



# VOICE FOR CHOICE

## Will the federal election be a game-changer?

The writ has dropped and candidates are already weaving their way across the country: Canada is officially in the midst of its longest federal election campaign since 1872.

While the contenders will focus on plans to keep Canada prosperous and safe, we must make sure they don't ignore one of the most important social policy issues to face Parliament in a generation: our hard-won right to physician assisted dying.

Seven months have passed since the Supreme Court struck down the *Criminal Code* ban on assisted dying. When the decision takes effect on Feb. 6, 2016, it will no longer be illegal for a doctor to help a competent adult end his or her own life, so long as the patient is experiencing intolerable, incurable suffering as a result of a grievous illness, injury or disability.

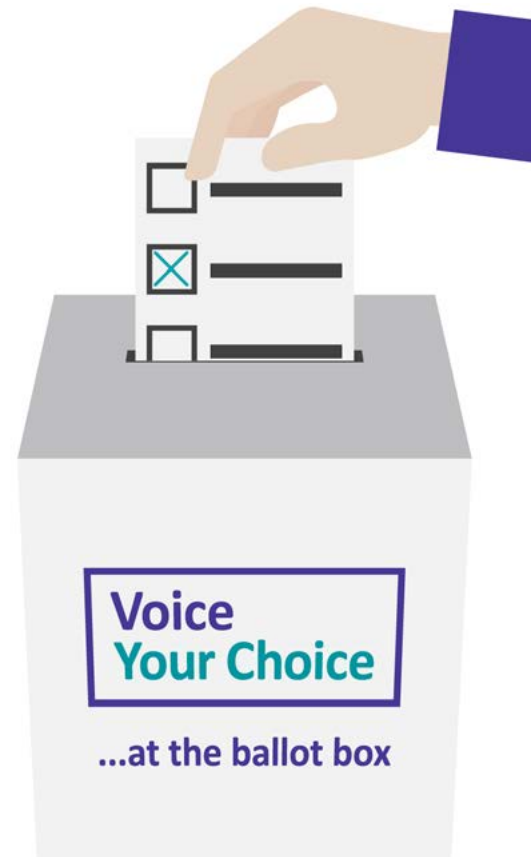
The outcome of the election promises to have a major impact on whether patients facing horrific diagnoses will have safe, reliable access to assisted dying by next February. Outgoing Justice Minister Peter MacKay has indicated the Conservative government, if re-elected, would ask the Supreme Court to postpone implementing assisted dying. Worse than a delay would be new, restrictive laws that impose cruel, unnecessary barriers upon gravely ill

patients looking to exercise their right to a peaceful death. We cannot allow this to happen.

### Voice Your Choice during the election

The major parties may be content to avoid debating assisted dying during the campaign. But we know patients facing a horrific death cannot afford more duck-and-cover tactics from federal politicians, especially with the Feb. 2016 deadline close at hand. So it's up to us to press our politicians for clear answers on the following question: "Do you support legislation that honours the wording and spirit of the Supreme Court's decision in *Carter* (for the right to die with dignity)?"

We have already begun mobilizing our supporters to participate in the government's online consultation on assisted dying. And, as part of our just-launched Voice Your Choice Campaign, we've developed toolkits on how to press candidates to reveal their views on assisted dying, drafted non-partisan



promotional materials for you to distribute in your ridings, and created compelling video content for you to share on social media. All you need to do is speak out.

The hard work won't stop once the votes are tallied on Oct. 19. The first stage of our campaign will culminate with our National Day of Action on Nov. 4. Our rallies, including one on Parliament Hill, will send a loud, clear message to the next government: we are watching.

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## MESSAGE FROM THE CEO

### Ontario leads a provincial charge

Unwilling to wait longer for leadership from the federal government, the provinces are working together to develop a harmonized approach on physician assisted dying.



Wanda Morris, CEO

In April, the Conservative government announced it would legislate but took no concrete steps to do so. In July, they named a three-member panel, which includes two panelists who testified **against** the right to physician assisted dying, to consult with Canadians. The federal election call just two weeks later put elements of the consultation on hold.

In light of these events, we questioned whether Ottawa was willing to accept the Supreme Court's decision or whether they were seeking to undermine it.

Fortunately, the feds are not the only game in town. On Aug. 14, the Government of Ontario announced a multi-provincial expert panel to assist all provinces and territories in framing legislation, to avoid a patchwork approach to physician assisted dying.

This is great news. We've met with provincial representatives in Ontario (and elsewhere) and found them keenly aware of the scope of the Supreme Court's decision and strongly committed to implementing it.

At Dying With Dignity Canada, we have long believed that physician assisted dying is a health matter — not a criminal one. Furthermore, some of the most

critical implementation issues to be resolved are questions of access. These are within provincial jurisdiction.

In choosing Maureen Taylor, Don Low's widow, as the panel's co-chair, the provinces have given a strong voice to those most impacted by assisted dying: patients and their loved ones. But this is by no means a solely pro-assisted dying group. It also includes vocal opponents of assisted dying, so all Canadians, whatever their views, have a voice.

### The CMA's great leap forward

The Canadian Medical Association (CMA) and DWD Canada have been at loggerheads for most of our history.

This is changing. Whether through the bridge-building of our Physicians Advisory Council, outreach from our staff, or simply as a result of the Supreme Court's decision, our relationship with the CMA has improved dramatically. Our two organizations now both want an assisted dying regime that meets the needs of patients and their physicians while protecting the vulnerable from coercion.

Of course, our positions differ slightly. Not surprisingly, the CMA tends to emphasize the concerns of physicians while we focus on the needs of patients. The CMA is also silent on areas that are outside their scope but within ours, such as the need to ensure patients can access assisted deaths without obstruction by institutions or pharmacists. But far more unites us than divides us.

This is a testament to the CMA's leadership, both professional and volunteer, and the physicians across the country who have worked so diligently to create alliances and bring change.

While everything could change at the CMA's annual meeting in August, I'm optimistic that they will stay the course.

—Wanda Morris

## Crunching numbers, creating awareness

A detailed analysis of our Personal Support and Advocacy calls makes front-page news.

Dying With Dignity Canada made national news again this summer, this time for the demographic insights we've gleaned about which Canadians may seek legal assisted death.

Each year, our Personal Support and Advocacy Program staff and volunteers field more than 100 calls from Canadians wishing to learn more about their options at end of life. We recently pored over 2.5 years' worth of records on these inquiries and identified a number of patterns.

Though not a representative snapshot of end-of-life care in this country, these findings provide valuable insights into the demographic profile, questions and concerns of gravely ill Canadians looking to die on their own terms.

Journalist Sharon Kirkey featured our

findings for a front-page story in the July 9 edition of the *National Post*. She interviewed Nino Sekopet, our Personal Support and Advocacy Program Manager, to learn more about what motivates people to seek information about their end-of-life options.

"Their opening line, in 90 per cent of cases is, 'I'm severely ill' or 'I anticipate that in a couple of years my condition will worsen to the degree that I won't be interested in living anymore, so what are my options,'" he told the *Post*. "They are actually asking, 'How can I die before my time comes?' And they're not interested only in medical options. They're interested in any option that will give them some kind of non-violent end of life."

The statistics raise troubling questions



Nino Sekopet

about family doctors' comfort with addressing sensitive issues around death and dying. Of the 399 individuals who called DWD Canada between Jan. 1, 2013 and May 31, 2015 to inquire about their end-of-life choices, only 12 per cent had a family physician who was supportive of their efforts to explore all their legal options. After excluding callers who didn't report having a family doctor, the rate of support ticked up only slightly, to 14 per cent.

"The evidence we've gathered suggests to me that death and dying is still taboo, even among the professionals who should be best equipped to address the subject," Sekopet says. "It's a shocking, sad story."

Though clients' experiences vary, their calls offer meaningful clues as to why many physicians can't, or won't, help patients with their research.

"Sometimes individuals go unprepared," says Sekopet, a trained psychotherapist. "I can imagine that very often, when they're asking questions, their doctors may dismiss these concerns as an impulse or not as a constant in the patients' lives."

"Patients asking about their end-of-life options sometimes get labelled as depressed, or their doctors will try to steer the conversation in a different direction," he adds. "It's something we have to challenge."

To find detailed information on the findings on our website, visit [www.dyingwithdignity.ca/psap\\_analysis](http://www.dyingwithdignity.ca/psap_analysis).



Introducing...

# Voice Your Choice

## A campaign for compassion

The chorus for compassion is growing louder. That's why we at DWD Canada are delighted to unveil the Voice Your Choice Campaign. A platform for our advocacy efforts moving forward, it's designed to channel our collective passion into lasting change.

As its name suggests, Voice Your Choice will centre on opportunities for you — the overwhelming majority of Canadians who support the right to physician assisted dying — to speak out. The main objective of the first phase of the campaign: demand new legislation that reflects the letter and the spirit of the Supreme Court's ruling in *Carter v. Canada*.

*Here's how you can Voice Your Choice in the weeks and months ahead:*

### IN THE PUBLIC CONSULTATION

AUGUST - OCTOBER

We will mobilize our supporters to participate in the national public consultation on assisted dying. Using our new digital engagement tools, we will direct legions of Canadians to the consultation's online submissions portal and supply them with the tools they need to craft an informed, impactful response.

### DURING THE FEDERAL ELECTION

SEPTEMBER - OCTOBER

Posing the tough questions at town hall debates. Meeting with local candidates one-on-one. Flooding their e-mail inboxes so they know where you stand. With February 2016 so close at hand, we will not rest until our federal politicians clearly state their plans to legislate a response to the Supreme Court's decision in *Carter v. Canada*.

### TO THE PROVINCES

SEPTEMBER - OCTOBER

After months of federal inaction and now with an election underway, it's time for provincial players to cough up answers on how they will ensure safe, fair and timely access to assisted dying for patients facing unendurable suffering. After all, healthcare is largely the responsibility of the provinces. Let's make sure they're doing their job.

### ON OUR NATIONAL DAY OF ACTION

NOVEMBER 4, 2015

No more dithering. No more delays. No pleading to the Supreme Court to put off the implementation of its historic decision. "Get your act together" will be the clear and unmistakable message we send to the new government on our National Day of Action on Nov. 4, 2015. While our supporters spread the word at rallies across the country, we will deliver our demands for new assisted dying legislation to the incoming Parliament.

### UNTIL THE JOB IS DONE

DECEMBER + BEYOND

The work of ensuring our hard-won right to a peaceful death is respected won't cease in November, after Christmas, or even on Feb. 6, 2016, when the Supreme Court's decision is set to come into effect. But don't worry — with so many of you gearing up to Voice Your Choice this fall, we have amassed more than enough momentum to see change through.

AUGUST

SEPTEMBER

OCTOBER

NOVEMBER

DECEMBER

## We're not there yet!

Three major barriers we must still overcome to allow Canadians meaningful access to assisted dying

Will assisted dying be available to all Canadians who face horrific deaths or catastrophic medical conditions? Or will implementation delays and complex regulations keep assisted dying virtually inaccessible to patients, no matter how much they suffer?

The answers depend on how our lawmakers address three challenges that will be at the centre of our advocacy as we push for new assisted dying legislation:

### 1 Safeguards should be reasonable, but not excessive.

Governments must not eviscerate the Supreme Court's decision by legislating onerous barriers to access rather than reasonable safeguards. Having a second physician confirm a patient's competence is a reasonable safeguard. Judicial reviews of every request, or requiring sign-off from a patient's entire family, are not.



### 2 Non-participating physicians and pharmacists must provide effective referrals.

Doctors may decline to provide assisted dying and pharmacists may opt out of filling prescriptions. But they cannot abandon their patients.



### 3 Patients need to be able to die wherever they live.

Hospitals, hospices and long-term care facilities cannot be allowed to prevent a willing doctor from assisting an eligible patient. Institutions, including hospitals, hospices and long-term care facilities that receive public funds, must not be allowed to prevent Canadians from exercising their legal right to an assisted death.



# The limits of consent: Do patients have a right to futile treatment?

Law student and DWD Canada volunteer Andrew Schipper examines two cases from Ontario.

“Who decides whether I live or die?”

This question lingers in the minds of those of us who support the right-to-die movement in Canada.

While rules vary by province, competent adults, or their substitute decision-makers, can generally refuse any medical test, treatment or intervention.

But is the reverse true? Can a patient demand a particular treatment from a doctor, even against the doctor’s judgment? Two recent cases in Ontario offer critical clues about patients’ rights to life support and resuscitation.

life support could not be discontinued without their consent. Rasouli’s doctors responded that they could not be compelled to continue treatment they deemed futile.

The Supreme Court ruled in favour of keeping Rasouli on life support, but this was not a black and white case. The Court found that **withdrawal** of life support is “treatment” in Ontario. Because consent is required for treatment, the doctors could not remove Rasouli from life support without it.

The Supreme Court’s decision did highlight another option for doctors.

spreading gangrene in his legs. DeGuerre and his daughter, Joy Wawrzyniak, who would act as his substitute decision-maker, established with his doctors that he was to be designated “full code,” indicating he was to be resuscitated in the event of a cardiac or respiratory arrest.

In the following weeks, DeGuerre’s condition declined, and he would eventually need to have his legs amputated above the knee. Unbeknownst to Wawrzyniak, DeGuerre’s doctors unilaterally changed his status from “full code” to “do not resuscitate.”

When he entered cardiac arrest, Wawrzyniak implored the doctors to resuscitate her father. However, their belief was that to do so would be futile. They did not attempt to revive him.

Wawrzyniak lodged a complaint with the College of Physicians and Surgeons of Ontario (CPSO), where she argued the doctor’s needed to obtain consent to change her father’s DNR status. In June 2015, the CPSO cautioned the doctors

for their failure to properly notify Wawrzyniak of the change to her father’s DNR status. The reprimand related to communication only. The CPSO insisted, as they had in previous appeals, that the doctors had exercised proper clinical judgment.

Wawrzyniak argued that *Rasouli* established a requirement for doctors to obtain consent for a DNR order. The CPSO’s statement does not concur and argues that the use of DNR orders “remains a grey area.”



Can a patient demand a particular treatment from a doctor?

Sunnybrook Hospital in Toronto

## Hassan Rasouli: Withdrawal of treatment

In 2010, Hassan Rasouli fell into a coma after developing bacterial meningitis following brain surgery. With Rasouli being kept alive by feeding tubes and a ventilator, doctors at Toronto’s Sunnybrook Hospital informed his family that he had no chance of recovery and advised that life support be discontinued.

When Rasouli’s wife refused consent to remove life support, a legal battle ensued that would rise all the way to the Supreme Court. Rasouli’s family argued that

Ontario has a Consent and Capacity Board, which has the authority to settle questions of treatment and capacity. If a physician faces a similar situation in the future, he or she can take their case to the Consent and Capacity Board, where the panel can rule on whether the treatment is warranted.

## Douglas DeGuerre: Demanding futile treatment

In 2008, Douglas DeGuerre was admitted to hospital — Sunnybrook in Toronto, as fate would have it — to treat the

## What do these cases tell us?

The *Rasouli* decision at the Supreme Court informed us about the need for physicians to seek consent to remove life support, either from the patient, their substitute decision-maker or ultimately through an arbitrator such as the Ontario Consent and Capacity Board. Douglas DeGuerre’s ordeal shows that, while consent is required for treatment to be administered, it is unlikely that we can demand treatment deemed futile by doctors.

—Andrew Schipper

## Riding the winds of change in Lethbridge

They're vocal, they're committed and they're blazing a trail for DWD Canada in southern Alberta.

Our Lethbridge chapter has grown by leaps and bounds in the two years since it was founded. In July 2013, John Warren, then vice-president of DWD Canada, convened a get-together of 20 or so friends to discuss what a group of thoughtful, passionate citizens could do to change the laws around physician assisted dying. That informal gathering has quadrupled and is now one of DWD Canada's most active chapters.

The dedicated group benefits from the wide range of experience and skills among its members, including Lethbridge chapter coordinators: Norma Boulton, Cheryl Bradley, Bev Potter, John Warren and Susan Whishaw. With their combined organizational savvy, they've undertaken a staggering amount of outreach in the local community.

They have been active in organizing speakers for three successful sessions at the Southern Alberta Council on Public Affairs and for one session at the Peace and Justice Committee of McKillop United Church. Volunteers from the Lethbridge chapter have engaged their community at Applefest and the 55+ Showcase of the Lethbridge Senior Citizens' Organization. Three times a year, four dedicated volunteers distribute DWD Canada's *Voice for Choice* newsletters to about 50 offices around town.

The Lethbridge chapter has also held film screenings of Terry Pratchett's *Shaking Hands with Death* and *How to Die in Oregon*. They held a summer social and fundraiser in 2014, which brought out 30 DWD Canada supporters, and planned another for this year.

## Grabbing headlines on our National Day of Action

Perhaps their biggest coup to date came ahead of DWD Canada's National Day of Action and Solidarity on Oct. 15, 2014. Because of the chapter's dispatches to the press, the Lethbridge rally made front-page news before it was even staged. Six local media outlets covered the demonstration itself, which attracted 75 DWD Canada supporters.

After the Supreme Court's landmark decision in *Carter v. Canada*, the chapter is dedicated to ensuring the best possible legislation for physician assisted dying. In June 2015, chapter coordinators sent a letter to 88 doctors in Lethbridge, asking for their support of physician assisted dying. And through e-mail, they've encouraged local DWD Canada members and supporters to press their MPs to speak out in favour of fair, timely access to physician assisted dying.

DWD Canada's national office thanks you for all your energy, passion and commitment. Well done, Lethbridge!



From left to right: Lethbridge chapter coordinators Cheryl Bradley, Bev Potter, Norma Boulton, John Warren and Susan Whishaw (with Chaco the dog).

## A quarter-century of compassion

It was an era of high interest rates, billowy shoulder pads and the fall of the Berlin Wall.

Much has changed since 1989, but Senta Chisholm's commitment to compassion and choice has remained a constant. A resident of Mulmur, Ont., she first donated to DWD Canada 26 years ago after witnessing her mother's long battle with Alzheimer's disease.

"In today's world people live longer lives but are often forced to spend their final

Senta continues to contribute despite the annulment of DWD Canada's charitable status earlier this year. In fact, she's a Defender of Dignity, having signed up for our monthly giving program in 2014.

"It was never about the tax receipt. I hope that other donors feel the same way and will continue to contribute," Senta says.

Our Defenders of Dignity provide DWD Canada with the stable funding needed to plan ahead. Monthly donations also reduce our administrative costs, meaning more donation dollars go directly into our political advocacy and support programs.

Plus, monthly donations are automated, meaning there's no need to rummage around for your chequebook at Holiday Giving time. "Because people are so busy with life these days, an annual contribution is easily forgotten," Senta points out.

We are immensely grateful for Senta and all of our monthly donors. They empower us to finish the job of winning Canadians the choice to die with dignity — for the next 26 years and beyond.



*Long-time DWD Canada donor  
Senta Chisholm*

*"It was never about the tax receipt. I hope that other donors feel the same way and will continue to contribute."*

years coping with prolonged and acute suffering, relying on others for care, all the while enduring declining quality of life and total loss of dignity," she says.

## Three generations of giving

For Andrew Schipper, pitching in to support the work of DWD Canada is a family affair. His parents, Stuart and Jane, have contributed generously to the cause. So have his paternal grandparents, Lionel and Carol.

A law student at Queen's University, Andrew volunteered his time and talent at our Toronto office this summer to research issues related to end-of-life care. He dug deep into B.C. legal briefs to find out what could be done to prevent another case like Margot Bentley's, and he picked apart flaws in the advance-care directive laws in other provinces. Some of his hard work is featured in this very newsletter!

Andrew's interest in the cause isn't purely academic. "When I told friends and family how I was spending my summer, it became clear that end-of-life choice is an issue that everyone cares about," he says. "I was amazed at the outpouring of support

I received and by how many people had their own stories about why being able to die peacefully is important to them."

DWD Canada would like to thank Andrew for carrying on the Schipper traditions of volunteerism and philanthropy. We wish him the best with his studies this fall.

*"When I told my friends and family, it became clear to me that end-of-life choice is an issue that everyone cares about. I was amazed at the outpouring of support I received."*

If you would like to volunteer with DWD Canada, please contact Kelsey Goforth, our National Volunteer and Events Coordinator, at [kelsey@dyingwithdignity.ca](mailto:kelsey@dyingwithdignity.ca).



*Law student and DWD Canada  
volunteer Andrew Schipper*