A timely call to action

On the same day the new Liberal government was sworn in, DWD Canada supporters renewed their call for strong, compassionate leadership on physician assisted dying.

It was the most memorable changing of the guard in recent Canadian history.

In a pageant of pomp and circumstance, incoming Prime Minister Justin Trudeau and his cabinet were sworn in at Ottawa’s Rideau Hall on November 4.

As fate would have it, DWD Canada’s National Day of Action fell on the same day. We picked the date in early summer, when suggestions of a Liberal majority would have been written off as far-off fantasy.

So, as Trudeau and his ministers smiled for the cameras, DWD Canada supporters across the country urged the new government to focus on the incredibly important work ahead. Cries of “What do we want? Leadership! When do we want it? Now!” reverberated in all 10 cities that participated in our National Day of Action. We renewed our call for politicians from all levels of government to ensure that patients facing unendurable suffering have fair, safe and timely access to physician assisted dying come Feb. 6, 2016, when the Supreme Court’s landmark Carter v. Canada ruling is set to come into effect.

In Ottawa, former MP and new DWD Canada patron Steven Fletcher — once the House of Commons’ most powerful advocate for choice — energized the crowd on Parliament Hill. “We have come so far, but our work is not yet done,” said Fletcher, who became a quadriplegic as the result of a 1996 car accident. “We must continue the fight until peace of mind at end of life is a reality for all.”

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MESSAGE FROM THE CEO

Let’s get political

Faced with unprecedented challenges and opportunities, DWD Canada has been more vocal than ever; writes CEO Wanda Morris.

The annulment of our charitable status in early March, and our resulting transition from a charity to a not-for-profit, freed us from our handcuffs. As a charity, we could spend only up to 10 per cent of our resources on political activities. As a not-for-profit, we are now restriction-free — and, jumpin’ jelly beans, have we taken advantage of it! We’ve blown that 10 per cent out of the water.

For the first time in our history, the majority of our activity right now is political advocacy, as we lobby for legislation and regulation that honour the Supreme Court’s decision in Carter v. Canada. We started soon after the high court made its decision, meeting with staff and MPs from the federal parties. We worked hard to educate the incumbent Conservative government and promoted a reasoned response to the ruling. History shows we were ultimately unsuccessful, likely as a result of the Tories’ early election call and the decisions they made based on political calculations.

We had greater success with the other parties. We secured statements on assisted dying from the Liberals, the Greens and the NDP, each of them signalling a willingness to follow our suggested direction. We also subjected local candidates to tough questions about their views on physician assisted dying (PAD). Once the writing was on the wall, our well-motivated supporters were active on the campaign trail, questioning candidates and securing statements of support for the Carter decision. Their valiant efforts paid off — PAD was a hot topic at many local all-candidates forums, and the party leaders were asked about end-of-life choice in one of the televised French-language debates.

Focusing on our goals

Lobbying for change is a bit like playing hockey. The teams on the ice have to play both offence and defence. As we pitched our proposed regulatory framework, we were quick to act on potential opportunities and threats. We responded to various government and regulatory consultations — seven so far — and countered critics on our blog and in the media. By creating treaties with other resources, we empowered our supporters to respond to questionnaires, submit stories and share the many compelling reasons they have for supporting PAD.

These are the gritty fundamentals that keep us in the game. But in order to win, we must also take bold strides to the goal. In the last week of October, the release of our “Blueprint for Leadership” was followed by the release of “Our Blueprint for Parliament,” which called for the dissolution of the federal panel on assisted dying, sparked a flurry of media attention. And after our enthusiastic show of strength on our National Day of Action, we have begun petitioning provincial and territorial governments across the country.

We began advocating for legal physician assisted dying more than 30 years ago. And now we are close. But to achieve a regulatory framework that respects Carter, we can’t afford to take our eyes off the puck. We will not rest until it is lying safely in the back of the net.

There are so many paths Canadian decision-makers could take to ready the country for legal assisted dying. Comprehensive federal legislation, minimal federal legislation, harmonized provincial legislation, synchronized regulation for physicians, or some combination of the above — all of these represent viable policy responses to the Supreme Court’s decision in Carter v. Canada.

The problem is, without coordinated leadership on the part of our lawmakers and regulators, we have feared that many patients would not be able to access their legal right to a peaceful death on Feb. 6, 2016 and beyond. An intervention was overdue.

So, together with the BC Civil Liberties Association, DWD Canada has developed a “Blueprint for Leadership on Physician Assisted Dying.” The document outlines what each major policy player must do to ensure that access to end-of-life choice is available to all eligible patients when the Carter decision comes into effect.

“Faced with unprecedented challenges and opportunities, DWD Canada has been more vocal than ever; writes CEO Wanda Morris.”

In brief, our recommendations include:

• Federal government: Disband the discredited federal panel appointed by the previous government. Introduce minimal legislation to amend the Criminal Code to allow PAD. Coordinate with the provinces and territories and their joint expert advisory group.

• Provincial governments: Ensure informed consent laws and other healthcare legislation allow for PAD. Create or amend legislation to protect physicians’ right to conscientious objection and patients’ rights to information and access (through effective referral). Legislate to guarantee access to PAD in publicly funded hospitals, hospices and assisted-living facilities.

• Regulatory bodies: Draft guidelines in keeping with the provincial proposals outlined above. Provide resources and training to physicians who are willing to provide PAD.

A prescription for preparedness

DWD Canada and the BC Civil Liberties Association issue a ‘Blueprint for Leadership’ on assisted dying. DWD Canada supporters in Toronto pose for the camera on our Nov. 4 National Day of Action.

To download the Blueprint, go to DyingWithDignity.ca/blueprint, or order a hard copy by calling our Toronto office toll-free at 1-800-495-6156.
Voice
Your Choice

The road to February 6

With only two months left until the Supreme Court’s decision in *Carter v. Canada* is set to come into effect, politicians, government bureaucrats and medical regulators from coast to coast are getting ready for the biggest change to the Canadian healthcare system in at least a generation. The map below provides an overview of what’s being done across the country to prepare for the decriminalization of physician assisted dying.

**BRITISH COLUMBIA**

Last year, the B.C. government consulted residents on a number of health-related topics, including end-of-life care. The resulting calls for legalizing assisted dying were so loud that an all-party subcommittee was created to address the issue. In November, the group issued a brief report with recommendations that would ensure access to PAD for B.C. residents. However, in a stunning move, the B.C. government refused to adopt the report. Our supporters are calling for its immediate adoption.

**ONTARIO**

The Government of Ontario made headlines this summer when it announced the Canada-wide (excluding Quebec) Provincial-Territorial Expert Advisory Group, mandated to make recommendations on how to implement assisted dying consistently across the country. Co-chaired by assisted dying advocate — and widow of Dr. Don Low — Maureen Taylor and stacked with knowledgeable, experienced and diverse experts, the committee is set to deliver its report by the end of November.

**NEW BRUNSWICK**

Draft regulations circulated by Saskatchewan’s College of Physician and Surgeons have some ambiguity. We just can’t tell whether their referral policy and proposed wait times are reasonable — and that’s not OK. Our supporters are calling on the College to clarify its positions on patient referrals and mandatory wait times.

**QUEBEC**

December 10. That’s the date when physician assisted dying will be legal in La Belle Province. Access will be limited to Quebecers at end of life; those with chronic but non-terminal illnesses will not be eligible, at least at first. Most of Quebec’s 29 hospices are vowing to block assisted dying from occurring on their premises, raising questions about whether choice in dying will be available for some of the province’s most desperately ill patients.

**ALBERTA**

The College of Physicians and Surgeons of Alberta was quick out of the gate with proposed regulations for assisted dying. But the draft rules favoured doctors’ interests over patients. If the recommendations are adopted, Alberta’s physicians will have no obligation to refer patients to ensure they have access to PAD. What’s more, the policy doesn’t include protections for doctors who wish to provide PAD but whose institutions don’t want them to do so. Our supporters have already let the CPSA know that this just won’t do.

**MANITOBA**

Last fall, the College of Physicians and Surgeons released draft regulations in October, but they too are problematic. DWD Canada criticized the proposed rules in the media, arguing that, if implemented, they would unfairly restrict access to assisted dying, especially for residents of remote rural communities. Our supporters are adding their voices to our call for change.

**NEWFOUNDLAND AND LABRADOR**

Involving stakeholders from government ministries and doctors associations, a provincial working group has been tasked with studying the future of physician assisted dying in Newfoundland and Labrador. The group is expected to deliver its recommendations by the end of the year. We look forward to providing input on behalf of patients.

**NOVA SCOTIA**

The College of Physicians and Surgeons of Nova Scotia has indicated that it plans to hold consultations on physician assisted dying. No details had been announced at the time of publication.
DNR orders: Peace of mind for a peaceful death

Learn about an important step you can take now to avoid unwanted medical intervention later.

If you’re nearing the end of your life and have poor health or a terminal illness, a Do Not Resuscitate (DNR) order could make the difference between achieving a peaceful death and enduring unwanted medical treatments with tragic consequences.

By learning more about DNR orders, you’ll be able to make informed decisions about them. You’ll also greatly increase the chances of having your end-of-life wishes followed.

What is a DNR order?

If your heart stops and paramedics are called to the scene, the standard practice is for them to administer cardio-pulmonary resuscitation (CPR) in an attempt to save your life. A DNR order is a form that indicates your desire that CPR not be initiated.

In most provinces, several DNR forms exist in addition to those designed to inform paramedics. Hospitals and care facilities often have their own forms, used to indicate a patient’s status as DNR or “full code,” meaning that all life-preserving measures should be taken.

Why wouldn’t I want CPR?

Whether or not you wish to receive CPR should depend on your state of health and your personal values. Far too often, patients receive CPR only to wish they hadn’t. While CPR can be life-saving, it may be ignored if your substitute decision-maker signals that CPR should still be performed. Speak to your substitute decision-maker to ensure your wishes will be followed. If your substitute decision-maker refuses to accept your wish to forego CPR, it’s time to find someone else who is able to advocate on your behalf.

You should also take steps to ensure that paramedics can locate your DNR form in an emergency. This is another reason why communicating with your family members and your substitute decision-maker is critical. Let them know where you keep your DNR order form, and leave it in an easy-to-find place (on the fridge is a popular spot).

Carry your DWD Canada Support Card in your wallet. When people are looking for your ID, they will find this card. It instantly provides contact information for your substitute decision-maker and, if applicable, the serial number for your DNR form. You can even keep a folded-up copy of your DNR order inside your wallet card to help ensure it is found.

—Andrew Schipper

Q & A with a champion of change

Vancouver’s Dr. Sue Hughson reveals what drives her to speak out for compassionate choice.

The drive for choice at the end of life enjoys both the support of Canadians who have no activist pedigree and those who have lots.

DWD Canada board member and Vancouver chapter head Sue Hughson falls into the latter camp. She was already a champion for women’s rights and for humanitarian, among other causes, before becoming an instrumental player in our advocacy on the West Coast.

We spoke with Sue this fall to find out why she got involved with DWD Canada, how she reacted when she first learned of the Supreme Court’s decision on assisted dying, and what she likes best about working alongside her compatriots in the cause.

Here’s what she had to say:

Q: What motivated you to first get involved in the movement?

A: The motivation is both professional and personal. In my professional life, I’m a full-time veterinarian. And in my personal and family life, I have seen too many family members and friends die deaths that they wished would unfold differently. Equally, I have seen a family member and a friend have the care that they wished to have. In particular, with my uncle, his family members made it possible for him to die at home by giving him palliative care and managing his pain. He did die comfortably, exactly the way he wanted to.

Q: What was your reaction when you first learned of the Supreme Court’s decision to strike down the old law banning assisted dying?

A: I had the privilege of being in the office of (B.C. law firm) Farris. We were waiting for a call from (BC Civil Liberties Association Executive Director) Josh Paterson as what the decision came about. Some of the people in the room had been front and centre in the case. When we first got the news, it was silent in the room.

On a personal level, I was going, “Are we sure? Is this right? Did I hear this correctly?” It probably took about 20 or 30 seconds to register. Then, Josh told us that the decision had been unanimous. And we all just cheered and embraced.

Q: What’s your favourite part of working with the people involved in our movement?

A: Just trying to keep up with the scope and breadth of our senior board members is personally very fulfilling. I have seen how hard they’ve worked to get physician-assisted dying where it is. That is something that Canadians can take heart in, if they choose. Being in the same environment with those people is pretty impressive.

And then on a local level, speaking to individuals is very fulfilling, too. With any volunteer association, you have people who can do certain things and can’t do others. I enjoy helping to direct people towards where they can make a contribution. I feel this is a very nice example of one grassroots organization that operates on a pretty shoestring budget and has managed to touch a great number of Canadians. All of those people doing one small thing has really added up to something much larger.

This interview has been edited for length and clarity.

—Cory Ruf

Complete a Do Not Resuscitate order can help you avoid unwanted treatment during a medical emergency. (Mario Beauregard/Adobe Stock)
Nigel Patrick Lawrence was a man of conviction. 

As a judge presiding over child welfare courts in Alberta for the latter half of his career, he challenged his colleagues in the courtroom to always put kids’ interests first. His judgments weren’t always popular, but no one could deny they were rooted in principle. “This is the Child Welfare Act and not the Parent Welfare Act,” he would quip.

Before he was appointed as a judge, “Pat,” as he was known to most of his friends and family members, served his community with a particular interest in healthcare and medical science. He sat on numerous boards and commissions that focused on quality healthcare and medical research.

Above all, his rock-solid conviction extended to his commitment to family. Pat was devoted to Stephanie, his wife of 55 years, and their three daughters, Gillian, Jennifer and Pamela.

He was on occasion outspoken and irrevocent but at all times fastidious, courteous, perceptive and compassionate. Patrick travelled to many places, took some good photographs, read many books and grew gorgeous lilies in his backyard.

Pat believed he had lived a full and good life, accomplishing everything that was important to him. So when Parkinson’s Disease, coupled with other ailments, made him feel that his body no longer served him with dignity, he expressed his wish to die on his own terms.

When the Supreme Court of Canada made its historic decision on assisted dying on February 6, 2015, Pat held out some hope that he might be able to die peacefully at home at a time of his choosing. But with the progression of his disease and, as he put it, the federal government “dragging its feet,” he had to make other plans.

This summer, Pat travelled to Switzerland to access physician assisted dying. And on August 26, surrounded by his family, he died in the peace and comfort he sought for himself. He was 80.

The night before, his daughter Pamela asked him how he was feeling. “Free as a bird,” he answered.

True to form, Pat wanted his commitment to helping others to extend beyond his lifetime. He wanted one of his many legacies to include that safe, fair and timely access to physician assisted dying be available to all Canadians, not just a privileged few.

Heeding Pat’s wishes, the Lawrence Family has encouraged friends and relatives to donate to Dying With Dignity Canada in his memory. The generous contributions of Pat’s supporters empower us as we work to make unwanted, unnecessary suffering at end of life a thing of the past.

We thank the Lawrences for continuing to honour Pat’s desire to see change through. Because of them, his commitment to improving the lives of others will continue to shine on Canadians for decades to come.

A number of speakers raised the spectre of the provincial medical regulators creating new rules that will unfairly limit Canadians’ access to their right to die with dignity.

“We cannot let the rules for physician assisted dying be written by unelected, unaccountable bodies.”

—DWD Canada CEO Wanda Morris

Supporters in Vancouver heard from Elayne Shapray, whose decades-long battle with Multiple Sclerosis led her to speak out for the right to a peaceful death. “The time for debating this decision is over,” she said. “It is time to enact this decision, without delay. “No more committees, no more discussion, no more fear tactics intended to stall and put barriers in the way of individual freedoms.”

In Toronto, DWD Canada Disability Advisory Council member Linda Jarrett hit home why physician assisted dying is a compassionate option for patients with debilitating chronic diseases.

“I love life,” said Jarrett, who also has MS. “But I am in a position where I know that the end of my life is something that I can’t tolerate. And when the time comes, I want the right to have a doctor help me out of this life.”

To make a donation
In Memoriam, go to Dyingwithdignity.ca/donate, or call our Toronto office toll-free at 1-800-495-6156.