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EXECUTIVE SUMMARY

In the first half of 2014, the Canadian Medical Association (CMA) in partnership with *Maclean's* magazine hosted a series of town hall meetings in all regions of Canada for the public on end-of-life care issues.

The national dialogue focused on three main issues: advance care directives, palliative care, and euthanasia and physician-assisted dying. The main aim of the consultation process was to seek input from Canadians on their perceptions and views about the status of end-of-life care in Canada. However, an important secondary purpose was to provide common definitions and terminology as part of an informed discussion on end-of-life care issues and to broadly inform the public about the current legal and legislative situation in Canada and abroad.

The national dialogue was launched in response to a need for leadership in fostering a societal discussion around end-of-life care issues. As validated in the town halls, the CMA was well positioned to provide the needed leadership in raising awareness about these issues.

Town halls were held in St. John's, NL (Feb. 20), Vancouver, BC (Mar. 24), Whitehorse, Yukon (Apr. 16), Regina, Sask. (May 7), and Mississauga, Ont. (May 27). A live web chat was also held on May 12 on the *Maclean's* website. Members of the public were also able to post their comments online during and after each town hall.

The town hall meetings were moderated by senior *Maclean's* editorial staff and conducted under the guidance of Dr. Jeff Blackmer, the CMA's executive director of ethics, professionalism and international affairs. Each meeting followed the same format, with discussions about the terminology of end-of-life care followed by questions to the audience and discussions about advance care planning and directives, palliative care, and euthanasia and physician-assisted dying.

While it was clear that members of the public often had diametrically opposed views on the controversial topic of euthanasia and physician-assisted dying, common ground was evident on many other important issues ranging from the importance of advance care directives to the need for a comprehensive palliative care strategy in Canada.

The aim of the national dialogue process was to further inform the medical profession on the views of the public on this societal issue.* A number of important conclusions and calls for action can be made as a result of the consultation process:

- All Canadians should discuss end-of-life wishes with their families or other loved ones.
- All Canadians should prepare advance care directives that are appropriate and binding for the jurisdiction in which they live.

- A national palliative care strategy should be developed.
- All Canadians should have access to appropriate palliative care services and many don't.
- More education about palliative care approaches and services as well as about how to initiate discussions about advance care planning is required for medical students, residents and practising physicians.
- The Canadian public is divided on whether the current Canadian ban on euthanasia and physician-assisted dying should be maintained or not.
- If the law in Canada is changed to allow euthanasia or physician-assisted dying, strict protocols and safeguards are required to protect vulnerable individuals and populations.

The content from this report and input from a parallel consultation process conducted with CMA members will form the basis for CMA advocacy activities on these issues and future policy development.

* There were no consultations in Quebec because a government-led public consultation had already been held in the province. (<http://www.assnat.qc.ca/fr/travaux-parlementaires/commissions/CSMD/mandats/Mandat-12989/index.html>)



"We need to hear more from Canadians about how their health care system can ensure not only a long, healthy life but also a good death."

— Dr. Louis Hugo Francescutti,
CMA President, St. John's

INTRODUCTION

During the winter and spring of 2014, the Canadian Medical Association (CMA) in partnership with Maclean's magazine hosted a series of town hall meetings across Canada for the public on end-of-life care issues. The meetings were held with the assistance of the Canadian Society of Palliative Care Physicians and the Canadian Hospice Palliative Care Association. A virtual online dialogue was also held on May 12.

This national dialogue focused on three main issues: advance care planning and directives, palliative care, and euthanasia and physician-assisted dying. One aim of this dialogue was to provide clarity for the public on the often-complex terminology surrounding end-of-life care issues and to broadly educate them about the current situation in Canada and abroad. However, the main aim of the meetings was to seek input from Canadians on their perceptions and views about these topics.

The consultation was launched by the CMA to provide Canadians with the opportunity to have a societal discussion on this issue as well as in response to a series of legal, legislative and societal factors that are stimulating a re-evaluation of the current Canadian landscape around end-of-life care. The dialogue was organized and conducted by the CMA at the direction of the association's Board of Directors, who felt the CMA was well

positioned to provide the needed leadership and direction in launching a dialogue about these serious issues.

Town halls were held in St. John's, NL (Feb. 20), Vancouver, BC (Mar. 24), Whitehorse, Yukon (Apr. 16), Regina, Sask. (May 7), and Mississauga, Ont. (May 27). All events were live streamed and Canadians from all regions were able to provide comments online. A live web chat was also held on May 12 on the Maclean's website. Participation at the meetings often exceeded 100 people, with more than 225 attending the session in Vancouver. Most town halls were also actively discussed on Twitter using the hashtag #eolCdn.

The town hall meetings were moderated by senior Maclean's editorial staff and conducted under the guidance of Dr. Jeff Blackmer, the CMA's executive director of ethics, professionalism and international affairs. Each meeting featured a panel consisting of Dr. Blackmer

as well as local palliative care physicians and patient representatives, and a series of videos designed to frame the discussion were also presented. The same format was used at each meeting: the panel discussed the terminology of end-of-life care and then questions (see page 3) were posed to the audience and discussions were held about advance care planning and directives, palliative care, and euthanasia and physician-assisted dying. The live web chat was led by CMA President Dr. Louis Hugo Francescutti, who also provided introductory and concluding remarks at each of the town hall meetings. Despite the often-emotional nature of the subject matter and the diversity of views expressed, all meetings were conducted with decorum, with participants respecting opposing viewpoints.

While it was clear that members of the public often had diametrically opposed views on the controversial topic of euthanasia and physician-assisted dying, common ground was evident on many other important issues ranging from the importance of advance care directives to the need for a comprehensive palliative care strategy in Canada.

THE CURRENT ENVIRONMENT

Several recent events and circumstances have put a new spotlight on euthanasia and associated issues in Canada and provided a backdrop for the CMA town hall meetings. The two most significant of these involve a Supreme Court challenge of current legislation banning physician-assisted death in Canada, and pending Quebec legislation in this area.

THE CARTER CASE AND THE SUPREME COURT

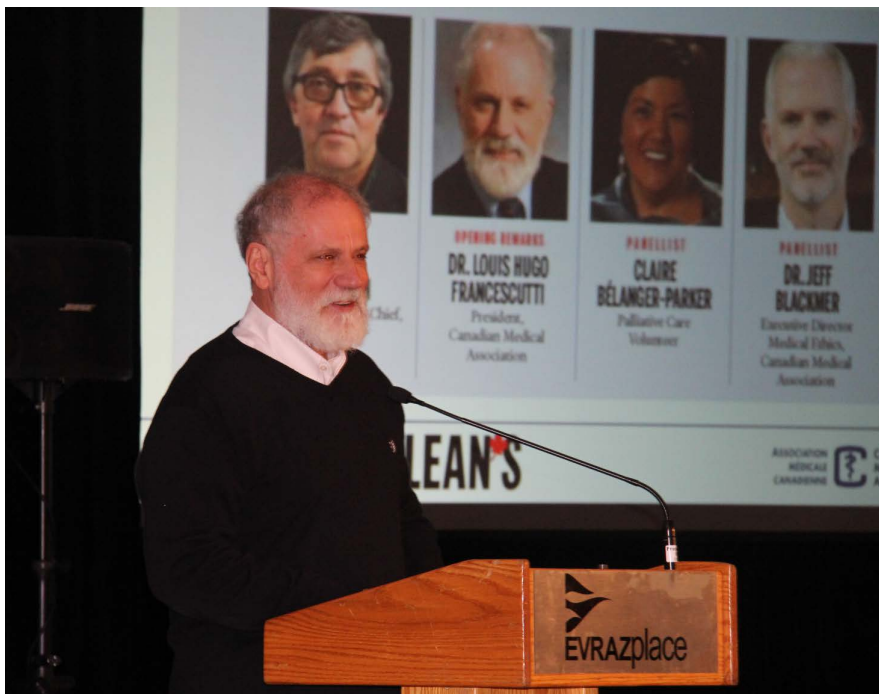
In 2011, the British Columbia Civil Liberties Association, Dr. William Shoichet, Gloria Taylor, who had an incurable disease, and the Carter family challenged the law against euthanasia and physician-assisted suicide. In 2012, the BC Supreme Court ruled the Criminal Code of Canada provisions against assisted dying violate the rights of the gravely ill and gave Parliament one year to rewrite the laws.

The court also granted Taylor, who had Lou Gehrig's disease, the right to an assisted suicide, making her temporarily

the only Canadian to legally have this right. However, Taylor died in 2012 without making use of this right. Kay Carter had ended her life by travelling to Switzerland and availing herself of the right to assisted dying in that country.

The federal government appealed the BC Supreme Court decision; the BC Court of Appeal overturned the lower court ruling in October 2013 and upheld the ban, stating in part that it was bound by the Supreme Court of Canada's 20-year-old decision concerning the Sue Rodriguez decision (in which the Supreme Court reached a 5–4 split decision to uphold the ban).

The Supreme Court of Canada granted the British Columbia Civil Liberties Association, the family of Carter and others permission to appeal the case. The Supreme Court of Canada is scheduled to hear the case on Oct. 14, 2014, and the CMA will be applying to act as an intervenor in the case. The federal government has said it has no intention of changing the existing criminal law against physician-assisted dying.



THE FOLLOWING QUESTIONS WERE ASKED AT THE TOWN HALLS

1. Advance care planning:
What is needed to facilitate discussions on advance care directives?
2. Palliative care: What is your vision of good palliative care services?
3. What is the state of palliative care in your community?
4. Do you feel you have access to these services?
5. What needs to be done to provide the palliative care services you feel are needed?
6. Physician-assisted dying:
What are your thoughts on physician-assisted dying?
7. If you had access to good-quality palliative care services, would that influence your position on euthanasia or assisted suicide?

"It is wrong to think there is no 'dying with dignity' in somebody else's care. Allowing people to care for you gives such an incredible gift to the people around you and brings a huge amount of dignity."

— Mississauga town hall participant

BILL 52 AND QUEBEC

In 2013, after four years of cross-province consultations, the Parti Québécois government introduced Bill 52 — An Act respecting end-of-life care. The bill would have legalized "medical aid in dying."

The legislation also mandated the provision of palliative care services in the province, set protocols for doctors sedating suffering patients until they die naturally, and provided guidelines to help competent patients with a terminal illness who want to end their life because of unbearable physical or psychological suffering. Two physicians would have to approve the request for medical aid in dying, which would have to be made in writing.

In February 2014, the Quebec National Assembly was dissolved and a provincial election was called before a final vote approving the legislation could be held. However, following his election, new Quebec Premier Philippe Couillard asked to have reintroduced Bill 52, which was passed by a majority on June 5 in a free vote at the National Assembly in Quebec City.

OTHER FACTORS

Other events that put a renewed focus on the issues of end-of-life care at the time of the CMA town halls included the following:

- Debates on these issues occurred at the CMA's own annual general council meeting in Calgary in August 2013. At that time, the CMA passed several resolutions calling for expanded palliative care ser-



vices and greater awareness of the need for advance care planning and directives. However, media attention focused on the debates in which delegates voiced some confusion about the proper terminology to be used when discussing euthanasia-related topics.

- In September 2013, eight days before his death from a brain tumour, Dr. Donald Low, a renowned Toronto microbiologist, published a video with an impassioned plea for terminally ill patients to have access to physician-assisted suicide.
- In February 2014, the BC Supreme Court ruled against family members of 82-year-old Margot Bentley, a woman in the latter stages of Alzheimer's disease who is being spoon fed against her family's wishes, as well as, it would appear, her own advance directives.
- In March, former Conservative cabinet minister Steven Fletcher introduced two private member's bills that would allow medical aid in dying in certain circumstances. One of the bills proposed by Mr. Fletcher, a Manitoba member of Parliament, would allow doctors to help people end their lives under certain restricted circumstances. The other bill would set up a commission to monitor the system.
- In April, the CMA and a Parliamentary all-party committee joined forces to advocate for the development of a national strategy on palliative care. The Parliamentary All-Party Committee on Palliative and Compassionate Care held a joint news conference with the CMA to announce its support for the CMA and the association's current initiative to encourage a national dialogue on end-of-life care issues.
- During the course of the dialogue two provincial and territorial medical associations — Doctors of BC and the Ontario Medical Association — released major policy papers dealing with palliative care and advance care directives.
- In late May, all parties in the House of Commons endorsed a motion by member of Parliament Charlie Angus calling for a pan-Canadian strategy to support and improve access to palliative and end-of-life care. While the motion may not be binding on the federal government, it does highlight an urgent need and adds to the mounting pressure on all levels of government to address this critical issue.

TERMINOLOGY

All of the town hall meetings started with a discussion of the terminology necessary to properly discuss end-of-life care issues. Dr. Blackmer said this was necessary because confusion continues to exist, even within the medical profession, about what some of the terms mean. Dr. Blackmer explained that while it was going to be impossible to obtain unanimous agreement on the meaning of some terms, "it is important we are all on the same page."

Through the use of videos, the CMA spelled out definitions that had been developed by its Committee on Ethics and approved by the CMA board. These include the following:

Advance care planning

A process in which individuals indicate their treatment goals and preferences with respect to care at the end of life. This can result in a written directive or advance care plan (i.e., living will).

PALLIATIVE CARE

An approach that improves the quality of life of patients and their families

facing the problems associated with a life-threatening illness. It involves the prevention and relief of suffering by means of early identification, assessment and treatment of pain and other physical, psychosocial and spiritual symptoms.

Euthanasia

Knowingly and intentionally performs an act, with or without consent, that is explicitly intended to end another person's life. In the CMA definition, euthanasia includes the following elements: the subject has an incurable illness, the agent knows about the person's condition and commits the act with the primary intention of ending the life of that person, and the act is undertaken with empathy and compassion and without personal gain.

Medical aid in dying

A situation in which a physician intentionally participates in the death of a patient by directly administering a substance themselves or by providing the means whereby a patient can self-administer the substance that causes his or her death.

Physician-assisted dying

The process in which a physician knowingly and intentionally provides a person with the knowledge and/or means required to end his or her life, including counselling about lethal doses of drugs and prescribing such lethal doses or supplying the drugs. This is sometimes also referred to as physician-assisted suicide.

Palliative sedation

The use of sedative medications for patients who are terminally ill, with the intent of alleviating suffering and managing symptoms. The intent is not to hasten death, although this may be a foreseeable but unintended consequence of such action.

During the town-hall meetings, Dr. Blackmer clarified some of the most important terms mentioned in the videos by noting the following:

- Advance care planning is a process that may result in a living will but not always. He said the conversation with loved ones is the most important part of the process.
- Stopping interventions such as feeding tubes with dying patients is considered to be withdrawal of care and is not euthanasia.
- "Passive euthanasia" is no longer used as a term, as patients and their families are recognized as having the right to stop receiving care.
- "Dying with dignity" should not be equated with euthanasia, as a dignified death is possible without euthanasia.
- Physician-assisted death and euthanasia are distinguished by who performs the action: in the former case the patient performs the action with the physician providing the means, and in the latter the physician or another person performs the action.
- The continuum of palliative care does not include euthanasia or physician-assisted death.



At the town hall meeting in Whitehorse, Dr. Blackmer added that euthanasia is not a part of the palliative care process. This was echoed by a number of the palliative care experts speaking at the meetings.

In Regina, an audience member expressed concern about the definition of “medical aid in dying” as she found it a confusing phrase. Dr. Blackmer noted the term was included in the glossary used in the dialogue because it was raised but not defined in Bill 52 in Quebec. He said because of the implication that physicians would be involved in this process,

the CMA felt it was important to clarify the term and specify that “medical aid in dying” referred to either euthanasia or physician-assisted dying. “It’s very clearly separate from palliative care,” he said.

In Vancouver, a question was asked about the difference between palliative sedation and the normal relief of pain and mental anguish that are offered every day on a palliative care unit. It was noted that palliative sedation is offered when symptoms are recognized to not be treatable and people may choose to sleep until death. At this town hall, another audience member talked about the hypocrisy of

distinguishing between palliative sedation and physician-assisted death because a person could foresee the natural consequences of their actions. Dr. Blackmer said while the consequence of the action may be the same, ethically it is the intent of the action that differentiates the two. This continues to be a controversial issue within the medical profession.

In general, the terminology proposed by the CMA was well accepted by audience members. Dr. Blackmer said the CMA has reached out to elected officials of all parties to promote more widespread use of this terminology.



“There are many experiences in our lives and things that happen to us that we cannot foresee. You can ask someone what they would want done if they had a head injury but there is really no way you could know without being in that situation. The same thing with tube feeding: How would you know in advance what you would want? Because once you’re in that situation you may change your mind with no way to communicate that. For that reason, I would really want someone who loves me to take care of me at that time.”

— Vancouver town hall participant



ADVANCE CARE PLANNING AND DIRECTIVES

The discussion of the importance of advance care planning and directives was put in context by recent survey results showing that while 95% of Canadians think it is important to have a clear conversation with a loved one about the type of care they want at the end of life, only 30% have had such a conversation and only 16% have done something as a result of the conversation.

At the town hall meetings, there was almost universal agreement about the importance of advance care directives and the need for people to have discussions with family members and loved ones about their wishes for end-of-life care at various stages throughout their life.

In responding to why the percentage of people making advance care directives or discussing this issue was so low despite its acknowledged importance, Dr. Susan MacDonald, medical director of palliative care for the Eastern Region of Newfoundland and president-elect of the Canadian Society of Palliative Care Physicians, attributed it to people's "inborn discomfort with death."

Dr. Danusia Kanachowski, a palliative care

physician in Whitehorse, said many people are hesitant to fill out an advance directive because it will be perceived as being final. "Our views change over time," she agreed, "so advance care plans can be changed and your proxy will know that." Dr. Blackmer added that some people are afraid that if they say they do not want to be kept on a ventilator, for example, then no one would ever put them on a ventilator. The key, he said, is to have a discussion with loved ones and physicians about quality of life and define under which circumstances use of a ventilator may be acceptable. "It doesn't have to be black and white. Medicine is never black and white," he said.

At the Whitehorse town hall an audience member described how, when she was filling out her advance care directive, she stopped in the middle of the process, because, while it was natural to say she did not want to suffer at the end of life, she knew herself to be a fighter. "I'm afraid what I said on this paper was maybe not what I would want." She said this situation scared her because she realized people might follow her written wishes rather than what she might want at that time. This is

"I think our society and our culture seems to be in a state of denial. Death should be as natural for us to discuss as birth control or sexually transmitted disease. It's a fact of life. We need to discuss it openly."

— St. John's audience member

why she said she would be hesitant to fill out a form at age 30 or 40 that might not reflect her current perspective at age 64.

Dr. Doris Barwich, president of the Canadian Society of Palliative Care Physicians and executive director of the newly founded BC Centre for Excellence in Palliative Care, said advance care planning gives people the opportunity to consider in advance their values and preferences and communicate these to other people. The literature shows this to be a win-win situation because it allows patients to be actively involved in their own care while providing health care providers with clear direction on how the patient wants to be treated.

Dr. Kanachowski said although it sounds “corny” to some, conversations about advance care planning are often described as “a gift” to those having to make decisions at the end of someone’s life because they provide clarity about what the dying person wanted.

“We all have an obligation to prepare our exit strategy,” said Claire Bélanger-Parker, a palliative care volunteer and panellist in Regina, said. “We need to leave our family well prepared for our departure.”

Dr. Blackmer said people make the mistake of thinking the discussion about advance care directives will “keep for another day,” and that day keeps getting

pushed further and further into the future. “We put it off and then it becomes too late.” He said the best time to have this discussion is when you are healthy, when there is not a crisis situation and everybody can discuss issues openly and rationally.

“My (two) children are in their 40s and I had to fly my daughter to Vancouver and buy several bottles of good red wine. It was a difficult start but I wanted them to know my choices (about end-of-life wishes) and so we spent about two or three hours over a meal in a restaurant discussing these issues. I have had emails from both of them since saying ‘Thank you. We feel much more relieved now knowing what you would want.’”

— 73-year-old survivor of breast cancer
at Vancouver town hall

Discussion at the Regina town hall meeting focused on the important role of the actual substitute decision-makers or proxies who are designated to make choices around end-of-life care when a person is no longer competent to make those decisions for himself or herself.

“It’s impossible to put down on paper every possible scenario ... it simply doesn’t work,” said Dr. Darren Cargill, a palliative care physician at The Hospice of Windsor and Essex County Inc. and panel member at the Mississauga town hall. This is why it

is so important to designate a substitute decision-maker or proxy who understands your values and wishes, he said.

“I see these advance directives from time to time and the ones I see are often designed by lawyers. I get the sense of someone who is trying to anticipate everything that could possibly happen and have some control in advance over it. The best control you can have is somebody who you can trust, who shares your values.”

— physician at Mississauga town hall

Dr. Blackmer said substitute decision-makers often need to be better educated as to their responsibilities. Proxies need to be available to doctors and other health care providers even if a living will exists, he said, because the law in most provinces requires the physician to talk to the proxy about the patient’s wishes and interpret the living will through this process. He explained that this role is very different from that of an executor of a will. It is for this reason, he said, that it is important that the proxy understand the person’s goals, aspirations and values to recommend the right action. At the Regina meeting, Dr. Ken Stakiv, co-medical director of palliative care services for the Saskatoon Health Region, added that the importance of the role of the proxy is such that selecting this person

“My son has to accept that I want to talk about dying. That’s very difficult for family. They don’t want to talk about that.”

— Whitehorse town hall participant



should not be left until the last moment. It is also important to appoint someone who is going to outlive you, he added.

Another important point made at the town hall meetings was that different provinces or territories can have different regulations and language respecting advance care directives and how they work. The nuances of these legislative requirements were discussed at each town hall. For example, at the Vancouver town hall, a notary public said it would be “irresponsible” not to have advance care choices spelled out in writing. He was also critical of the use of the term “living will” as he said this does not apply in British Columbia, where the proper terminology is “representation agreements” as spelled out in legislation. “We’re in BC, not Toronto,” he said. “Get it in writing.”

“Surely it’s not that complicated. Why can’t we just have something simple.”

— Regina audience member describing the complexity of a living will template

One of the main concerns raised repeatedly by audience members when discussing advance care directives was that such directives were not always followed by the physicians or health care providers caring for the patient.

At the Vancouver town hall, specific reference was made to the Margot Bentley case, where Bentley was allegedly kept alive against the wishes she had expressed in an advance directive. Dr. Blackmer noted there has been a lot of discussion about the story and the case was an extremely difficult one because of the type of care that was provided and the specific legal circumstances surrounding it. He stressed that the circumstances are very specific to this particular case.

Dr. Barwich added that one of the difficulties and limitations with advance care directives is that they cannot force health care providers to do something that is illegal or contrary to their duty to care, such as to assist in euthanasia. “We have



limitations which we live within and unfortunately this is one of them.”

“My wife’s aunt had an advance care directive that said ‘no ventilator’ and the doctor and the family decided that was not what she meant ... so nine months later she died on a ventilator.”

— St. John’s audience member

“Recently my husband had brain surgery and was not doing very well. I said to the doctors ‘you know, if he continues like this I know he doesn’t want to live.’ And they said, if you don’t have a representation agreement on the chart we will do resuscitation. I raced home to get that representation agreement and put it on the chart.”

— Vancouver town hall participant

“My father passed away last November at the age of 96 and he had 96 good years and six rough weeks. When dad moved to Regina in 2011, he sought a Saskatchewan lawyer to make sure he had a Saskatchewan health care directive. Being of very sound mind and able to communicate his wishes with the lawyer and myself he drew up a careful plan. Then, last June when he was admitted to hospital here in Regina they asked him,

‘Do you have an advance care directive’ and I said, ‘Yes, here it is.’ And they said, ‘Oh well, put that away. We want you to fill out our forms and fill out this new form. Could you read it carefully and make decisions now please.’ I said, ‘No, a very short time ago when he was able to make decisions he filled out this form and I’d like you to use this.’ Reluctantly they took it and they highlighted only the area that said ‘do not do the following’ but they did not highlight the paragraph earlier that said ‘in the following situation do not do the following.’ I was very concerned that it did not reflect his wishes so I think there needs to be some discussion about standardization. I recognize how difficult it is for health care professionals to look at a hundred different types of health care directives and understand each one individually”.

— Regina town hall participant

“Filling out a living will, for me, was a liberating process. It didn’t mean ‘come and get me now, I’m ready to go’ because I’m not. It gives a certain level of comfort to my children and my spouse in that situation. I think it allows people to live a fuller life.”

— Whitehorse town hall member

"My grade 12 sociology class is looking at this topic currently. What would you want young people to consider most when thinking about end of life issues? Many of these students are our future caregivers."

— question to Dr. Francescutti during the online dialogue

"One area would be advanced care planning. This is something families can talk about right now, tonight."

— Dr. Francescutti's response

The importance of involving the attending or family physician in discussions about advance care planning was also raised by a number of people. A nurse at the Vancouver meeting said what is missing in much of care is physicians having conversations with patients about what a diagnosis really means, what the prognosis is and what the impacts of the treatments offered are in terms of outcome and the role of the entire health care team, including nursing members. A Mississauga town hall participant made a similar point about the importance of educating patients about the potential impact of treatment decisions and the option of not receiving those treatments.

Good communication can help to relieve much of the discomfort that surrounds the situation and also to build trust, especially if it takes place with providers who are trained in talking about these issues, said Wenda Bradley, a family caregiver and community nurse and panellist in the Yukon.

At the Mississauga town hall, Dr. Cargill talked about the importance of communication as part of the art of medicine. He said many physicians are unprepared and

untrained to initiate discussions around advance care planning and he said very productive conversations can be initiated by just asking the patient "What is important to you?" He noted that many patients welcome having their physician start the discussion about advance care plans and he said it was amazing how far many patients get through the health care system before the issue is raised.

Dr. Kanachowski stressed that advance care planning is not just one conversation, as both the public and physicians often believe, but rather a number of conversations that occur over time. She said physicians need to be encouraged to talk about end-of-life care planning and what is possible and that this is part of their job. End-of-life care is about planning, she said, rather than just dealing with an immediate and acute medical problem, which is usually the case when someone sees a physician. An audience member in Whitehorse said it may be that the system is not properly acknowledging and remunerating physicians or nurse practitioners for the amount of time necessary to adequately discuss end-of-life care with patients.



PALLIATIVE CARE

CMA President Dr. Francescutti introduced each town hall with a description of his mother's positive experience with palliative care before she died from colon cancer last June. "It was a pleasant experience," he said, because his mother brought the family together and she received outstanding care at the West Island Palliative Care Residence in Montreal. He said his mother was impressed by the compassion of the staff in helping her and in supporting the family. "She left feeling that she had come to the final chapter in a place that was taking care of her needs. That's what palliative care is. The thought of how she passed away gives me comfort every single day," he said.

At each town hall, panellists and audience members tended to talk about the excellence of palliative care services in the centre where the meeting was being held but the absence of such services in other communities or more remote areas. Dr. Stakiw put this most bluntly at the Regina meeting when he noted that while palliative care services are well organized and generally well run in urban centres in Saskatchewan, the situation "falls apart" even just a few miles outside of these centres. Bélanger-Parker said that the lack of such services on First Nations reserves in Saskatchewan is "shocking." Dr. Cargill attributed the excellence of palliative and hospice care services in certain communities to individuals and grassroots movements who have advocated to get these services.

The excellence of care provided by specialist palliative care centres and multidisciplinary teams was often contrasted by the "horrible" deaths of family members who were not able to access such services.

"My dad died in Regina in a facility on Jan. 27 and it was horrible. I have sat with thousands of people in my career who have died and it has been beautiful. When my dad died I stood up and said, 'Take him now, I have had enough of this.' It was a lack of education. My dad lived in Regina and he didn't get palliative care. I was in touch

with palliative care but they couldn't help the generalist physician because he didn't request it or didn't want it. So not only did my dad suffer but I suffered and my family suffered. We have to do something about educating our generalists and seeing that palliative care is delivered to all Canadians." – Regina town hall participant

Experts in palliative care took pains to explain the scope of the services being offered. Dr. Barwich explained that the concept of palliative care evolved a number of years ago in response to medicine become much more technology based, disease oriented and lacking a focus on the person with an advanced or terminal illness. The aim of palliative care is to compile a team and resources that can meet the patient's physical, mental and spiritual needs, she said. It is also to acknowledge the narrative of dying where the person's wishes are honoured with good pain and symptom management. In St. John's, Dr. MacDonald said she wanted to extend the definition of palliative care because she looked after the living rather than the dying. She said her work is a wonderful job rather than a sad job as she works with family physicians and other specialists to help manage the physical and psychosocial symptoms of the people for whom she cares.

"Palliative care brings the whole family together," said Renae Addis, a family caregiver and director of fund development and communications for The Dorothy Ley Hospice. Addis, who was on the panel of the Mississauga town hall, said before her mother received palliative and hospice care, she and her sister were performing many tasks nurses would be doing in caring for her. Access to palliative care "allowed me to be a daughter again," she said.

"I know some of the most tender experiences in my life are at the bedsides of people who are dying," said Louise Donald, a palliative care volunteer and member of the panel in Vancouver.

Asked to explain the difference between palliative care and end-of-life care and who can provide palliative care, Dr. MacDonald said palliative care involves a longer period

"I had a really good experience with palliative care. My mother had chosen to stay home to die ... and we realized how much strain there was on our father to care for her. So a week before she died we moved her to palliative care and it was a relief for all of us because it was such an incredible experience for all our family to have somebody look after her, while we were focusing on taking care of dad and each other."

— St. John's audience member

of time and has a broader focus. She defined it as the provision of symptom management, she said, for people who have a life-limiting or life-threatening condition, no matter what age. She said family doctors provide palliative care as do community-care nurses. "Most of palliative care is basic good medical and nursing care," she said.

Dr. Kanachowski said many doctors see palliative care and end-of-life care as being synonymous when actually palliative care can begin "far upstream" when a person first becomes ill with a life-threatening illness. She said a study of people with metastatic lung cancer showed that those who received palliative care services from the time of diagnosis lived longer, with better symptom control and quality of life.

"When it comes to end-of-life care you only have one chance to do it right," Dr. Stakiw said, noting that palliative care specialists want to work with people with a life-threatening disease early in the process even if they are on the road to recovery.

In St. John's, one audience member noted that through knowing the right people and having the right connections, she



was able to provide excellent care for her mother, including 24/7 home visits from her family physician. Because of this care and from having an advance care directive, she said, her mother was able to spend her last days in her own bed, surrounded by her family. The woman said she has connected with many others since her mother's death who have not been as fortunate in having the same knowledge and support. She questioned whether patients and families know they have the option of not dying in hospital and that there are options and support available. She said the three most positive elements that came out of the last month of her mother's life were that her mother got her wish to die at home, that she felt "great" that she was able to provide this for her mother and that other family members were able to witness such compassion.

The lack of training for medical students in pain management and other aspects of palliative care was an ongoing theme. Dr. MacDonald noted that 10 of the 17 medical schools in Canada offer fewer than 10 hours of palliative care training and Dr. Blackmer said this was in stark contrast to the average of 80 hours of education in pain management received by veterinary students.

An audience member in Regina talked about the need for buy-in from physicians, health care providers and health regions for proper palliative care services and said that this currently doesn't exist. She also reiterated the need for proper education but said that without a recognition of the need for these services, teaching people how to deliver proper palliative care would be wasted.

"Eight years ago, my mother at the age of 98, in excellent health and living alone,

had a frankly psychotic episode as the result of dehydration. She was taken to the hospital — it was a long weekend and her own doctor was out of town — and the duty doctor had her put in the general medical ward. She was put in restraints and deemed to be refusing medication because in her paranoia she felt all the people were trying to poison her. When I arrived at 6 pm on Sunday, I had to threaten legal action and demanded a statement in writing as to why they were not hydrating her. She did have a DNR [do not resuscitate order] and we were prepared to let her go, but not screaming hysterically in restraints in a hospital bed. They did begin to hydrate her and we put some medication into the fluids they were giving her. In three days, she was in good spirits complaining she would lose her volunteer job if she was not released from



hospital. She died two years later in her sleep. The point based on this is how do we convince people in a general medical ward that palliation is what is needed?"

— Vancouver town hall participant

"My husband just recently passed away. He was in a hospice for two months but he just did not get the care he needed there because there were 16 patients and only two nurses and two helpers on a shift. He had trouble with his breathing and the machine broke down so they had to rush him to Burnaby General [Hospital] because the hospice couldn't help him. There, he died peacefully. So I'm putting a plug in for Burnaby General Hospital because they did more than the hospice could do. There is just not the

funding there [at the hospice]. They can't give people the care they really, really need."

— Vancouver town hall audience member

"My mother is 92. She has four or five major [conditions] and was recently diagnosed with a bowel infection and she did not want the antibiotic. I spoke on her behalf and the doctor understood. The difficulty was with her general practitioner who had a difficult time understanding why the family would deny something."

— Mississauga town hall audience member

At the Mississauga town hall there was some discussion of the role and value of patient navigators — advocates who work within the health care system to ensure patients are matched with the proper care and services — in this case, with specific reference to palliative care. Dr. Cargill noted that given the complexity of our current health care system, such navigators are playing an increasingly valuable role.

The need for a national palliative care strategy and proper funding for palliative and hospice services was raised repeatedly. "We're running as fast as we can," said one hospice worker, who pondered how a comparable level of service could be provided without volunteers, given the low level of funding from the publicly funded system.

Dr. Blackmer said that it is incomprehensible that palliative care services are not funded properly even though death is one medical condition everybody will experience. "The reason is, it's not politically sexy. It doesn't score political points with the government."

"I had to advocate strenuously on behalf of my mother for palliative care, thus missing out on the time I could just be with her. End-of-life planning and advance care directives, as well as palliative care, should be on the continuum of care offered to all Canadians. The right care should not be dependent on how well the family

can advocate for the individual; it should be offered. We have the right to receive compassionate, end-of-life care and to have a team of caregivers who value and understand palliative care as the specialty that it is. My concern lies in the fact there is not a consistent standard and approach to palliative care across the country."

— Whitehorse town hall participant

"As a full-time worker in the health care system, I think a huge need is to increase the level of palliative and hospice care available to all Canadians."

— Online dialogue comment

"Having a loved one who is dying is hard enough but when you have to come out of your own home and actually move somewhere else to be with your loved one who is dying, it makes it horrible for everyone, so I think we need to put money into the communities."

— Whitehorse audience member

A 96-year-old audience member in Regina talked about his wife dying eight years ago in palliative care. "Anybody, in that stage of life, if they can get palliative care, their troubles are over," he said, because she was able to get all the pain relief she needed. He described palliative care as a "godsend" and said the only problem is that not everybody who needs it can get access to it.

"My understanding is that in my health care authority there is one person for advance care planning. There has to be money behind getting the message out to everybody and please don't make it a volunteer-driven initiative."

— Vancouver town hall participant

"Everyone should have access to palliative care because we will all die."

— Whitehorse audience member



EUTHANASIA AND PHYSICIAN-ASSISTED DYING

Despite its emotionally charged nature and the divergent views expressed, debate on the topic of euthanasia and physician-assisted dying at all the town hall meetings was consistently marked by civility and respect for the views of others. At each meeting, Dr. Blackmer summarized the current public policy environment concerning medical aid in dying in Canada, including Bill 52 in Quebec and the Carter case before the Supreme Court of Canada. He also summarized the CMA's current policy, which frames the issue as a societal one and currently opposes physician involvement in physician-assisted death. He also listed the jurisdictions (currently nine) where euthanasia is legal. Dr. Blackmer noted that in jurisdictions such as Oregon where patients have legal access to medication that can end their life, they often choose either to not fill the prescription or to not use the drug once they have

it because it is the control and respect for patient autonomy that emerges.

Audience members expressed both views that supported the current laws in Canada prohibiting euthanasia and physician-assisted dying and views that called for a change in those laws to permit these practices.

"I had a grandmother who had Alzheimer's and I have thought about it a lot. I know that if I started having symptoms of Alzheimer's I would like access to The Pill [a lethal dose of medication]."

— Whitehorse town hall participant

"I think palliative care is an absolutely necessary part of our medical system. And 'yes' we need more of it. I also believe that if we had all the palliative care that anybody could possibly need, there are those that don't want to go through that process. I believe in their voice and their choice."

— Vancouver town hall participant

"By refusing a person's legitimate request to die, you are in fact causing that person immeasurable harm and suffering."

— Mississauga town hall participant

"Unfortunately, in Canada we are creating a two-tier health care system in that only Canadians with money can travel to these European and American jurisdictions to receive end-of-life assistance."

— Mississauga town hall participant

"We cannot proceed until we get a variety of opinions from fellow Canadians, or we run the risk of creating solutions and a society that does not support all beliefs and values. This is what this series is about."

— Online dialogue participant

In response to a question posed by the CMA at all town halls, many agreed that if a good system of palliative care was available to all Canadians this might

significantly reduce the call for a change in the law. Many palliative care experts such as Dr. Barwich who served on the panels at the town halls said it was premature to even discuss changing the law regarding euthanasia until access to palliative care services is available. On the other side of the argument, a speaker at the Mississauga town hall argued that palliative care still fell short of adequately controlling pain in a significant number of patients and so physician-assisted dying remained an acceptable option.

"I was at home feeding the dogs and the cats and the fish when he [my husband] died. He would have liked me to be there to hold his hand. He would have liked to have said 'I want to die today at 3 pm — tell Louise.' And I would have been there."

— Mississauga town hall participant

"There are so many people becoming part of the aging population and there is no way there is going to be enough palliative care facilities created. So people really should have a choice whether they want physician-assisted dying. I treat my animals better than the death I had to watch my mother go through and my God I'm not going through that sort of thing."

— Whitehorse town hall participant

Many who opposed legalizing physician-assisted dying cited the "slippery slope" argument that indications for physician-assisted dying could be expanded significantly despite initial safeguards. This would especially put vulnerable populations, such as seniors with dementia, at risk, they argued. While those against euthanasia cited countries where euthanasia is legal and indications have been expanded, such as Belgium and the Netherlands, proponents of assisted dying countered with the example of Oregon, where strict controls remain in place.

A 96-year-old participant at the Regina town hall questioned why a democratic society such as Canada could not build enough safeguards to protect against the

slippery slope if physician-assisted dying was made legal. "There's no such thing as a slippery slope," he said.

"To address the 'slippery slope' argument — some people abuse pain-killing drugs, but we do not ban them for all, but legislate [through] regulation."

— Online dialogue comment

"One has to think very carefully about what we are letting ourselves in for if the CMA was to support the government in legalizing euthanasia."

— Retired palliative care specialist, Regina

"I think we need access to physician-assisted dying and voluntary euthanasia in situations where palliative care won't work. If somebody has an untreatable suffering that is going to last for two months, there are some kinds of suffering that only death can end."

— Vancouver town hall participant

Dr. MacDonald said there are many vulnerable groups within Canadian society, including the disabled, children and the disenfranchised. She said she agreed that drafting any legislation to protect all of these people would be almost impossible. She said in her experience it is healthy people who are most vigorous in arguing in favour of legalizing euthanasia. Dr. MacDonald said only a small percentage of

people would consider euthanasia but everybody is going to die so people should be vigorously arguing for good palliative care.

The issue of how the perceptions of those with serious or terminal conditions can change if they received good care was raised several times. Dr. Blackmer said his clinical work involves people with spinal cord injuries. He said studies have shown even health care providers believe many people with quadriplegia have a quality of life that is only a two or a three out of ten whereas if you ask that person they will rate it at an eight or a nine especially once they have had a chance to adjust to their new life. He said in his work he often sees patients who, when they have just been injured, ask to have their life terminated. But after adjusting to their new reality, he said, they often value the independence they still have.

"[When I was] nine, my grandmother, who I lived with at the time, died of stomach cancer. The nurses taught me how to change the stoma on her stomach. I remember being with her and then also remember when she died. Maybe this is selfish but I wouldn't have wanted to have been robbed of that. I don't think she would have chosen to rob me of that and that bond that we shared. I know she was in a lot of pain ..."





but I think if she was dying now she might have felt she should have chosen physician-assisted dying and we would have been robbed of that bonding period of time and those most crucial memories I have of her."

— 34-year-old Whitehorse town hall member

"They [my parents] said they wanted to die but there was nothing we could help them with. If they had been my dog or my cat I would have put them down and I would have had no qualms about doing so. But that wasn't an option."

— Whitehorse town hall participant

(The comparison about the ease with which family pets can be euthanized versus the current legal situation for humans in Canada was made by a number of participants at different town hall meetings.)

"We have palliative care for physical suffering but there is emotional suffering as well. I am 87 years old. I have outlived all my siblings and all my old friends and I can no longer do most of the things that I really enjoy. I live in a facility which is very comfortable and very good. I have a 96-year-old companion who is blind and can almost not hear at all but she has a lively intelligence and is trapped in this shell. What palliation can be offered to her? I have a radical proposal to make. Most of the people in my age group have

ailments which are painful, uncomfortable but not terminal so we are doomed to live an unlimited amount of time with pain, discomfort, boredom and loneliness. What palliation is there for that? I would like a law that says if you are over 75 or terminally ill you have the right to ask for physician-assisted death."

— Vancouver town hall participant

"What about the mentally ill? They might want to kill themselves tomorrow or the next day. And if you have a law they would just do away with themselves. But if you talk to them and with psychotherapy and medication they might change their mind. So I really oppose euthanasia on all counts. It has absolutely no respect for life whatsoever."

— St. John's audience member

"I think, as physicians, you see dying more. I think that it is really important that you do the right thing. I worry about the ethics of physicians if they go from prescribing medicine to prescribing something that kills. How is that going to change physicians and our medical ethics and how is that going to change our patients' trust?"

— Whitehorse town hall participant

"I want the option to choose when and where and how I die."

— Mississauga town hall participant

"It seems to me that there are many people for many reasons at different times of life who may want to end their lives. It seems to me that for the vast majority of people palliative care is the answer."

— Regina town hall participant

"I want it to be a choice of how I go and when I go. Nobody can take that from me."

— Whitehorse town hall participant

Dr. Blackmer noted that the physicians go into the profession to relieve pain and suffering and the oath they take obliges them not to hasten death. Legalizing physician-assisted dying would blur the lines about what physicians are supposed to be doing, he said. "Our philosophy is that of care and not killing," a physician stated at the Vancouver meeting. At the Mississauga town hall both a physician and a member of the public raised concerns about the ethical dilemma facing physicians if they were involved in physician-assisted dying while at the same time striving to treat and cure patients.

The Mississauga town hall featured a lengthy discussion about the potential role of physicians and specifically the CMA in supporting what was described as the majority public opinion wanting to change the law to allow physician-assisted dying and support the right of patients to determine their own fate. Dr. Blackmer responded that while the medical profession had a right to its own opinion, it would ultimately be society that would decide what Canada would do and that the profession would be respectful of that.

While the perspective of First Nations peoples was not specifically provided directly at any of the town hall meetings, the CMA was urged to gain a better understanding of how different First Nations dealt with death and the dying process. One observer noted the value First Nations people put on the dying process and the sense of community and sharing that is enabled when a person is dying.

CONCLUSIONS

The aim of the national dialogue process was to provide both the public and the medical profession with a societal perspective on the issue of end-of-life care. The meetings and the online dialogue allowed for the discussion to happen and provided some key observations.

- The terminology developed by the CMA to discuss end-of-life care should be widely communicated to health care providers, policy-makers and the public.
- All Canadians should discuss end-of-life wishes with their families or other loved ones.
- All Canadians should prepare advance care directives that are appropriate and binding for the jurisdiction in which they live.
- Canadians should revisit their end-of-life care wishes periodically, recognizing that health care providers will interpret these wishes on the basis of a number of variables, including written advance care directives, conversations with loved ones and, input from a substitute decision-maker.
- A national palliative care strategy should be developed.
- All Canadians should have access to appropriate palliative care services.
- Funding for palliative and hospice care services should be increased.
- More education about palliative care approaches and as well as how to initiate discussions about advance care planning is required for medical students, residents and practising physicians.
- The Canadian public is divided on whether the current Canadian ban on euthanasia and physician-assisted dying should be maintained or not.
- If the law in Canada is changed to allow euthanasia or physician-assisted dying, strict protocols and safeguards are required to protect vulnerable individuals and populations.
- The potential impact on the Canadian medical profession of legalizing physician-assisted dying should be carefully considered and studied further.

