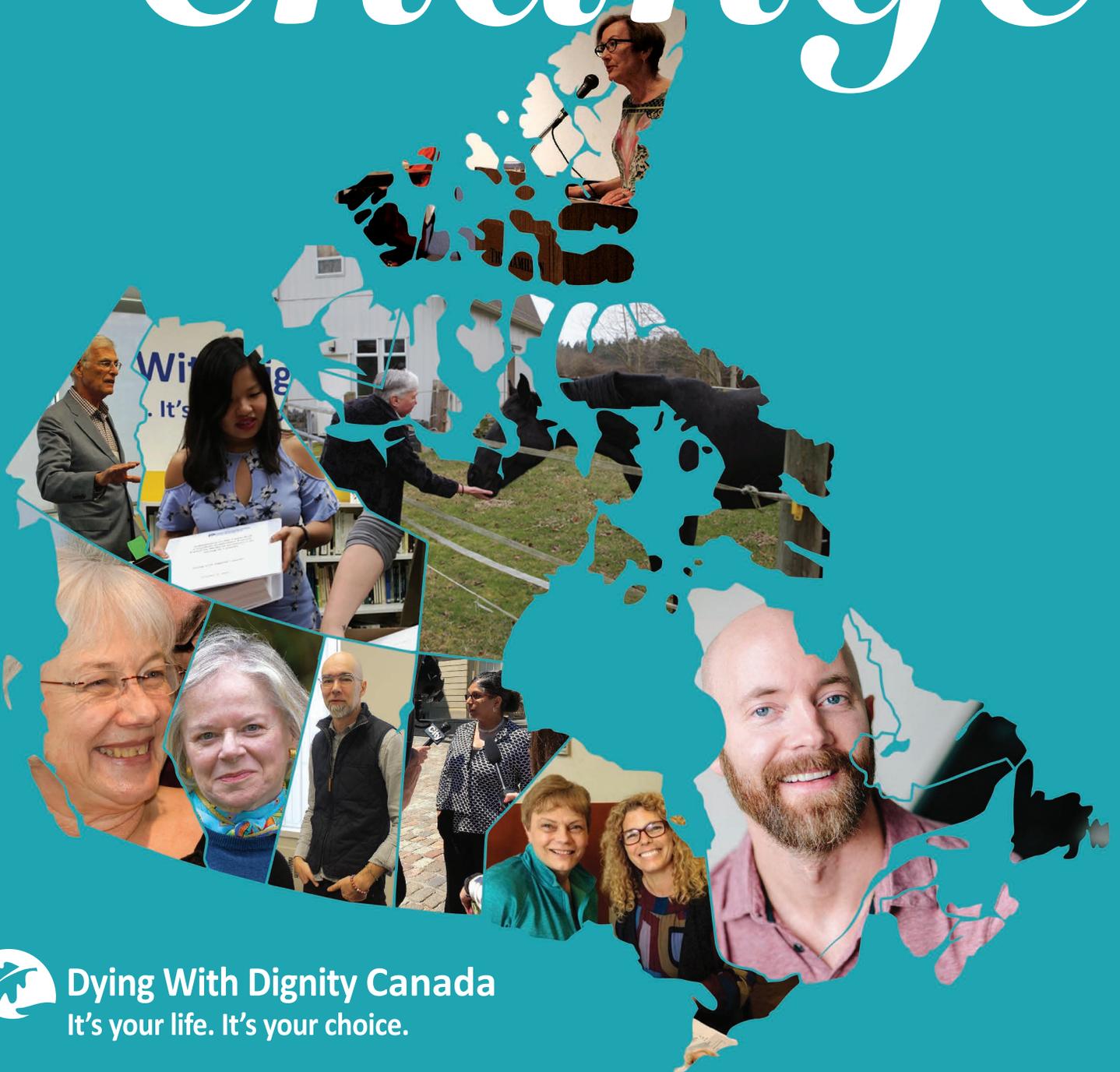


# At the *heart* of *change*

2017  
ANNUAL  
REPORT



**Dying With Dignity Canada**  
It's your life. It's your choice.

## Message from the CEO

Encapsulating 12 months in the life of Dying With Dignity Canada is always a daunting task. Conveying the full who, what, where and when of a single year could fill a book the length of a George R.R. Martin fantasy sequel.

However, we fear that the plot for 2017, with its careening twists and turns, would strike readers as a little too far-fetched. The events would certainly seem unbelievable to us had we not lived them ourselves.

The truth is, serving as the leading defender of your end-of-life rights is stranger and more exciting than fiction. Each week presents us with new opportunities and challenges that no other non-profit in Canada has ever encountered. The stakes at play are dizzyingly high: nothing short of the future of your right to choice in the face of intolerable suffering.

This annual report is our attempt at distilling the highlights of our year “at the heart of change.” The title, we should note, is intended to have more than one meaning. On the surface, it represents DWDC’s role at the forefront of the movement for fair choice. Go a bit deeper and you’ll discover that it’s the people — the Canadians who propel our work and inspire us to keep going — who are truly at the heart of change.

As you flip through the pages of this report, you’ll learn more about these individuals and their impact. You’ll find out about the

work of the volunteers in our independent-witness program, who help break down a surprising barrier to access posed by the federal assisted dying law. You’ll read about the courageous Canadians who are speaking out about what it’s like to support a loved one on a journey with assisted dying. You’ll also learn about the radically collaborative approach that the members of our staff have adopted in order to address the needs of the individuals who seek out our Personal Support Program.

We should also make mention of a special two-page feature story that appears in this report. It’s about the heartbreaking dilemma that faced B.C.’s Adam Ross. On August 31, 2017, Adam ended his own life to escape the agony of an intractable chronic pain condition. He had wanted the choice of an assisted death available to him, so he wouldn’t have had to die alone. But he ultimately concluded that the option to die with the help of a clinician was out of reach, because of unfair and potentially unconstitutional restrictions in Bill C-14, Canada’s federal assisted dying law.

We are immensely grateful to Adam’s family for allowing us to share his story. It hints at how far we still have to go to ensure that Canadians’ end-of-life rights are respected, once and for all. More importantly, his memory — and the memory of other Canadians who died before they



could realize their right to compassionate choice — encourages us to be a stronger and more ambitious force for justice.

That’s why, even though they are not physically with us, these men and women continue to stake a claim at the heart of change. Our successes are their successes. Our progress is a part of their legacy.

—Shanaaz Gokool

## Empowering storytellers to speak their truth

By harnessing the power of personal stories, DWDC has become a stronger, more effective advocate for Canadians.

Never underestimate the power of a personal story.

Sue Rodriguez taught us that. So did Kay Carter. And Gloria Taylor. And Nagui Morcos. And Dr. Donald Low. By sharing their stories, these courageous individuals shifted public opinion and pushed the country closer to recognizing your right to a peaceful death.

Years later, storytelling now plays a key role in *defending* your right to assistance in dying — which is why we at Dying With Dignity Canada have made a concerted effort to give Canadians a platform to share their journeys with choice. Empowering our supporters to speak their truth has not only strengthened our human-rights advocacy; it has boosted the impact of our education and personal support programs as well.

How did DWDC leverage the power of personal stories in 2017? In the summer, we called on our supporters to send us their testimonials on the impacts of Bill C-14, the federal assisted dying law. We launched this action after the Council of Canadian Academies (CCA) — the group of researchers tasked by the federal government to study the future of assisted dying in this country — announced that they would not be consulting ordinary Canadians as part of their work. If the CCA wasn’t going to seek out your voice, then we were going to bring your voice to them.

In the end, we received 746 letters, which we



Liana Brittain (right) says that sharing the story of her husband’s journey with assisted dying “has given Paul’s death meaning and helped me grieve the loss of my loved one.” (Courtesy of Liana Brittain)

included in our official response to the CCA. It’s difficult to put into words just how moving our supporters’ testimonials were. Let’s just say that more than a few tears were shed during the compiling of the letters.

The CCA’s final reports to Parliament are due at the end of 2018, so it’s too early to gauge how much influence your letters will have had on the process. However, a CCA representative did reach out to tell us that the personal narratives contained in our submission were “quite compelling” — a positive sign for what’s ahead.

## A space for healing in the digital sphere

In addition, 2017 saw DWDC’s digital channels emerge as a space where Canadians with first-hand experience with assisted dying could share their stories with the world. With support from DWDC Digital Communications Coordinator Rachel Phan, storytellers like Ontario’s Liana Brittain, B.C.’s Jana Buhlmann and Nova Scotia’s Sylvia Henshaw opened up on our blog about what it was like to care for a spouse who had chosen to die with the

help of a clinician. These deeply personal testimonials attracted more than 10,000 views on our website and gave strength to

Canadians who were embarking on a similar journey.

That’s why our efforts to empower storytellers are about more than just educating the public. It’s also become an important pillar of our work to support individuals and families who are navigating their legal end-of-life options. Reading these stories has led many people to discover DWDC’s Personal Support Program. In many cases, the authors received messages of gratitude from other people who supported a loved one on a journey with medical assistance in dying (MAID).

Thus, by creating new spaces for storytellers, DWDC is becoming a hub for a small but growing community of Canadians — those who are grieving a unique form of loss and want the support of others who have gone through a similar set of experiences.

Of course, simply putting one’s story into words can be a big step in the writer’s healing process. Just ask Liana Brittain, whose late husband, Paul Couvrette, asked her to speak out about his decision to access assisted dying in the face of a terminal cancer diagnosis.

“The volunteer work I do for this not-for-profit organization has given Paul’s death meaning and helped me grieve the loss of my loved one,” Liana says. “Together, we have built a legacy of which my husband would be proud.”

Moving forward, we at DWDC will continue to give storytellers like Liana a platform to raise their voice. As we learned in 2017, harnessing the transformative power of personal stories is perhaps the single most important thing we can do to effect positive change — whether it’s for one person or for the country as a whole.

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DWDC Digital Communications Coordinator Rachel Phan

## In pursuit of justice

In 2017, participating in – and informing Canadians about – key court cases emerged as a major thrust of DWDC’s human-rights advocacy work.

At Dying With Dignity Canada, we are always on the lookout for threats to your choice and for new opportunities to protect it.

In 2017, this meant taking strides to participate in, and inform Canadians about, major court cases concerning your right to a peaceful death. In doing so, we established ourselves as a formidable player in the legal battles over the future of assisted dying in Canada.

In the spring, we went to court to defend an Ontario policy that requires physicians who oppose assisted dying to refer patients who request it to another agency or provider. Launched by a coalition of anti-choice doctors, the legal challenge would have major implications for patients’ rights all across the country.

As official interveners in the case, we argued that the College of Physicians and Surgeons of Ontario’s (CPSO) policy on effective referral strikes a fair balance between a person’s right to care and a doctor’s right to religious freedom. Kelly Doctor, our pro bono lawyer, reminded the court that individuals who request assisted dying are some of this country’s most vulnerable, physically compromised patients. In her 20-minute presentation, Doctor cited the affidavit of a physician who had provided assisted dying and testified that two of his patients would have been physically unable to call or email a referral service by themselves. Their ability to access MAID depended on their doctors’ willingness to connect them, directly or indirectly, with the care they were seeking.

In addition, Doctor noted, connecting a patient with a willing provider or referral service doesn’t mean that the objecting physician endorses MAID, nor does it mean that the patient will ultimately access life-ending treatment. “A referral is about giving the person a choice,” she said.

A panel of Ontario Superior Court judges



Lawyer Kelly Doctor (third from right), of Goldblatt Partners LLP, delivered oral arguments in court on DWDC’s behalf on June 15, 2017.

agreed, ruling in January 2018 that the CPSO’s policy was constitutional and could remain in place. It was a resounding victory for patients’ rights.

Less than a week after the court hearings into the CPSO’s referral policy, we were involved in another case that would reshape assisted dying in Canada. In April, we came into contact with a 77-year-old Ontario woman who would end up going to court to assert her right to a peaceful death. Two physicians had told the plaintiff in *AB v. Canada* – who was afflicted with severe, chronic osteoarthritis – that she qualified for an assisted death. However, the doctor who was supposed to provide her with life-ending treatment got cold feet because of the confusion surrounding a controversial rule in Bill C-14, Canada’s assisted dying law: the requirement that the patient’s natural death must be “reasonably foreseeable.”

AB leaned on DWDC during this ordeal. Shanaaz Gokool, our CEO, provided AB with regular personal support. We arranged for a doctor on our Physicians Advisory Council to assess her via telemedicine. Later, on June 19, we were there in the courtroom when a judge confirmed that AB’s death was “reasonably foreseeable.”

In his decision, Justice Paul Perell provided clarification on how healthcare practitioners ought to go about applying the law. A patient, he wrote, needn’t have a terminal or fatal illness for their natural death to be reasonably foreseeable. In addition, when determining a patient’s eligibility for assisted dying, “the physician need not

opine about the specific length of time that the person requesting [MAID] has remaining in his or her lifetime,” Perell noted.

AB was overjoyed with the result. Not only did Perell clear the way for her to access an assisted death, but his ruling also promised to help other Canadians whose doctors or nurse practitioners had been applying the eligibility criteria too conservatively. She implored us to spread the word about her case far and wide, so that it would benefit as many Canadians as possible. This would become part of AB’s growing legacy.

## Gearing up for more

Our increasing influence in the legal sphere is a trend that shows no sign of slowing. We, along with L’Association Québécoise pour le Droit de Mourir dans la Dignité, have been accepted as official interveners in a court challenge against unfair restrictions in Bill C-14 and in Bill 52, Quebec’s assisted dying law.

We will continue to educate the public, policymakers and healthcare professionals about AB’s story and what it means for access to assisted dying. And, guided by the experienced lawyers on our Legal Advisory Committee, we will continue to scope out opportunities to participate in cases where your choice is on the docket.

Our goal here is the same as it’s always been: to ensure that the scales of justice lean in the direction of patients’ rights, where they belong.

## Partners in protecting patients’ rights

DWDC’s work with healthcare professionals was instrumental in breaking down barriers to assisted dying access.

They are our eyes and ears inside the healthcare system, alerting us to the major roadblocks separating Canadians from their right to choice.

We connect them with the leading jurists and policymakers in the field of end-of-life rights and amplify their voices in the national news media.

Dying With Dignity Canada’s deepening bonds with assessors and providers of assisted dying have empowered and inspired both sides. More importantly, these relationships have had game-changing impacts for assisted dying access across the country.

referrals. We also worked with several clinicians, including PAC Chair Dr. Jonathan Reggler, to speak out about the harms of allowing public healthcare facilities to ban assisted dying on their premises. Responding to another emerging barrier to assisted dying access, we collaborated with the Canadian Association of MAID Assessors and Providers (CAMAP) on a joint statement calling for fair compensation for healthcare professionals who are involved in this important area of practice.

In each case, our clinician allies informed us about a major obstacle facing patients in their care. In turn, we provided them with a platform to raise their concerns.

practitioners participated in each webinar.

Naturally, we learn a lot from the health professionals in attendance. But they learn a lot from us, too. Take, for example, our efforts to spread the word about the June 2017 court decision in *AB v. Canada*.

In his ruling, Justice Paul Perell confirmed that suffering Canadians needn’t have a terminal or fatal illness in order to qualify for assisted dying. In addition, he wrote that, when assessing whether a person’s natural death is reasonably foreseeable – a confusing requirement in the law that has caused heartache for patients and health professionals alike – a clinician needn’t provide an estimate as to how long the individual has left to live.

Having provided personal support to the plaintiff in *AB*, DWDC CEO Shanaaz Gokool was well-positioned to provide background on the ruling. In September, she, along with a doctor on our Physicians Advisory Council who had assessed AB, delivered a virtual presentation about the case to clinicians. The providers on the call then took the lessons learned and shared them within their own professional networks.

Make no mistake: the ruling in *AB* – and our efforts to raise awareness about it – has allowed clinicians to apply the federal assisted dying rules in a manner that is less restrictive and more patient-friendly. It broke down barriers for Robyn Moro, who wanted to end the intense suffering she experienced on account of Parkinson’s disease. The 68-year-old B.C. woman had joined the *Lamb v. Canada* court challenge after she was told she did not qualify for assisted dying.

However, her doctors changed their minds after we notified them about the decision in AB’s case. Ultimately, Robyn died at home on August 31, with medical assistance, in the presence of her loved ones.

Robyn’s story might have ended differently were it not for the culture of cooperation at the heart of Canada’s right-to-die movement. We believe wholeheartedly that, when it comes to protecting your choice, collaborating with healthcare professionals is just what the doctor ordered.



Dr. Stefanie Green is the president of the Canadian Association of MAID Assessors and Providers and a member of our Physicians Advisory Council. (Chad Hipolito)

Our allies in the medical profession played a crucial role in our human-rights advocacy last year. In March, we supported Dr. Chantal Perrot, a Toronto member of our Physicians Advisory Council (PAC), when she agreed to testify to Ontario legislators about what happens when patients who request assisted dying are denied a proper referral. Members of our PAC helped inform our written submissions on the CPSO court case in support of effective

“The support and encouragement DWDC provides to assessors and providers like myself has been strong and unwavering from the outset,” says Dr. Perrot. “We would not be where we are today without this support.”

In addition, DWDC supported clinicians in 2017 by facilitating a monthly online discussion forum where providers compare notes and offer each other peer support. On average, about 30 physicians and nurse



From the left: DWDC's Personal Support Program Manager Nino Sekopet; National Events and Volunteer Coordinator Kelsey Goforth; CEO Shanaaz Gokool; and Communications Officer Cory Ruf.

## Personal support without silos

At Dying With Dignity Canada, helping Canadians navigate their legal end-of-life options is a team effort.

After the legalization of assisted dying, Canadians flocked to us to get their questions answered. As the organization at the heart of the change, we felt we had no choice but to support these individuals and families however we could.

Our response has not only transformed our work, but it's also altered how we think about what we do. Now, everyone on the roster at Dying With Dignity Canada's national office, no matter their job title, plays a role in providing support to people who are navigating their legal end-of-life options. The insights we glean from these interactions guide us in our human-rights advocacy.

Our Personal Support Program remains at the core of DWDC's efforts to ease the burden for suffering individuals and their loved ones. Last year, Nino Sekopet, the program's manager, handled nearly 900 requests for information and emotional support. This represents a 25 per cent increase over 2016.

In reality, though, bridging the enormous gaps facing Canadians required an all-hands-on-deck approach in 2017. Whether they expected to or not, everyone in the office participated in providing personal support. Our administrative staff were often the ones to pick up the phone when a person was calling for help. Rachel Phan, our digital communications coordinator, triaged inquiries that came in through social media. Kelsey Goforth, as the

coordinator of our independent-witness program, fielded calls from individuals who needed their requests for assisted dying signed by one of our trained volunteers.

And then there was DWDC CEO Shanaaz Gokool. In 2017, Shanaaz provided personal support to the plaintiff in *AB v. Canada*, whose case is mentioned several times in this report. After being formally approved for assisted dying, AB was told by her doctor that he wouldn't proceed because of confusion surrounding the eligibility rules. In constant, excruciating pain as the result of chronic osteoarthritis, the 77-year-old grandmother contacted us in search of a solution.

As a chief executive, Shanaaz isn't usually the main point of contact for individuals seeking personal support. But AB's situation was complex, and it spoke to the heartbreaking problems posed by ambiguities in the federal assisted dying law. Solving it might require the participation of someone with Shanaaz's expertise, influence and professional connections. Plus, she recognized early on that AB's case had potentially life-altering implications for other Canadians whose choice was on the line.

Helping out, Shanaaz concluded, was just the right thing to do.

DWDC supported AB in several ways in the weeks before a judge issued his ruling in her case. Shanaaz visited AB

at her home to learn more about her situation. She arranged for a doctor on our Physicians Advisory Council to provide a second opinion on AB's eligibility for assisted dying. In addition, Shanaaz communicated with AB's lawyers, supplying them with information and contacts that would prove useful in the case.

In June, Shanaaz was in the courtroom when Justice Paul Perell announced that AB did indeed qualify for an assisted death. When the two women spoke on the phone later that day, AB was "giddy with disbelief," Shanaaz said. AB then implored us to use her story to help Canadians in her same position.

As you read through this report, you will learn more about how we have leveraged AB's experiences to help others. It's a story we would never have been able to tell were it not for our "silo-free" approach to personal support. By thinking creatively, collaborating with others, and embodying DWDC's commitment to *putting the person first*, Shanaaz empowered AB to break down barriers and, in the process, gave her a platform to spread her message of hope.

This is but one example of how our personal support work informs our human-rights advocacy, and vice versa. Being there for AB deepened our understanding of Canada's assisted dying rules; the lessons learned have equipped us to better serve the people who need our help.

## Agents of change

In 2017, our volunteers and chapters broke down barriers to choice – and shone a light on new ones they spotted along the way.

Dying With Dignity Canada's volunteers are the lifeblood of our efforts to protect Canadians' rights and inform them of their legal end-of-life options.

In 2017, our supporters contributed a total of more than 12,500 volunteer hours, an increase of about 14 per cent over the previous year. Much of the uptick can be attributed to the growth of a groundbreaking initiative that has grabbed headlines and, more importantly, helped suffering Canadians overcome a major barrier to their choice.

We rolled out our independent-witness program in 2016 in response to the problems posed by a safeguard in the federal assisted dying law. Bill C-14 requires individuals who apply for assisted dying to get their requests signed by two independent witnesses. To qualify as "independent," a person cannot be directly involved in the applicant's care, nor can they stand to benefit financially from the person's death.

Here's where the problem lies. People who qualify for medical assistance in dying are some of this country's most frail, physically compromised patients. At this stage in their lives, they may have little to no social contact with anyone aside from their caregivers. Also, the suffering individual may not be comfortable – or even capable of – picking up the phone to ask a neighbour for help.

This led us to start training volunteers who could sign an applicant's form when no other eligible witness could be found. Now, DWDC's independent-witness program boasts a roster of more than 200 volunteers. That number continues to rise as more Canadians learn about the program and its impact.

In 2017, our volunteers signed a total of 325 requests for assisted dying. Most often, the person contacting us to ask for witnesses was a clinician or social worker – a sign of our volunteers' reputation for professionalism and sensitivity. Sometimes a patient or caregiver would call after being referred to us by a provincial healthcare agency. Now that's credibility.

DWDC supporters empower Canadians in other ways. Our regional chapters hosted

a total of 25 events across the country last year, including 15 Advance Care Planning workshops. A number of volunteers signed up as speakers for our End in Mind online education series. In total, our 2017 events – both online and in-person – attracted thousands of participants.

*"Each volunteer can actually make a difference in the life of someone who is suffering and wants choice at end of life."*

*–Susan Desjardins, chair, DWDC's Ottawa chapter*

What's it like to be a DWDC volunteer at this moment in the organization's history? The experience has been a "transformational" one, says Susan Desjardins, chair of our Ottawa chapter.

"Each volunteer can actually make a difference in the life of someone who is suffering and wants choice at end of life," she told us at our Annual General Meeting in May 2017. "At this time, we're really part of a transformation of Canadian society. To be a small part of that is a momentous opportunity."

As Susan knows, our volunteers are much more than just boots on the ground. They are also our eyes and ears in the field, supplying us with intel and expertise that have proven invaluable in our work. Our independent witnesses tip us off to new obstacles to choice that they spot in the healthcare system. The professionals on our Board, our Physicians Advisory Council and our Legal Advisory Committee aid us in the development of policies that keep us relevant in the post-Bill C-14 era. The members of our Disability Advisory Council ensure that our positions are informed by the lived experiences of a key constituency of Canadians whose rights and choices are at stake.

All of this is to say, DWDC would not be the organization at the heart of change without the contributions of our dedicated volunteers. We couldn't be more grateful.



# Twelve Months at the Heart of Change

For Dying With Dignity Canada, 2017 was about tackling unexpected challenges and seizing new opportunities. Here's a timeline of some of the big moments of the year.



DWDC hosts the inaugural webinar in our new End in Mind online education series. The first edition focuses on the future of our work to defend Canadians' end-of-life rights.

At a press conference on Parliament Hill, CEO Shanaaz Gokool joins a group of politicians and advocates calling for fair access to assisted dying. The announcement comes on the two-year anniversary of the Supreme Court's decision in *Carter v. Canada*.



DWDC announces that outgoing Senator Jim Cowan would be joining our Board of Directors. Nancy Ruth, another retiring senator, joins our Patrons Council.

CEO Shanaaz Gokool presents to Ontario legislators about our concerns surrounding Bill 84. The legislation includes a proposal that would allow public healthcare facilities to hide their policies on assisted dying from the public.



The *New York Times* publishes a 6,000-word profile on the last days of John Shields, a B.C. activist who ended his life with medical assistance. Journalist Catherine Porter interviewed several DWDC staff members and volunteers while reporting the story.

After weeks of silence, Dr. Schipper issues a statement announcing that he is resigning as chair of the CCA's panel on advance requests for assisted dying.

The Council of Canadian Academies (CCA) announces the names of the researchers who will report to the government on the future of Canada's assisted dying law. DWDC learns that the chair of the panel on advance requests for assisted dying had made derogatory comments about supporters of end-of-life choice. We later make a public call for Dr. Harvey Schipper to clarify his past statements.



DWDC unveils What's in Your Plan?, our campaign to get Canadians thinking about their wishes for care at end of life. The launch coincides with National Advance Care Planning Day.

Adam Maier-Clayton, an outspoken advocate for the right to assisted dying, dies at 27. In media interviews after his death, DWDC credits Adam with sparking a national conversation on the end-of-life rights of Canadians with severe mental illness.



< MAY 25

^ MAY 11

^ APRIL 27

^ APRIL 16

^ APRIL 13



Representing DWDC, Toronto lawyer Kelly Doctor delivers arguments in court in support of the College of Physicians and Surgeons of Ontario's policy on effective referral for assisted dying.



DWDC marks the one-year anniversary of the passage of Bill C-14.

An Ontario judge issues his decision in the case of a 77-year-old woman who went to court to establish her eligibility for assisted dying. The ruling in *AB v. Canada* would eventually dispel some of the misconceptions that surround the federal assisted dying rules.

DWDC publishes *Challenges to Choice: Bill C-14, One Year Later*. The report explores the impacts of the federal assisted dying law on Canadians' right to a peaceful death.



^ JUNE 13

^ JUNE 15

^ JUNE 17

^ JUNE 19

JULY 12 >



Hundreds of DWDC supporters tune in online to watch four brave Canadians open up about their experiences supporting a loved one through a journey with assisted dying. Our last End in Mind webinar of the year, it was the first event of its kind to be hosted in this country.

Communications Officer Cory Ruf presents to a committee of Manitoba legislators on why the government's bill on assisted dying poses a grave threat to residents' right to assisted dying.

DWDC files its official submission to the CCA. Urging an approach that puts the person first, our response contains the letters of 746 Canadians who wanted to share their thoughts on the future of assisted dying in this country.



DWDC learns that we — together with our Quebec sister organization, AQDMD — will be allowed to make arguments in support of Nicole Gladu and Jean Truchon in their court challenge against aspects of Bill C-14.

DWDC invites Canadians to send in personal stories and perspectives for us to include in our official submission to the CCA. The public call for letters is part of the relaunch of Voice Your Choice, our campaign to ensure that Canada's laws respects your constitutional rights.

The plaintiff in *AB v. Canada* dies, with medical assistance, in the presence of her loved ones. DWDC CEO Shanaaz Gokool, who had provided her with personal support, was with AB when she died.

^ NOVEMBER 28

^ NOVEMBER 6

^ OCTOBER 6

^ SEPTEMBER 27

^ AUGUST 17

AUGUST 3 ^





# ‘The toughest of all places’

In August 2017, B.C.’s Adam Ross fulfilled his choice to die with dignity – the last option left to free him from a prolonged, untreatable pain condition. He died alone, without anyone’s assistance, taking care to minimize the burden on the people he loved. His story reveals how much work still needs to be done to ensure that Canadians have fair alternatives in the face of unbearable suffering.

Adam Ross chose a warm and starry night at the end of August to free himself from the pain. Alone on a bench in Vancouver’s Lighthouse Park, he took in the view laid out before him. The spot he had chosen was secluded, at a cove overlooking Burrard Inlet.

He lit two candles, sent his sister a text that she had known would one day come, and felt the sensation of the night air on his skin for the final time. Then, he carefully breathed in a substance that – painlessly – released him from his body and the relentless suffering that had been his reality for seven years.

Despite the daily agony he endured due to his chronic pain condition, Adam would not find solace in Canada’s assisted dying law because, at 37 years old, his natural death was not “reasonably foreseeable.” Like far too many Canadians, Adam had to die alone, without medical assistance and without his parents and four siblings at his side.

Adam’s life and his departing letter remind

us of the gains our movement still has to make to ensure fair, equitable access to assisted dying. While thousands of suffering Canadians continue to be abandoned by our laws, Dying With Dignity Canada presses forward.

*“He was a person who listened very well and always contributed in a meaningful way.”*  
–Brian Ross, Adam’s father

Adam came into the world on June 13, 1980, on the heels of his twin brother, Paul. In his youth, he was a risk-taker with a steely stubbornness, who once insisted on hopping a freight train to Vancouver for a weekend of fun with buddies. He grew to become a thoughtful, articulate and deeply intelligent man, with an infectious sense of humour. Throughout his life, he went to tremendous lengths to take care of his physical and mental health, choosing to eat well and stay active. But above all, he cared deeply for the people he loved.

“He was a person who listened very well and always contributed in a meaningful way,” Adam’s father, Brian, says. “He developed such lasting and deep friendships with many people from many walks of life. It was amazing.”

Following his first career in the electrical trade, Adam pursued a Bachelor of Science degree at Thompson Rivers University. His studies helped him discover his purpose and passion: becoming a dentist.

“[Adam’s mother] Anne and I, knowing how hard it can be to get into dentistry schools, once asked Adam what his Plan B was. His response was, ‘There is no Plan B.’”

Adam’s brother remembers how, “when Adam put his mind to something, it got done, whether it took one day or 10 years.”

Adam accomplished his goal, graduating with honours from the University of Toronto’s Faculty of Dentistry. But already, Adam had been struck by a devastating twist of fate. While using physiotherapy exercises in an attempt to correct some shoulder and postural problems he was experiencing,

he suddenly sustained a traumatic upper cervical injury that would shape the next seven years of his life. It was 2010.

## ‘Left with a choice-less choice’

In his final letter to his family and friends, Adam writes about the injury: “It felt like a fire had been lit at the base of my neck on the left side and all the muscles of my neck and upper back were in spasm. The pain was like nothing I had ever experienced in my life and I knew something terribly wrong was going on inside of me.”

Adam’s first diagnosis was chronic myofascial pain syndrome, characterized by deep, aching pains and knots in muscles that would worsen over time. Despite the debilitating daily pain Adam now endured, he “continued to try to lead the life [he] had worked so hard to achieve.”

Meanwhile, he was doing everything he could to understand and alleviate the pain. Chiropractic work, physiotherapy, intra-muscular injections and other interventions at pain clinics – as well as many courses of different medications – would prove unsuccessful.

Adam left his dental practice in January 2016. He was hopeful that his condition would improve once he relieved himself of the physical stresses of dentistry. But no relief ever came. He developed a rare condition called cramp-fasciculation syndrome, which caused uncontrollable cramping and twitching in the muscles of his arms and legs. Adam’s quality of life had diminished to the point where he was unable to carry out any form of exercise and was confined to his couch for many hours of the day.

“Adam’s chronic pain mediated every moment of his experience. This made it almost impossible for him to derive pleasure from the normal, natural aspects of daily living,” explains his eldest sister, Sally. “He was finally left with a choice-less choice.”

It was likely in 2016 when Adam began to seriously contemplate his own death. He considered travelling to Dignitas in Switzerland, but was ultimately put off by the amount of paperwork and travel involved, and the uncertainty surrounding his eligibility.

That same year, Canada passed its own assisted dying law, Bill C-14. But where there was uncertainty about Dignitas, there was no uncertainty around Canada’s law:

Adam would not qualify at home. Because his natural death was not “reasonably foreseeable,” he knew the option of dying with the help of a clinician was off the table.

Adam watched with interest as other Canadians began to speak out: B.C.’s Julia Lamb launched a constitutional challenge to the law, while Ontario’s Adam Maier-Clayton publicly advocated for the end-of-life rights of Canadians whose primary underlying medical condition is psychiatric.

“My brother once shared with me his agreement with Adam Maier-Clayton’s point that people with certain diagnoses are in a privileged position under the law,” Sally reveals. “In the face of the diverse ways that complex pain or disease manifest, medical science and our healthcare systems are not equipped to help in every case, or even ease the burden enough for many sufferers to the point where they can cope.”

*“Adam was very conscientious of not dying before we all were connected in some way with him and his decision.”*  
–Anne Ross, Adam’s mother

When Adam Ross eventually made the decision to let go of his body, it was one he did not take lightly. He worked compassionately to try to help his loved ones understand why this was his only option. He wanted them to trust that he had done everything he could to save his life.

“Adam was very conscientious of not dying before we all were connected in some way with him and his decision,” Anne shares. “He was extremely thoughtful, courageous and brave.”

“Adam didn’t want to hurt anyone or cause us sorrow,” Brian adds. “I think that’s probably why he struggled for so long.”

Adam considered every detail of his planning in a manner that radiated integrity. One of the paramedics who had been sent to recover the body later expressed how touched the team had been by the degree of Adam’s care, diligence and self-respect.

Adam’s prior work to mitigate the shock could only go so far in preparing his family members and friends for the unfolding grief and loss. “He knew and verbalized how hard this was going to be on us,” Anne says. “You never want to think about someone having to die on their own. It was so traumatizing for us.”

## Adam’s legacy

Adam’s family hopes that his story and death will help drive much-needed change in Canada and lead more people to contemplate the rights of individuals with chronic pain or less well-understood medical conditions. They also wish to bring attention to the unfairness of an assisted dying law that excludes many Canadians on the basis of their diagnoses.

“Adam’s dying process would of course have looked very different for him and our family if the larger context of his ‘pain journey,’ as he called it, would have allowed for help from a physician in the final stages,” Sally affirms. “After all reasonable and appropriate medical treatment has failed to alleviate a person’s prolonged suffering, what are the next humane steps we can take to best support the reality of such a brutally difficult journey?”

Anne and Brian – both longtime DWDC supporters – know that sharing their son’s story would be important to him. “He would have liked to have seen this dialogue happen in our society,” Anne says.

In his final letter, Adam articulates his love for life and the people he cared for, the personal peace he had come to in his choice, and his deep regret for the sadness his death would cause. “My pain has allowed me to understand what truly matters... Unfortunately, the miracles I witness each day are not enough for me to choose to endure this much pain... I don’t want to die, but to be free of the pain that I am condemned to live with, I have no other choice... The toughest of all places in the world to be.”

He continues, “Of course, I imagined dying in a different manner, as it should be our right to choose when and how we would like that process to go, especially when you live with unbearable incurable pain that will not take you from this world naturally. But, like so many other aspects in this life, the human race has far to go in this regard.”

Then, true to his thoughtful nature, Adam encourages us with the gift that death can offer to those open to embracing the opportunity: “Nothing brings people closer than loss,” he concludes. “So be closer.”

–Rachel Phan

**Dying With Dignity Canada thanks the Ross family for sharing their story with Canadians. To read Adam’s final letter, visit [dyingwithdignity.ca/adamross](http://dyingwithdignity.ca/adamross).**

## Media matters

In 2017, Dying With Dignity Canada's outreach in the media helped shape the public's understanding of the Canadian experience with assisted dying.

When a big story on assisted dying breaks in Canada, our phones ring off the hook with calls from journalists looking to get our take. That was the case in 2015, when the Supreme Court struck down the *Criminal Code* ban on assisted dying, and it's still the case today.

Increasingly, though, we at Dying With Dignity Canada are the ones breaking the news, tipping off journalists on the latest developments related to your end-of-life rights. In 2017, we raised the alarm on the emerging barriers to assisted dying access that we encountered in our work. In addition, we provided a conduit for Canadians who wanted to share their journey with choice with the general public.

One of the most important stories we were involved in breaking came out of Winnipeg. In June, we received a tip about a controversy brewing at St. Boniface General Hospital, where assisted dying is not allowed. The hospital's board, our source said, had voted in late May to allow assisted dying on its premises. The vote came after months of internal discussions at St. Boniface about the harms of requiring desperately ill patients to be transferred off-site to receive, or even be assessed for, assisted dying.

But the policy to allow assisted dying in "rare circumstances only" was short-lived. The Catholic Health Corporation of Manitoba (CHCM), a faith-based organization that oversees more than a dozen publicly funded healthcare facilities in the province, responded by adding new members to St. Boniface's board and forcing a second vote. The hospital's ban on assisted dying was back in place



DWDC CEO Shanaaz Gokool speaks to reporters in Toronto on June 19, 2017.

only days after it had been lifted — and our source had documents to prove it.

We put him in touch with Jane Gerster, the health reporter with the *Winnipeg Free Press*. The resulting story made the paper's front page the very next day. More importantly, it sparked a countrywide dialogue about the injustice of allowing public hospitals' politics to trump patients' human rights.



Noreen Campbell

Liaising with whistleblowers and uncovering secret documents sounds exciting, and it is. But we're even prouder of our participation in stories that put an intimate, human face on issues surrounding choice at end of life. Take, for example, our efforts to help B.C.'s Noreen Campbell to

share her story with Canadians.

A nurse, healthcare educator and a member of DWDC's Disability Advisory Council, Noreen made a request for assisted dying on June 19, 2016, just two days after it was formally legalized in Canada. She had already undergone treatment for an aggressive form of oral cancer before being diagnosed with chronic pulmonary obstructive disorder, or COPD. The condition severely restricted her breathing — she likened it to sucking in air through a McDonald's straw — and it was getting worse. She feared suffocating to death and saw ending her life with a doctor's help as a kinder alternative.

As one of the first Canadians to be assessed for assisted dying under the

new federal law, Noreen gleaned rare insights on what it's like to try to exercise one's right to a peaceful death. Always a consummate teacher, she wanted to share the lessons she had learned. She enlisted DWDC to help her get the job done.

In the weeks before Noreen's death in January 2017, we introduced her to trusted journalists at the *Victoria Times Colonist* and *The Globe and Mail*. On New Year's Day, she sent us an email asking whether we could pitch CBC Radio host Dr. Brian Goldman — whom Noreen called her "hero" — on interviewing her for his program, *White Coat, Black Art*. He said yes without hesitation.

*"To think that all this is possible if you live within the right borders. Lots of work [to do], Canada — but good to be a Canadian today."*  
—Noreen Campbell

The newspaper and radio stories featuring Noreen were the first of their kind in English Canada. They offered the country a glimpse into what it means to take control of the dying process. This is what Noreen had wanted and what had motivated her to ask for our help in spreading her message of hope.

"If our work producing this interview... helps to relieve anxiety about progressive disease, encourages palliative care, and brings peaceful death — awesome," Noreen told Dr. Goldman by email on January 12, the day she chose to end her suffering. "To think that all this is possible if you live within the right borders. Lots of work [to do], Canada — but good to be a Canadian today."

## Financial information at a glance

When you invest in Canadians, they return the favour.

That's always been our experience here at Dying With Dignity Canada, and it was definitely the case in 2017. Last year, our annual revenues jumped 15 per cent from 2016, to a total of \$876,798. As a result, the \$92,000 deficit we had budgeted for going into 2017 would narrow to \$62,748 by year's end.

The generosity of our donors, old and new, is responsible for the better-than-expected returns. Nearly 3,000 individuals and families gave to DWDC over the course of 2017, a 12 per cent increase over the previous year. In addition, our Defenders of Dignity monthly-giving program grew from 708 donors to a total of 888.

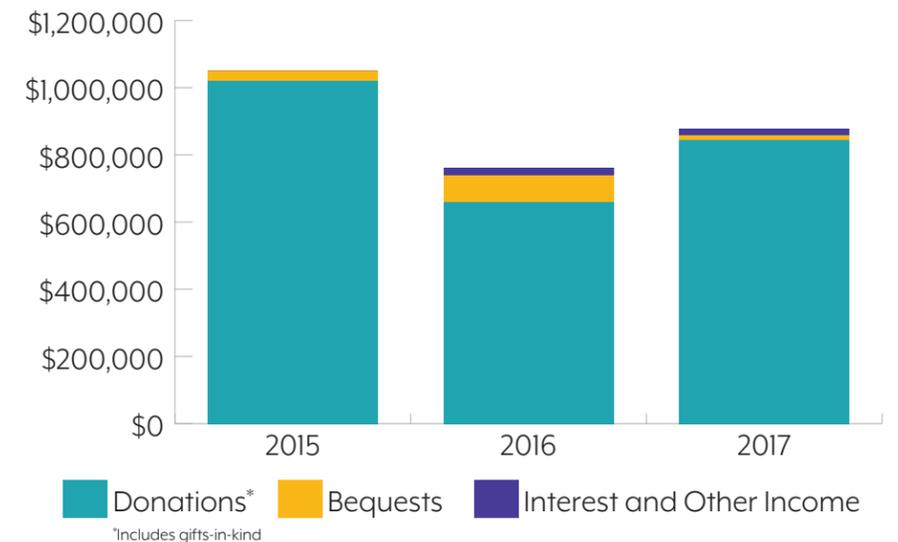
We attribute the growth of DWDC's donor base to the ever-expanding reach of our programs — from exposing and breaking down barriers to assisted dying access in the healthcare system, to the rewarding work we do to support individuals and families who are navigating their legal end-of-life choices. From coast to coast, Canadians saw how DWDC is effecting change in their communities, and they wanted to find out how they could make us an even stronger force for justice.

As a donor-funded organization, we know that our supporters expect us to use their dollars to make as big of a difference as possible. We take pride in the fact that, in 2017, eight out of every 10 dollars we spent went towards our programs.

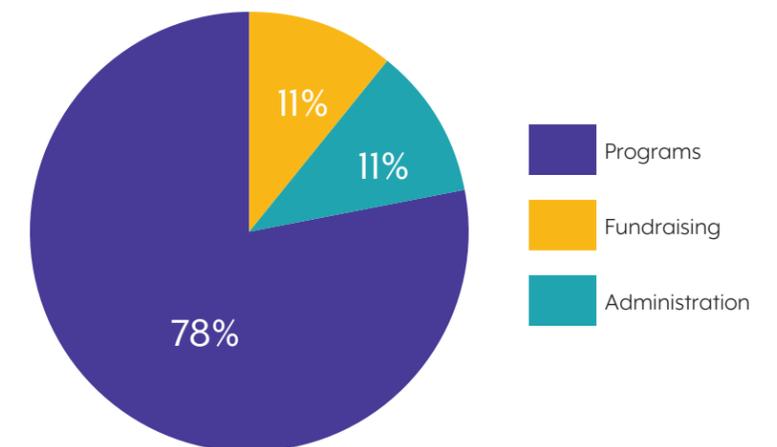
In sum, our experiences last year lead us to believe that we've found a formula for healthy growth. By investing in Canadians, respecting donors' dollars and always *putting the person first*, we continue to grow our base of support and solidify our position at the heart of change.

This is now the keystone of our fundraising strategy. It's also at the core of who we are.

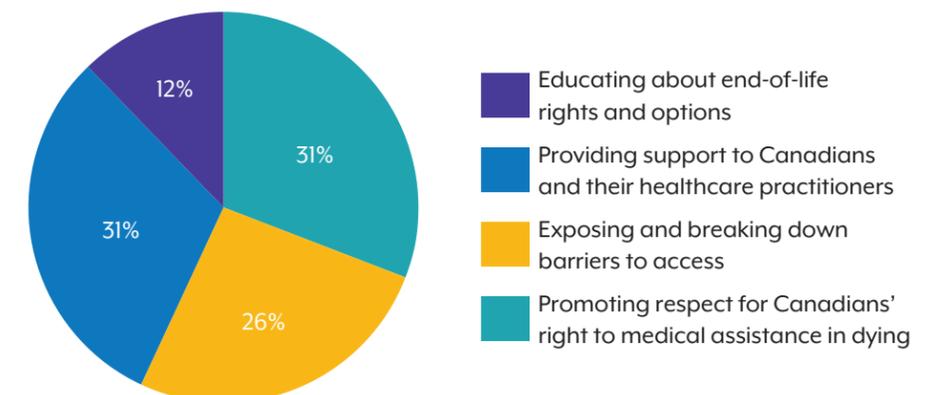
Annual revenues, 2015 to 2017



Where the money goes



Program spending by type



## Counting the ways we count on you

Whether they contributed monthly, left a legacy in their will, or gave for the first time ever, DWDC's donors fueled our successes in 2017.

Françoise Hébert has devoted hundreds of hours to making Dying With Dignity Canada a formidable force for justice.

She first signed up to volunteer for the organization in late 2012, six months after she retired from her role as CEO of the Alzheimer Society of Toronto. By early 2013, Françoise was already representing DWDC in media interviews. By the spring, she had been elected as a member of our national Board of Directors, helping to steer the ship during a critical time in our history.

Today, Françoise continues to propel DWDC forward, even when she's not busy volunteering. She is one of a group of nearly 900 donors who give to the organization on a monthly basis. By committing to donate at regular intervals, Françoise and our other Defenders of Dignity provide us with a foundation of financial support that allows us to plan for the future and respond quickly in times of need.

### 'You have made it easy for me'

"I've just made the decision that this is the cause I want to support above all others, and you have made it easy for me to do

that," says Françoise, explaining why giving monthly appeals to her. "You take it off my credit card every month, which means I actually get points for it. I like the fact that I don't even have to think about it."

She describes her interest in DWDC's work as "deeply personal and passionate." It is significantly informed by her mother's experiences with a rare form of muscular dystrophy. "I saw my mother suffering through a horrible death," Françoise says. "She ended up basically wasting away."

Her mother, she says, would never have asked for help to hasten her death. But if Françoise were in the same position, she would want the comfort of knowing that she would have choice in the face of unbearable suffering. "It's about having that option, recognizing that very few people will avail themselves of it."

In part because of her 10 years with the Alzheimer Society of Toronto, Françoise is especially passionate about DWDC's work to defend the end-of-life rights of Canadians with conditions, such as dementia, that rob victims of their mental capacity as a matter of course. "I'm a great believer in advance requests for assisted dying, something that you would create when you have the capacity to make an



Françoise Hébert

informed decision," she says. "I have seen how awful a death is in the final stages of dementia. I never want to go there, ever."

### Leaving a legacy

We are immensely grateful to Françoise, who, like all of our donors, fueled our successes in 2017. She has also taken steps to ensure that DWDC will be a strong defender of Canadians' rights far into the future. As a member of the Christie Bentham Legacy Society, she has committed to leaving DWDC a significant gift in her will. The organization, she notes, is the only non-profit or charity that she has listed as a beneficiary.

"Dying With Dignity Canada needs my money and spends it wisely," Françoise explains. "The fact that you're frugal, the fact that you're very effective, and the fact that it's this cause — that's what did it for me."

## 2017 DWDC Major Donors

Dying With Dignity Canada would not be at the heart of change were it not for the contributions of our donors. We are immensely grateful for their generosity and their commitment to defending Canadians' end-of-life rights.

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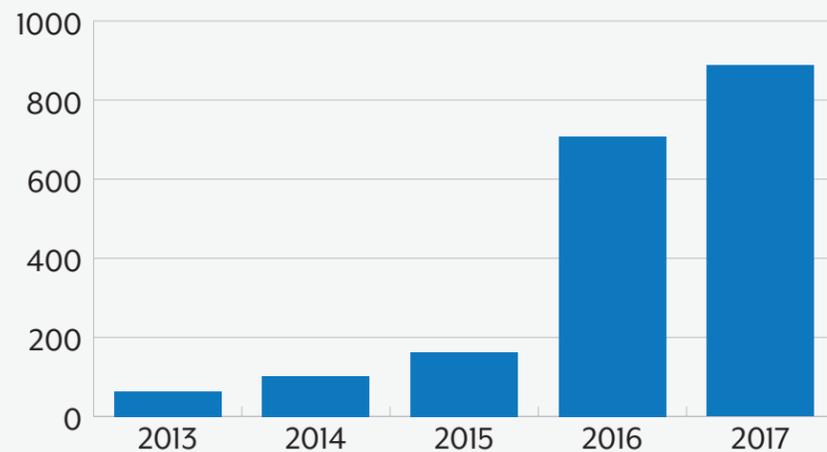
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### The Growth of our Defenders of Dignity Program, 2013 - 2017



### Making the commitment

If you would like to become a monthly donor, please mail a void cheque to: Dying With Dignity Canada, Suite 802 – 55 Eglinton Ave. E, Toronto, ON, M4P 1G8. Alternatively, you can call us toll-free at 1-800-495-6156 or visit us online at [dyingwithdignity.ca/donate\\_now](http://dyingwithdignity.ca/donate_now) to set up your donation.

If you would like more information about leaving a legacy, please contact Laura Satin Levin, DWDC's fund development officer, at 1-800-495-6156 x26 or at [laura@dyingwithdignity.ca](mailto:laura@dyingwithdignity.ca).

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## Christie Bentham Legacy Society

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We would like to recognize the members of the Christie Bentham Legacy Society, who have committed to leaving a future legacy gift to DWDC. We thank these incredible donors for their dedication to protecting the rights and choices of generations to come.

|                               |                            |
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