



Advancing Together:

Dying With Dignity Canada's
2019 Impact Report



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



Message from our Chair of the Board of Directors

In my three years on the Board of Directors for Dying With Dignity Canada (DWDC), I've seen dynamic change and major gains for the end-of-life rights movement. 2019 was no exception, including noteworthy court victories in landmark cases for patients' rights and those suffering across the country. This year also saw volunteers mobilizing cross-Canada to respond to witnessing requests and other key legislative pieces in the lead up to and following the federal election, as well as the continued events, workshops, and other educational initiatives from our chapters across the country. Our volunteers and supporters are some of the most dedicated advocates I've encountered, and it's a win just to have them in our court.

The Board of DWDC is energized and heartened by these developments, and as we look towards 2020 and our 40th year, we thank everyone who has played a part in getting us to where we are today. It has been four decades of remarkable change and progress, and we are grateful to all those who have advocated tirelessly on behalf of people across the country to ensure their rights and access to end-of-life choice are protected. It is with deep gratitude that I thank you all for your support and dedication to this cause.

Sincerely,

The Honourable James S. Cowan CM QC
Chair of the Board of Directors, Dying With Dignity Canada

2019 – 2020 DWDC Board of Directors

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Message from our CEO

It is a landmark time in the end-of-life rights movement and a dynamic period in the history of medical assistance in dying (MAID). I am in awe of the dedicated people who make up this organization and movement — the volunteers, staff, board, and supporters, some profiled within this report — who are fighting for the right to end-of-life choice across the country.

With that, I welcome you to take in Dying With Dignity Canada's 2019 Annual Report. Here you'll read about the achievements of the previous year and find inspiration to galvanize for the successes to come. For me, the hands in DWDC's logo represent the way we hold people through suffering, grief, and understanding how complex legislation affects their lives. 2019 was filled with notable moments of this kind of holding — person-centred support, innovative and accessible education initiatives, and steps forward for eligibility in advocacy. We look forward to carrying this progress forward into our 40th year, and the future, with you.

Thank you for being the heart of our community and our movement, and for making our work possible.

Sincerely,

Helen Long
CEO, Dying With Dignity Canada



Volunteers from DWDC chapters across the country

A year of advocacy victories and changes ahead

2019 was another busy year for Dying With Dignity Canada (DWDC), as the board, staff, and volunteers worked tirelessly to advocate for changes to medical assistance in dying (MAID) legislation so that it would comply with the Canadian Constitution and the Canadian Charter of Rights and Freedoms.

Following the passage of Bill C-14 in 2016, it was evident that we still had a way to go in ensuring that Canadians could access MAID as an option. This was notable in how Parliament had defined one of the criteria for eligibility, having a “grievous and irremediable medical condition.” The definition included a requirement that “natural death has become reasonably foreseeable.” In related Quebec legislation, the requirements were even more severe: that the person must be at “end of life.”

DWDC went into 2019 supporting two court challenges to Bill C-14 as an intervenor:

Truchon v. Canada, Quebec: The plaintiffs, Jean Truchon and Nicole Gladu, were denied access to an assisted death because, in spite of meeting all other eligibility criteria, they were not at “end of life” as required by Quebec’s law. DWDC made its case in the Truchon challenge in February, arguing that the “reasonably foreseeable” provision of Bill C-14 went against the principles of fundamental justice and was therefore unconstitutional due to its vagueness, creating unequal access to MAID. In September 2019,

Justice Christine Baudouin of the Quebec Superior Court handed down her decision in favour of Mr. Truchon and Ms. Gladu, finding that Quebec and Canada’s MAID laws were too restrictive, and striking down the “reasonably foreseeable” clause and “end of life” criteria.

Lamb v. Canada, British Columbia: Julia Lamb met all eligibility criteria under the federal law, save one — her natural death was not reasonably foreseeable. DWDC was granted intervenor status; however, the case was adjourned in June without going to trial after the Attorney General of Canada submitted evidence to the court from an expert witness stating that Ms. Lamb’s natural death was reasonably foreseeable.

A year of advocacy victories and changes ahead continued

Furthermore, DWDC intervened in a challenge to the requirement of the College of Physicians and Surgeons of Ontario that its registrants who conscientiously object to MAID must still provide effective referrals to other providers willing to assess or provide MAID. DWDC supported the College with stories of real people who had experienced the heartbreak of family members falling through the cracks and not being able to access their right to MAID. Fortunately, the court dismissed the challenge to the College's requirement.

An election campaign in the late summer and early autumn provided an opportunity for DWDC supporters to go out and talk to their candidates about the issues of access and eligibility, and the opportunities for improving legislation, all supported by DWDC's election campaign toolkit. We heard from Canadians and candidates alike that the toolkit was a success in facilitating discussions about how we can, and should, improve MAID legislation.

Following the election, the federal government launched an online public consultation on the removal of the "natural death has become reasonably foreseeable" clause and on allowing advance requests for MAID. DWDC urged supporters to take to social media to mobilize their personal networks and encourage support for these issues, resulting in engaging nearly 300,000 people across the country.

In the fall of 2019, DWDC announced its position with respect to changes to the legislation based on ongoing input from you, our supporters. In December DWDC also commissioned a new Ipsos-Reid poll that asked Canadians about their support for removing the "natural death has become reasonably foreseeable" clause and allowing advance requests for individuals concerned about losing the capacity to consent after being approved for MAID (known as Audrey's Amendment). We were thrilled to see that respondents to the poll strongly supported both the removal of the "natural death has become reasonably foreseeable" clause, and the proposal to waive final consent at the time of delivery of MAID for individuals already assessed and approved.

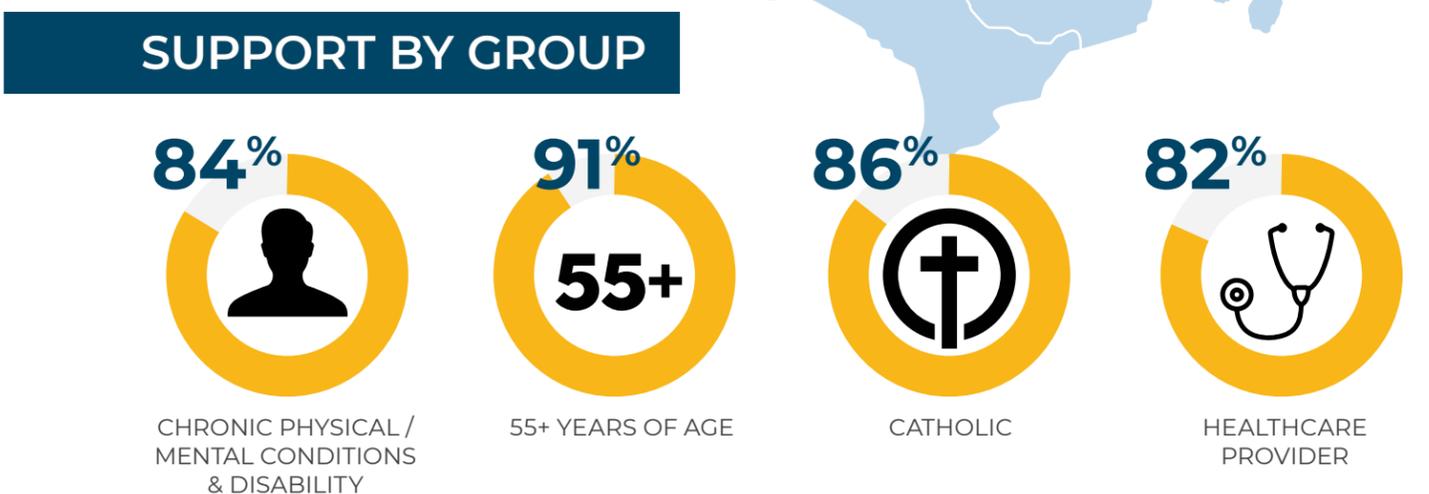
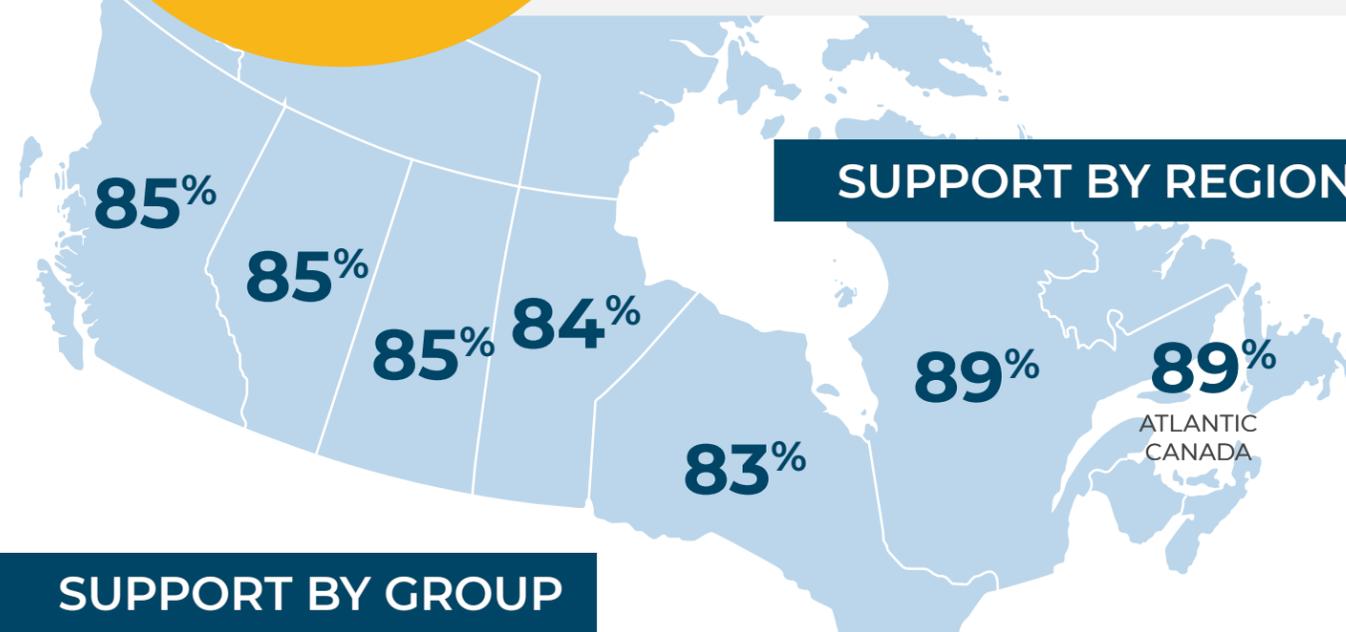
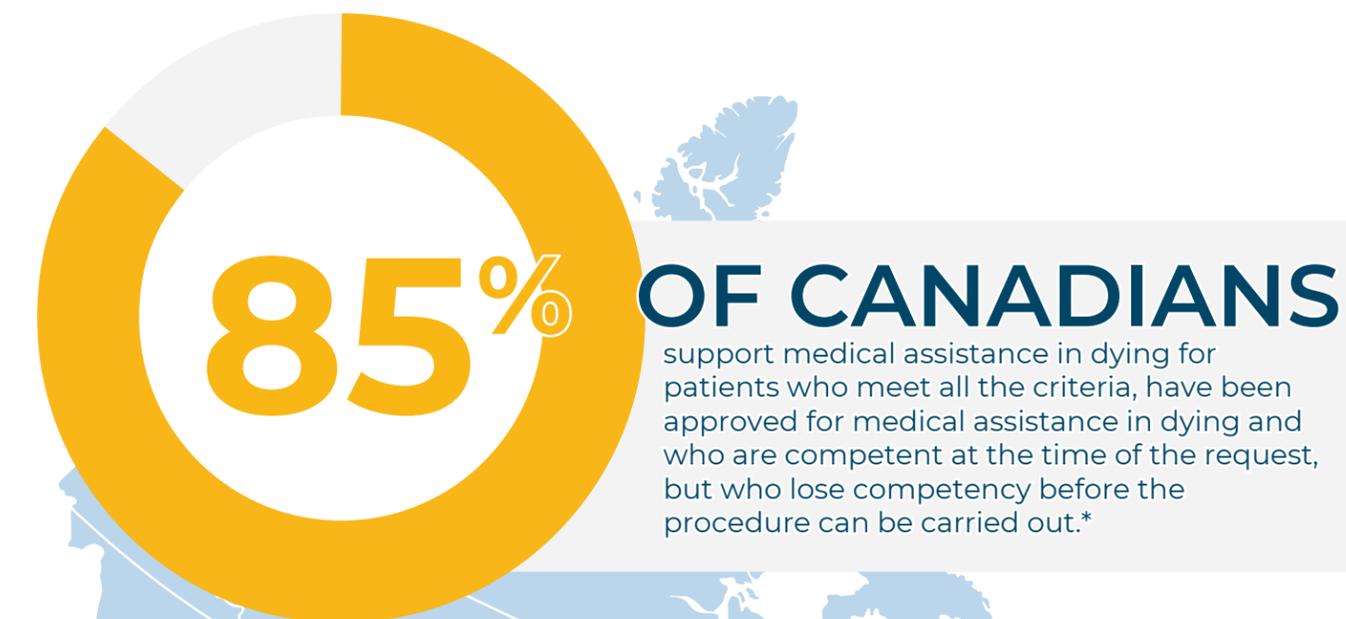
With your continued dedication and support, DWDC will advocate that parliament update the current MAID legislation by removing the "natural death has become reasonably foreseeable" eligibility criterion and adopt Audrey's Amendment without adding barriers to access, while ensuring the public has meaningful opportunities to provide feedback on the future of MAID in Canada.

"Dying With Dignity Canada helped Audrey change the national conversation about assisted dying. They gave Audrey a platform to share her brave and courageous outlook on life, and death. Audrey knew pushing for an amendment to the law would not help her; but it would

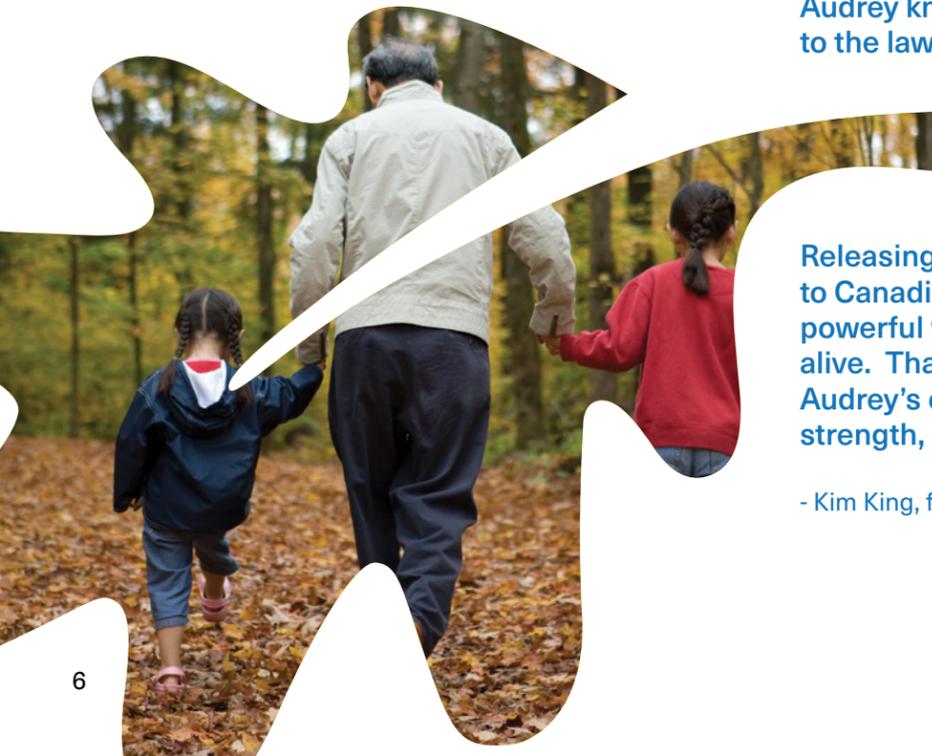
give generations of Canadians comfort and peace. Their advocacy gave Audrey a renewed sense of purpose in her last months of life.

Releasing the video of her final plea to Canadians, in February 2019, was a powerful way of keeping her advocacy alive. Thank you, DWDC, for championing Audrey's cause and your expertise, strength, mentorship and kindness."

- Kim King, friend of Audrey Parker, MAID advocate



*Those respondents who said they "somewhat support" or "strongly support" to the following statement: "Would you support or oppose medical assistance in dying for patients who meet all the criteria, have been approved for medical assistance in dying and who are competent at the time of the request, but who lose competency before the procedure can be carried out?" Ipsos survey, February 2020. Result is considered accurate to within +/- 4 percentage points, 19 times out of 20.



Jule Briese and her husband Wayne have been together for 51 years. After Wayne was diagnosed with Alzheimer's disease in January 2018, writer and educator Jule embarked on a journey to raise awareness and support for Dying With Dignity Canada's work. In this Q & A, Jule shines a light on her experiences and what drives her to generously use her art to support end-of-life rights.

How did you come across Dying With Dignity Canada (DWDC) and why is the issue of end-of-life choice so important to you?

I knew the organization's work was so critical in understanding and supporting what difficult diagnoses mean for people's lives. I would say that DWDC was offering the help and information we felt we needed and couldn't find anywhere else. What is missing today in the discussion around dementia is compassionate support for both care companions and their partners with dementia who would choose medical assistance in dying (MAID) before their window of giving informed consent is jeopardized. This is about the right to choose one's personal quality of life and the option for MAID when that personal quality of life has been severely compromised.

Your book, *The Hot Chocolate and Decadent Cake Society – Alzheimer's and the Choice for MAID* tells the story of your husband's Alzheimer's diagnosis. When did you decide to write this book, and why?

This book of poetry and prose focuses on the first year of our journey following Wayne's Alzheimer's diagnosis, and processing my own emotions around it. The title, *The Hot Chocolate and Decadent Cake Society – Alzheimer's and the Choice For MAID*, reflects the need for compassionate support long before MAID is administered. I thought of my husband's love for hot chocolate and decadent cakes. This book was also created to reflect the importance of advocacy for advance requests for MAID for those with dementia who want access to MAID when their quality of life has been severely compromised.

Why did you choose to fundraise for DWDC?

I connected with members of the DWDC team about fundraising on their behalf after we became donors ourselves. I decided to contribute with every sale of my book, and hold performance fundraisers with

proceeds going to DWDC. I have been fortunate to have DWDC appreciation cards to hand out to my audiences featuring work by an artist who chose to access a medically assisted death (Kathleen "Kathy" Farago, who accessed MAID in September 2017).

I chose the organization because I think DWDC's work creating awareness around support for advance requests for MAID is so critical. Advance requests for MAID for those diagnosed with dementia would eliminate the fear of losing capacity of giving informed consent and no longer require those like my husband to make the difficult decision of accessing MAID earlier than intended.

If you wanted people to understand your and Wayne's story, what would you want them to take away?

Alzheimer's fits under the umbrella of dementia. Those challenged with dementia have the right to be emotionally supported in their right to define what quality of life is for them, what would compromise this quality of life and ultimately what end-of-life choice they would make. I'm not advocating MAID is the only way. I'm advocating for the right to choice, whatever that choice may be.

*A warm thank you to Jule for her generosity – both her support of DWDC, and also her opening up to share her art and poetry about her and Wayne's experiences. Anyone interested in reading *The Hot Chocolate and Decadent Cake Society – Alzheimer's and The Choice For MAID* or a performance by Jule or information about her workshop can email tranquilshorescreative@gmail.com.*

If you're interested in learning more about supporting DWDC in a way that feels right for you, please contact donations@dyingwithdignity.ca.

Donor Profile

Jule Briese



Yes, there are tears and sorrow. There is laughter and gratitude for what is and what was. There also is mourning for what won't be. Through it all my husband's right to choice shines into the shadows...
not time yet
our journey together
still unfolds

- Jule Briese
Excerpt from *The Hot Chocolate and Decadent Cake Society: Alzheimer's and the Choice for MAID*

CROSS-COUNTRY DEVELOPMENTS: HIGHLIGHTS OF 2019 FROM ACROSS CANADA

VANCOUVER, BRITISH COLUMBIA:

- Vancouver DWDC volunteer witnesses assist with 218 witnessing requests, increasing access to end-of-life choice for suffering people in the area.

EDMONTON, ALBERTA:

- The Edmonton chapter of DWDC rallies together to protest Bill 207, an Alberta private member's bill that would have restricted access to medical assistance in dying (MAID) under the guise of doctors' conscience rights. After this period of advocacy engagement, the bill was voted down at a committee meeting.

CALGARY, ALBERTA:

- The Calgary chapter of DWDC holds 29 events over course of 2019, including education workshops, grief support sessions, and chapter meetings.

MONTREAL, QUEBEC:

- In *Truchon v. Canada*, Quebec Superior Court Justice Christine Baudouin strikes down Bill C-14's "reasonably foreseeable" rule as well as a clause in Quebec's Bill 52 restricting MAID access to only those applicants who are at "end of life." DWDC intervened in court in support of the plaintiffs.

NORTH RUSTICO, PEI:

- DWDC launches a new Prince Edward Island chapter to mobilize the community and raise awareness about end-of-life rights. The newly minted chapter hosted their first event in North Rustico in October.

TORONTO, ONTARIO:

- Court of Appeal for Ontario makes the decision to uphold the CPSO's policy on effective referral, a victory for patients' rights. As an official intervener in the appeal, DWDC made a written submission to the court and delivered oral arguments.

BY THE NUMBERS: DYING WITH DIGNITY CANADA'S SUPPORT AND EDUCATION SUCCESSES

In 2019, our Support and Education departments were busier than ever connecting with people across the country. These services included healthcare navigation, clinician sharing webinars, and education workshops to help you understand and access your end-of-life rights and options.

SUPPORT



1,100+
people assisted through
DWDC's Support
Program in 2019

Helped close to

900

patients with their
MAID access forms
across the country



EDUCATION



More than

7,500

hours of volunteer time
were put in by chapter
volunteers across Canada

Over

60

events were held
by chapters across
Canada in 2019





Liana Brittain

Carrying Legacies Forward:

Dying With Dignity Canada's newest council

The newest Dying With Dignity Canada (DWDC) Council is carrying on the memories of their loved ones who chose to access medical assistance in dying (MAID). Meet the First Person Advocates' Initiatives Council (FAIC), its founder Liana, and two of its dedicated members, Jenny and Jack.



Jenny Hasselman



Jack Hopkins

In January 2019, Liana Brittain knew that the First Person Advocates' Initiatives Council was on a roll. After the medically assisted in dying (MAID) death of her partner Paul, she committed herself to media appearances and writing a blog, but the peer support with people who were struggling after their loved ones were gone felt different.

"I wanted to talk to someone else who'd been through the same experience, so there was that bonding aspect of talking to another widow who's been there."

Liana began thinking of how else she could work towards the goal of a peaceful death for others using this shared-experience model. She recognized that everybody was a stakeholder — the healthcare practitioners, the politicians, the nonprofits — but also wanted to make sure people with first-hand experience supporting a loved one through MAID also had a seat at the table.

Liana and others in her network realized it was going to be critical to create a communal voice of lived experience, and the DWDC First Person Advocates' Initiatives Council (FAIC) was born. With the four pillars of DWDC's strategic plan (Education, Access, Support, and Eligibility) as the primary focus, their work is guided by the realization that they can light a path to make the process less opaque for others.

Every member of FAIC has been through the MAID journey with someone they loved. One of the dedicated members is Jack Hopkins, Vice Chair of the FAIC, who is a master's graduate in Digital Media from Ryerson University. He says, "I became aware of DWDC's advocacy work during my own granny's journey with MAID back in 2017. As 2019 began, I wanted to devote some regular time to helping their work, as I know it's so important from my first-hand experience."

Jenny Hasselman lives in Halifax, Nova Scotia, and works as a Director of Events for a marketing company. She and her husband Dan have two children aged 5 and 9 years old. Jenny supported her mother in accessing MAID in July of 2018. Jenny says, "I was struggling with my sadness and mixed emotions... I was seeking the understanding and support of others who might be feeling the same unease and confusion and very specific grief around the MAID process. My hope is to help others understand that this is a uniquely challenging road, but one that we are all familiar with and understand."

However, the First Persons Advocates' Initiative Council is more than an advisory council — it's also an active working group. Jenny is currently the Secretary, as well as working on special projects related to MAID grief. She says the Grief and Education components are the areas she feels the most drawn to, as they speak to her own experience of understanding more about the MAID process and the unique challenges that it poses. "MAID is still so new to many people's experiences, so there is a lot of work to be done to help with education and provide information to support patients and their families and friends through grief."

Jack works on special projects related to advocacy, focusing on looking at the gap between MAID's current regulation in Canada, versus how much we know it must be changed. He says, "We have projects I'm excited about that address some of the barriers in the law. These involve internal team project work, as well as others outside DWDC."

Today, there are 19 members of the FAIC. It's made up of people across the country working in professions as diverse as the TV and film industry, theatre, law, corporate CEOs, and retired professors. The speed with which the FAIC has come together coast to coast in 2019 reveals just how powerful their mission is, and the legacy of their loved ones is reflected in their innovative and important work. In memory of Liana's husband, Jack's grandmother, and Jenny's mother, they are working hard to help those who need resources, access, or support through a loved one's MAID journey.

"This is a first of its kind, not only in Canada, but in the world," says Liana. "No other nonprofit has empowered patients and their loved ones the way DWDC has. We're in a position of leadership in Canada and abroad, and we're making sure we get it right."

We thank Jenny Hasselman, Jack Hopkins, FAIC founder Liana Brittain, and the entire DWDC First Person Advocates' Initiatives Council for their dedication and work on behalf of people across Canada. Learn more about volunteering and DWDC's incredible councils at <https://www.dyingwithdignity.ca/volunteer>

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We are deeply appreciative to our donors for their ongoing generosity; you make our work possible.

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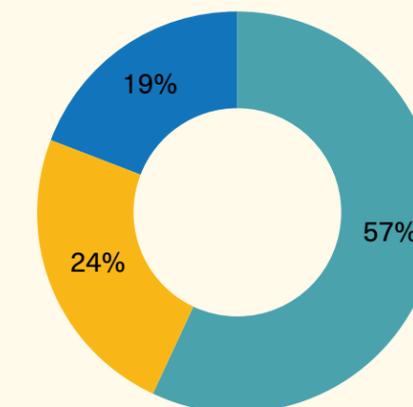
We would like to recognize the members of the Christie Bentham Legacy Society who have pledged a future legacy gift to DWDC. We thank them for their generous commitment to protecting the rights and choices of future generations.

FINANCIAL SNAPSHOT

Dying With Dignity Canada received generous support from our community in 2019, allowing us to further our work forwarding end-of-life rights. Alongside receipt of a remaining portion of David Jackson's \$7M bequest were several other bequests, as well as monthly and annual donations from over 4700 people across the country.

Our Board of Directors understands that Canadians are counting on us not only to make strategic investments that expand the impact and reach of our programs, but also to ensure the sustainability of our organization.

DWDC invested in our advocacy, education and support programs substantially in 2019. We devoted \$1,163,672 to our mission work and have worked hard to invest in growth of our programs and operations, out of expenditures for 2019 totalling \$2,053,605.



Programming
57%

Fundraising
19%

Administration
24%



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