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**Standing Committee on
General Government**

Compassionate Care Act, 2020

1st Session
42nd Parliament

Monday 23 November 2020

**Comité permanent des
affaires gouvernementales**

Loi de 2020 sur les soins
de compassion

1^{re} session
42^e législature

Lundi 23 novembre 2020

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LEGISLATIVE ASSEMBLY OF ONTARIO

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

**STANDING COMMITTEE ON
GENERAL GOVERNMENT**

**COMITÉ PERMANENT DES
AFFAIRES GOUVERNEMENTALES**

Monday 23 November 2020

Lundi 23 novembre 2020

The committee met at 0900 in room 151 and by video conference.

**COMPASSIONATE CARE ACT, 2020
LOI DE 2020 SUR LES SOINS
DE COMPASSION**

Consideration of the following bill:

Bill 3, An Act providing for the development of a provincial framework on hospice palliative care / Projet de loi 3, Loi prévoyant l'élaboration d'un cadre provincial des soins palliatifs.

The Vice-Chair (Mr. Mike Schreiner): Good morning, everyone. The Standing Committee on General Government will now come to order. We are here for public hearings on Bill 3, An Act providing for the development of a provincial framework on hospice palliative care.

We have the following members in the room: MPP Gélinas, MPP Shaw, MPP Fraser, and our presenter, MPP Oosterhoff. The following members are participating remotely: MPP Bailey, MPP Ghamari, MPP Harris, MPP Kramp, MPP Wai and MPP Glover. We are also joined by staff from legislative research, Hansard, and broadcast and recording.

To make sure that everyone can understand what is going on, it is important that all participants speak slowly and clearly. Please wait until I recognize you before starting to speak. Since it could take a little time for your audio and video to come up after I recognize you, please take a brief pause before beginning. As always, all comments should go through the Chair. Once again, in order to ensure optimal sound quality, members participating via Zoom are encouraged to use headphones and/or microphones if possible.

Are there any questions before we begin?

MR. SAM OOSTERHOFF

The Vice-Chair (Mr. Mike Schreiner): I now call on MPP Sam Oosterhoff, the bill's sponsor. You will have 15 minutes for your presentation, followed by 45 minutes of questioning, divided into three rounds of six minutes for the government members, three rounds of six minutes for the official opposition members and two rounds of 4.5 minutes for the independent member.

You may begin now.

Mr. Sam Oosterhoff: Thank you, Chair. I wish to begin by thanking the members of the committee for inviting me to present this morning. My thanks go to all of you for your hard work and attention to the pieces of legislation that appear before this committee, before proceeding again to the Legislature. I know the work of committees such as this is vital to perusing and improving bills which are intended to better the lives and livelihoods of Ontarians across our beautiful province.

Today, you are being asked to consider Bill 3, the Compassionate Care Act. The bill you are being asked to consider today and over the next couple of days is about death and dying; it's also about living. In many ways, the subject we're speaking about is the elephant in the room, the unspoken reality that we all share: All of us in this room will die. Although there are sad and tragic circumstances where people pass away due to accidents and other rapid and unexpected ways, the vast majority of us in this room and Ontarians across the province should be able to plan for and see their death coming down the road in the foreseeable future. Whether it is due to disease, sickness or old age, over 90% of us will likely need and would benefit from some form of palliative care before we die.

As a Christian, I don't fear death. I remain confident and energized in the reality of the resurrection and the assurance of things not yet seen. But I know that death is a reality and, for many, an incredibly painful reality that tears at the very heart, spirit and strength of what makes us human. End-of-life care needs to be respectful of this pain and anguish, and it needs to address the hurt that plagues so many across our province and nation who look for meaningful end-of-life care without necessarily finding it.

Palliative care focuses on the relief of pain and other symptoms for patients with advanced illnesses and on maximizing the quality of their remaining life. It may also involve emotional and spiritual support as well as caregiver and bereavement support. It provides comfort-based care as opposed to curative patient treatment. Patients can receive palliative care in their homes, in hospitals, in hospices and in long-term-care homes, in a variety of different situations.

I wish to acknowledge the significant work done by the Ministry of Health and Minister Elliott to improve palliative care services here in Ontario. Our government has committed \$74.7 million a year to provide palliative and

end-of-life care for Ontarians. Moreover, I know that Ontario is investing over \$36 million in capital funding to build an additional 200 hospice beds across the province. When these beds open over the next three years, the government will also provide an additional \$21 million a year in operational funding for nursing, personal support and other services delivered to patients in these beds.

I also want to acknowledge the work of the Ontario Palliative Care Network and the many partners across the province who serve to advise the government on palliative care in Ontario. I also wish to acknowledge the member for Ottawa South's work to bring about that important network. However, there is more work that needs to be done.

When Bill 3, the Compassionate Care Act, was first introduced in its original form as Bill 182 in December 2017, I heard from many hospices and family members of patients across the province—people like Nancy Salvador, who spoke about the amazing care her husband had received in hospice. She said, “When my husband was dying of cancer ... years ago, sometimes he had to be hospitalized, but as much as possible we cared for him at home. At that time, we were very blessed to have hospice nurses come to our home every day. They were never rushed, and lovingly cared about each member of our family. If it was difficult to manage his pain level, sometimes I would even have to call them in the middle of the night, and it was such a comfort to have the nurse give me more suggestions as to what to do to make him feel more comfortable, and when to take him to the hospital. I am sure that ... palliative care would benefit other families in trying times.... I thank God for hospice nurses.”

My office has also heard from those who see the need for more, such as a former PSW who wrote me, saying, “A year ago, my mother died in a ‘nursing home’ where she was not known and, therefore, not cared for as sensitively as she might have been had she been allowed to return to the retirement home she had been living in for the past 15 years of her life (after being sent to the hospital with complications from a breast cancer diagnosis). It was her right to be amongst those who were familiar to her and, therefore, loved her like family. It was very painful to watch her have minimum care and, on some occasions, rough handling, where she ended up due to our government's choice of an available bed.

“The nursing home did its best but, unfortunately, fell short of allowing my mother's palliative care to be the best it could be. It is unconscionable to have to endure this kind of end-of-life treatment for someone who contributed to society as a veteran and as a generally dignified human being! I still cannot accept this forced circumstance and, as a former PSW, I know from whence I speak ... there is no recourse to today's system of the last, what should be, precious moments of a dear one's life. Just sad and very frustrating.”

Chair, this is a situation we all have a duty to improve.

So what is Bill 3, the Compassionate Care Act, and why has it been brought forward? Bill 3, as the title of the bill describes and as the explanatory note distinctly details, requires the Minister of Health to develop a provincial

framework designed to support improved access to palliative care. The minister must table a report setting out the provincial framework in the Legislative Assembly within one year after the bill comes into force. Within five years after the report is tabled, the minister must prepare and table a report on the state of palliative care in Ontario. Each report must be published on a government of Ontario website.

The reason for this legislation is simple. Although there have been improvements in recent years, Ontario still has a patchwork of palliative care, with varying levels of care depending on where you live in the province. In particular, rapidly growing urban centres, the north, and small towns are struggling to ensure the proper access to palliative care that Ontarians expect and deserve.

Many of the presentations the committee will hear in the coming days will go into more detail about this need and the importance of a strategy to address this urgent issue, so I will not detail the many areas that we can work to improve. Suffice it to say that, thanks to members also in this room, I have seen a clear, cross-partisan coalition for this bill and this issue.

I do, however, without going into too many details, wish to briefly read from an endorsement letter from the Canadian Society of Palliative Care Physicians. They describe the following reasons for the need for this legislation:

“(1) Our health care system does not equitably meet the needs of Canadians who are nearing the end of life and their families. Access to palliative care depends on where you live, how old you are, and what you are dying from....

“(2) We know that the need for palliative care resources will only become greater as Canadians continue to age. For the first time in history, there are more seniors in Canada than children. By 2024, the aging will be even more pronounced: Canadians aged 65 years and older will account for more than 20% of the population while children under 15 years old will represent just over 16% of all Canadians. Aging equates to higher demand.

0910

“(3) All Canadians, including Ontarians, who have a grievous and irremediable medical condition have the right to seek medical assistance in dying but they do not yet have the right to access palliative care. Approval of your private member's bill would help to ensure that Canadians have options to reduce suffering at the end of life.

“(4) There are no standards for the provision of palliative care nationally or within Ontario; nor are there standards for the education and credentials for health care providers who provide palliative care. Approval of your draft private member's bill will ensure that standards and accountabilities are set so Ontarians can be assured of receiving quality palliative care from appropriately trained providers.

“(5) Data regarding access and quality of palliative care services is disjointed within Ontario and across the country. Key indicators need to be collected provincially and nationally as we do for other areas of health care. This will allow us to compare ourselves to similar jurisdictions and to monitor our progress as implementation unfolds.

“(6) Your private member’s bill will create supports for patients, families and caregivers including quality information about palliative care services, advance care planning tools, income support and job protection. All Ontarians will need these supports on one or more occasions in their lives. The information is applicable to all Canadians and should be shared through national resources that provide high quality, cost-effective, accessible information....

“(7) Strategic investment in palliative care makes economic sense. Evidence shows that it can:

“(a) Reduce the cost of delivering care.

“(b) Free up scarce resources in acute care, such as beds in intensive care units (ICUs), for patients who truly need them.

“(c) Improve the quality of life and quality of care of patients with serious illnesses and their families.”

Chair, I wished to quote from the letter from the Canadian Society of Palliative Care Physicians because I feel that their letter succinctly details the need for this legislation.

I wish to also acknowledge other members from all parties who have brought forward support for and championed palliative care in Ontario. MPP Fraser, the member for Ottawa South, was a strong advocate in his time in government. The member for Hamilton West–Ancaster–Dundas has spoken passionately and personally about pediatric palliative care and the unique needs of support for our youth and children. The NDP critic for health, France Gélinas, has also spoken about many of these needs.

My colleagues in the government, and specifically the Minister of Health, Christine Elliott, as well as her team, have shown sincere care and interest in moving this piece of legislation forward and in helping to address our collective responsibility to the families of this province.

I also wish to acknowledge my staff, and specifically, Crystal Mason, who has worked tirelessly on this file since I came to office in 2016 and has done excellent work connecting with stakeholders, families and patients across the province.

Although palliative care is about a meaningful and supported end-of-life journey for each and every Ontarian, Bill 3, the Compassionate Care Act, is not really about death at all, but rather about life. What I mean by that is it’s about living the good life and having a good death right up until the very end. It’s about supporting people such as Pieter Harsevoort, who passed away from spinal muscular atrophy shortly before the introduction of the first round of this legislation. I knew Pieter, and he lived most of his life accessing palliative care while he served as a special education teacher at an elementary school in Hamilton. Pieter was able to bring so much meaning to people’s lives and was able to touch so many people with love while he was accessing palliative care.

The story of improving people’s lives through palliative care is not limited to any particular area of our province. The need for palliative care is not limited to any particular area of our province. Whether it’s the GTHA, remote, rural communities, Indigenous partners, or even in areas that we may not expect it, like in downtown urban centres, the need is there.

Committee members, the Compassionate Care Act is about dignity, respect and meaningful support for families and individuals in their end-of-life journey. It’s about fulfilling our commitment to ending hallway medicine and listening to front-line providers. Ultimately, I am confident that these goals will resonate with you, as they have resonated with all members of the Legislature at second reading. I hope and I trust that I can count on the support of all members of this committee to send Bill 3 back to the House for passage and royal assent. Thank you.

The Vice-Chair (Mr. Mike Schreiner): Thank you for your presentation.

The first round of questions will begin with the official opposition, and you will have six minutes. MPP Shaw.

Ms. Sandy Shaw: Thank you very much, MPP Oosterhoff. This is an important bill, and I appreciate your acknowledgement of the work of those who have come before you on this. I know you’ve been diligently at this. This bill has been on the books for two and half years now.

I would just like to hear from you, if you could give us some opportunity to describe—you’ve talked about what palliative care is like currently in the province, but COVID-19 has made access to palliative care and essential caregivers very difficult. You mentioned pediatric palliative care. Can you talk a little bit about how the experience of COVID-19 has made people’s—has it made it difficult for people to access palliative care during this last year?

Mr. Sam Oosterhoff: Absolutely, and you will also be hearing about that from many of the presenters who are going to come before the committee.

There are three challenges that come to mind. The first one, of course, is that one of the most important aspects of palliative care is the ability to be surrounded by family, friends and loved ones when you’re passing, and obviously, access to facilities is very different in the COVID-19 world; the ability to mingle with each other is very different. When I think of some of the most tragic stories that I’ve heard from COVID-19, frankly, whether it’s in a long-term-care home or in other settings—it’s where loved ones aren’t able to be with their loved one as that person faces the end of their life. That’s incredibly tragic. We understand why that’s necessary in some situations. To your point, member, that has been something that we’ve heard. Trying to have flexibility while maintaining health protocols for COVID-19 and also ensuring that there’s compassionate access—because we need to have compassionate access when it comes to family and caregivers—is a tough balance, and I know it’s one that has been a struggle for hospice providers.

I was speaking with—the name slips me at the moment—the executive director of Matthews House and the Vaughan hospice group. The amount of outpouring that they’ve had from the community, even from those who are passing from COVID-19, and their gratitude for hospices underlines the need more than ever.

The second piece that has always been a challenge but that has been exacerbated by COVID-19 is, of course, fundraising. There’s a delicate balance within the space when it comes to hospice palliative care ensuring adequate

funding, and also ensuring that there's community engagement—because we don't want hospices to become bureaucratic, desensitized clinics; they need to maintain that unique homely attribute. That has been a challenge because fundraising has declined, as a result, in all charitable sectors.

And then, third is staffing, of course, just like in every other aspect of health care—trying to access staff that's needed. That's a challenge in every area.

Ms. Sandy Shaw: I think Belinda Marchese is the executive director.

Mr. Sam Oosterhoff: Yes.

Ms. Sandy Shaw: Thank you for that answer.

Maybe you could help me understand what actual direct additional funding you've provided to hospices and also hospital palliative care during COVID-19—what response has that been?

I appreciate your answer on people being able to visit their loved ones who are in palliative care. We put forward our More Than a Visitor Act, the essential caregiver act, to allow families to be able to visit their loved ones in long-term care and also in palliative care. I know it is a balance between harm and risk. At the same time, we've heard some awful stories where families have not been able to be with their loved ones, whether they're in long-term care or whether they're young children in a hospice.

I would like to hear from you a little bit about what your government has done specifically in terms of funding or in terms of policy that has made it easier, in this context, for families to be with their loved ones near the end.

0920

I will just share with you that my dad passed away very recently, during COVID-19. We were very lucky; it was during a time when we were able to be with him at home—because of the COVID-19 restrictions, we were able to be there. My sister is a nurse. We had all the resources, a home to be in. We were able to be with him at the end—but it made it perfectly clear to us that others weren't able to be there.

The Vice-Chair (Mr. Mike Schreiner): You have one minute.

Ms. Sandy Shaw: If you could very specifically talk about what you've done to make sure the funding is there, the access is there and the equity of access during COVID-19 is there, that would be really helpful.

Mr. Sam Oosterhoff: First of all, my condolences to you and your family on the passing of your father.

Ms. Sandy Shaw: Thanks, MPP Oosterhoff.

Mr. Sam Oosterhoff: I wasn't aware of that. I'm glad you were able to access a hospice in that situation.

First of all, I would just preface it by saying I don't work within the Ministry of Health. I don't always have access to all the numbers. I know there have been a number of different surge funds that have been allocated for COVID-19 supports also within health care. There has been an increase, I believe, of about \$3.4 billion for the health care budget, which would include, obviously, some allocations for hospice.

The minister, when I've spoken with her, has indicated that they want to ensure that there is additional support funding—

The Vice-Chair (Mr. Mike Schreiner): That's the amount of time we have for this round.

The next round will go to the independent member. You will have 4.5 minutes.

Mr. John Fraser: I want to begin by thanking MPP Oosterhoff for sticking with it and bringing this bill forward. I know he cares very deeply about this. It's important to him, and it's very important work. Keeping momentum going all the way back from 2011, which was the Declaration of Partnership and Commitment to Action—that was a pretty incredible thing to see inside the community here in Ontario, more than 60 partners coming together and agreeing on simple principles about how to advance this. That's how important it is.

We will probably hear over the course of these hearings the kinds of pressures there are on hospices. MPP Oosterhoff is right: It's a balance of pressures and supports. I think what we'll hear is that we need to give some more supports. We do want to have community investment and community participation in hospice. That's what makes it work. It's a community-based solution. So I think we'll hear a lot about that, which will be a good thing, because it will help to inform the government, as well, while we're talking about this bill and how we can strengthen the structure around advancing this.

The only thing that I've noticed, which I think we can figure out as a committee—it's just reporting back and taking a look at those timelines as they figure into government's. I don't know if you're open to looking at saying, "Can we shorten that time or do interim reports?"—because five years is actually beyond the span of a government. More importantly, we're in a situation where we don't want to take our foot off the gas. I don't know if you'd like to comment on that.

Mr. Sam Oosterhoff: Again, I didn't go into this area during the initial presentation. There was federal legislation brought forward, as well, around this, and the five-year reporting time frame was the one that they're using. I'm hoping we can work with the federal government when it comes to the reporting around some of this, because as they're taking a national strategy approach, we should obviously be collaborating and incorporating some of that. I think it wouldn't be a bad idea to have interim reports coming forward in between.

One of the really key pieces that I'm hoping to see coming out of this—and I want to tie it back in with the question from the member from Hamilton West–Ancaster–Dundas. One of the pieces that's tied in there is that this funding that's coming forward—we have to make sure it's allocated efficiently and properly. I was speaking with a colleague of mine from Mississauga, and she was telling me that Mississauga doesn't have a hospice. Mississauga and Niagara, we're significantly less—we're looking at building our third in the south end.

We want to make sure that as those supports come forward that you're speaking about, they're done in a way that is equitable and that is ensuring access more broadly.

Mr. John Fraser: One of the things that you'll have to do is take a look at compassionate communities, because—

The Vice-Chair (Mr. Mike Schreiner): You'll want to speak through the Chair.

Mr. John Fraser: Pardon me, Chair. It just comes naturally. We know each other.

It's interesting; you can see in a small rural community that they could build a hospice and almost support it solely themselves—

The Vice-Chair (Mr. Mike Schreiner): One minute.

Mr. John Fraser:—but you may find in an urban area, getting that critical mass of people—it's not that they're not there, but it all depends on the capacity of the community, the leadership, who's there, the clinical leadership. That's the beauty of it, but I know that's the tricky thing for governments.

I think it will take an interesting tool to be able to achieve that equity—not just funding, because you need that other community component.

Mr. Sam Oosterhoff: Yes, and to that point, the key piece is going to be not commandeering. This is not intended to commandeer palliative care in Ontario. It's intended to bolster and support those existing organizations and to create more impetus or more of a healthy ecosystem for the creation of that, but not to say, "Okay, we're going to take it over. So long. We'll have it run through the ADM of such and such."

Mr. John Fraser: It won't work.

Mr. Sam Oosterhoff: Yes, exactly.

The Vice-Chair (Mr. Mike Schreiner): That's all the time we have for this round.

We'll now go to the government members. I recognize MPP Harris.

Mr. Mike Harris: Thank you very much, MPP Oosterhoff, for bringing this important bill to committee here today. For me, this hits pretty close to home.

One of the first things that I did when I was elected in 2018, like many of us here who are sitting around the table, was to reach out to many of the organizations in my community in Waterloo region and try to get a pulse of what was going on. One of those was the Hospice of Waterloo Region. They were in the process of trying to break ground on a new site in northeast Waterloo. It would be only the second hospice site that we would have in a region of roughly 600,000 people—a little bit more if you roll in some of the surrounding communities like Guelph. As the Chair of the committee today will be well aware, we often share a lot of our services between the two regions because we're so closely tied, not only geographically, but we have a lot of people who work and live, or vice versa, in each community. They're only about 25 minutes away from each other.

One of the things that they were trying to do was deal with the provincial government. They had about \$2 million in funding that was locked up for well over a year, from what I understand, from the previous government. Then, of course, as you have transition moving into a new government, often some things, unfortunately, fall through the cracks. Getting that \$2 million unlocked for them so they

could start their site surveys and planning was one of the first things that I did as an MPP.

I think we can all agree that we want to try to help our health care community, especially hospice and palliative care, any chance we get.

As you know, MPP Oosterhoff, much like you, I represent a largely rural riding that has some population centres spread throughout—it's about 60% rural. One of the issues that we run into all the time is the fact that there is not palliative care, whether that be through a hospital or through hospice care or other means, available to people who live in these rural communities who want to stay with their families but still want to have a dignified, meaningful death.

I was hoping that you would be able to explain a little bit how your bill would help promote hospice or palliative care in rural communities and allow people to remain in those communities and be supported by their family and loved ones and compassionate caregivers.

Mr. Sam Oosterhoff: Thank you for your advocacy for your local hospice. I think hospices, as health care organizations, have unique relationships with their local elected representatives, just based on their very hands-on approach. I interact a great deal with our local McNally House in my riding, and I want to thank everyone at McNally House for the incredible work that they do. So I'm glad to hear that.

You used an interesting phrase quite early on in your comments, and that was, "fall through the cracks." Falling through the cracks is exactly what we don't want to have happen, even in a transition of government. Whether it's a new government coming in, whether it's the middle of an election campaign, whether it's a minority government, we shouldn't have to worry about the provision of or access to—whether it's capital funds or operating dollars or just being able to ensure that we have them come in.

0930

In your situation, I'm very glad to hear that you were able to be an advocate and to create or unlock that capital funding. But they shouldn't have had to go to you in the first place, to be perfectly blunt. So that's what this bill is trying to remedy—and the reason for that is that it's disjointed, it's one-offs.

For example, right now we're building 200 hospice palliative care beds—I know there were some that were started under the former government. We've added a bit to that. Okay, so here we are. Now we have 200 coming up. When these 200 are built, then what? Are we going to wait five more years and then have another tranche come down the pipeline when we realize that, oh, there's a huge need again? I don't think that's what the people of Ontario want. I don't believe that's what the Minister of Health wants either, from the conversations I've had with her. That's why we're using this as a tool to say, "Where are the gaps? And what are the gaps coming down the road, not just today but into the future?"

I look at my riding and your riding, and they're actually very similar in the sense that although they have—

The Vice-Chair (Mr. Mike Schreiner): One minute.

Mr. Sam Oosterhoff:—significant rural areas, they also have growing urban populations. In those centres, a lot of people are commuters, but a lot of them are people moving into communities, whether it's for affordability reasons or for lifestyle reasons. So we need to be looking not just at what our communities look like today and whether or not the six beds that we have in our community today are good enough, but if we are going to be needing those 10 beds in 10 years. I know a lot of that work is being done already at the local hospice level.

Again, going back to McNally House in my riding: They're very, very good at it, and they're looking at doing an expansion. But there need to be more avenues for them to have those preliminary conversations with the ministry, to say, "I know you're looking at this framework. As you're looking at your five-year reports, think about the fact that by the time that next five-year report comes out, we're not going to need six; we're going to need 10. You need to build that into your planning process."

The intent of this legislation is to have that more comprehensive approach—including rural communities.

The Vice-Chair (Mr. Mike Schreiner): That's all the time there is for this round.

The next round of questioning will begin with the independent member. MPP Fraser.

Mr. John Fraser: Thank you very much for allowing me the time to do this. It's not my regular committee, but it is a really important committee, especially right now.

I want to go back to a question around your approach in the bill to communities. I did mention compassionate communities. How do these things grow? They grow because communities are able to get the critical mass and the leadership to be able to move forward with a visiting home hospice or a hospice or providing hospice in long-term care. To be frank, it's something that we worked on in the last government. It's something that we didn't get done that I really wish we had got done. There are 13 compassionate communities across Ontario, and I think it's a movement that will enable communities to help government to help people who need hospice palliative care. It's one of those things, really, when we look at it critically—you said it very well: We can't just move in and say, "Here you go." Even with the capital funding—again, we started moving with that. It was an important thing to do to support hospice.

To get back to what I was trying to say, just in terms of looking at your bill and somehow recognizing that communities have a huge role to play in driving this—I think there are a couple of other things around that. I don't know if you have any thoughts on that or if it's something you've thought about.

Mr. Sam Oosterhoff: Absolutely.

I should have really begun my whole introduction with this: I'm not a palliative care expert. I've never claimed to be a palliative care expert, and I will never assert myself to be one, either, because there are far, far smarter people who have spent their whole lives working in this space and understand—far better than I could ever hope to understand—the intricacies, the equilibriums, the needs of communities and how those can be best encouraged and

facilitated. I just want to preface every comment that I've made already and every comment from here on in with that caveat.

I think one of the most important pieces of this is saying that the minister is going to be listening to those people and having those people in this process. I don't think you can have five people or 10 people, frankly, sitting around a table and saying, "Here's what that looks like," because of the fact that every community is different. Ottawa is a great example of that. You have Roger Neilson House, a fantastic pediatric centre, which is very different from Bruyère, right down the road—they're very different types of settings—which is very different than my small McNally House. Trying to recognize where that community is at and to ensure that that community is fully engaged in the process is absolutely fundamental to this. Where that balance lies—I don't have the answer, but I think this legislation will help us get to a better sense of what that answer is. Without talking to those people, we're not going to find that out.

The Vice-Chair (Mr. Mike Schreiner): One minute.

Mr. John Fraser: MPP Shaw mentioned long-term care. In terms of continuing to support palliative care inside long-term care—because in long-term care, everybody is on that palliative and then end-of-life trajectory. I think we have to look at how we involve community in that, too. How do we incent that? How do we support that?

I appreciate very much you bringing this bill forward. I look forward to the committee hearings. I know I'll be able to share a little bit of time. It's really important work, and I look forward to working with you on it.

Thank you, Chair. I'll try to speak through you from now on.

The Vice-Chair (Mr. Mike Schreiner): Thank you.

The next round of questions, a six-minute round, will begin with the government members. I recognize MPP Kramp.

Mr. Daryl Kramp: Thank you, Chair—and a sincere expression of thanks to PA Oosterhoff for bringing this bill forward. It's incredibly important. One of the mantras of hospices is, no one ever wants anybody to die alone—and to have that kind of compassionate care at those moments in life. I do take it a little bit personally in that I've been involved in the direct creation of two hospices, with some of our responsibilities. My wife is a volunteer, and has been for a few years, at those moments when people need that personal touch. You hear so many of the relatives' stories of the impact, not just on that individual, of course, but on the entire family, many of whom, of course, are always trying to be around there at that moment. They need guidance and support.

There are many stories I'd like to tell about this, but now is the time, I think, more importantly, to recognize the contribution that PA Oosterhoff has been making to bring this to reality.

I would certainly like to acknowledge the bipartisan support on this issue. I think it's phenomenally important. That's how we make things really happen within the bowels of the structure of the Legislature.

Of course, the devil will be in the details. So, Mr. Oosterhoff, the actual strategy and the elements of that are going to be tremendously important in developing—what are some of the items that you personally would hope to see included within the actual strategy of the hospice?

Mr. Sam Oosterhoff: Thank you very much, MPP Kramp, for your advocacy.

We've done a bunch of thanking of all the politicians and everything; I want to definitely make sure we thank the front-line providers, because at the end of the day, they're the ones who deliver palliative care.

I know we have Mahoganie Hines, a palliative care nurse, speaking next. She's from the Niagara region. She has really inspired me to be more active on this file, as well. She's a unique woman who has dedicated herself to an area that is very difficult and challenging mentally and physically and professionally. There are so many different needs in end-of-life care—and what those look like.

So I just want to make sure we acknowledge all those people who—the volunteers, yes, and the executive directors, yes, but most importantly, those front-line care providers in hospices who, each and every day, are doing that work in remarkable ways.

A lot of the components that I want to see in this—again, I have to go back to my caveat: I'm not an expert in hospice palliative care. I heard in the sector from many, many different people that there's a disjointed approach, that we need to be taking a more coherent and cohesive approach to this. When Marilyn Gladu's legislation came forward federally, there were a lot of people who I knew within the hospice space or people who have been involved who said that we need something like this provincially—because I know they're looking federally, but so much of this is actually provincial, and provincially there's a huge amount of need. So I want to have that caveat in there.

0940

One of the key things I would like to see would be specific emphasis around rural, northern, remote and Indigenous considerations. I think communities in the north and in rural areas, specifically Indigenous communities, haven't always been seen—either because of the lack of population or access or whatever the reason might be—as needing the same levels of palliative care. Maybe that doesn't necessarily look like a 10-bed hospice in Sioux Lookout or anything like that, but we do need to ensure that there's a lens that is taking into consideration those needs versus an urban—even a centre like mine is not truly rural. If you go up north, they don't consider us rural, because we still have urban centres of over 20,000 people—over 30,000 now in Grimsby. So that would be a key lens that I would like to see included, from what I've heard.

The other one is data collection, but not useless data collection. Sometimes I think we can collect so much data that doesn't get put anywhere, or it might get put somewhere and then it just gets dusted off every 30 years—“Oh, we'll put that into the archives.” Useful data that can actually be tangibly turned into optimizing care in meaningful ways, to me, is going to be key to this, whether that looks like—even just patient ages. People are surprised at

how many people are in hospice who are not necessarily 85-plus years, like people think.

The Vice-Chair (Mr. Mike Schreiner): One minute.

Mr. Sam Oosterhoff: Again, I want to acknowledge the work of the member for Hamilton West–Ancaster–Dundas on pediatric palliative care. That's an area that's under-represented, aside from maybe the odd story in a national paper about a very tragic case or an inspiring case of a young warrior, a young hero. In broad parlance, people are very uncomfortable speaking about the fact that young people die, and I understand that, because, again, it's that elephant in the room. But there needs to be a lens around those considerations as well, because their needs are different and the way that they receive care is different, both physically and psychosocially.

Mr. Daryl Kramp: Thank you. I'll pass to one of my colleagues to give them an opportunity.

The Vice-Chair (Mr. Mike Schreiner): MPP Wai, I'll recognize you, but you have 10 seconds.

Mrs. Daisy Wai: Thank you very much, PA Oosterhoff—

The Vice-Chair (Mr. Mike Schreiner): That's all the time we have for this round. I'm sorry.

We'll now move to the official opposition. MPP Shaw.

Ms. Sandy Shaw: MPP Oosterhoff, I want to pick up on the theme of falling through the cracks. As you've mentioned—thank you very much—there is the Nancy Rose Act that is on the order paper, and that's specifically designed to address pediatric palliative care.

With all due respect, I just feel compelled to say that it's very difficult to deliver palliative care in Indigenous communities when they don't have clean drinking water. Neskantaga comes to mind. They're not even living in their communities right now.

When it comes to pediatric palliative care, as in all palliative care, the resources that they need are not there. This is an under-resourced sector. In Ontario, there are really just three hospices—Emily's House, Roger Neilson House in Ottawa, and Darling Home in Mississauga. Roger Neilson House is connected to CHEO, as you know.

In addition, there's excellent pediatric palliative care being delivered in hospitals as well as hospices. In Hamilton, McMaster Children's Hospital delivers excellent pediatric palliative care. We're going to hear from some of those doctors during the course of these deputations. I think McMaster Children's Hospital is one of the busiest hospitals. It's a hub for south central Ontario, and that community does not have a dedicated pediatric palliative care hospice.

My question to you is, how would this bill ensure that, as you mentioned, the unique needs of pediatric palliative care are addressed and it doesn't happen—which has happened—that it gets added at the end or subsumed, or that they think that children's palliative care is just smaller equipment and smaller beds? It's really quite distinct. Can you tell me how this bill will ensure that this is addressed as a distinct and important need?

Mr. Sam Oosterhoff: That's a very important question.

I think some of the practical outworkings of what that's going to mean are going to come down to the working group and the provincial framework that's built in with the consultation piece, and who is making those recommendations and that consultation. So I think it's going to be vital that we have care partners within that consultation who represent that specific area.

I would say from my perspective, subsection (e) is really the key one there that facilitates consistent access to palliative care across Ontario. That is for everybody. Whether you are a child or whether you are 90 or whether you are 40, that consistency needs to be in place in order to ensure access. That's really a fundamental ethical consideration.

When it comes to pediatrics specifically, I intend this to include that. That said, one of the pieces that's going to matter so much is that as those consultations unfold, those voices are being heard. I will happily advocate to ensure that those voices are included, including the ones that you've mentioned.

Ms. Sandy Shaw: I'm going to push you a little further on that.

The Nancy Rose Act is on the order paper. As we know, it's named after my sister, who passed, so it's very personal. But at the end of the day, I just want to make sure that pediatric palliative care gets the attention that's due.

Would you consider amending this bill to include a specific reference to pediatrics, so that it's not just implied and it actually specifically says as a subset, "pediatric hospice palliative care"?

In the Nancy Rose Act, we actually say "develop and implement," which is different than your bill, which says "to provide a report." To me, implementation implies action. I'm assuming you said that the report will mean action; it remains to be seen.

The second part about the implementation is that there are so many people on the ground doing such excellent work, as you alluded to. The provincial pediatric palliative care steering committee has done excellent work. They've created a hub-and-spoke model. They've done incredible work—because they know that they aren't able to provide the care, the equity of access across the province. They've done work to try to have done all the heavy lifting that a government might need to be able to have effective, efficient and equitable access to pediatric palliative care.

My question is, one, would you consider an amendment to include pediatric hospice palliative care? And the second thing is to ask you to very specifically pay attention to some of the work in pediatric palliative care that I think can inform the work you're trying to do.

Mr. Sam Oosterhoff: Absolutely. I think it's key to take that into consideration.

The Vice-Chair (Mr. Mike Schreiner): One minute.

Mr. Sam Oosterhoff: I would say, when it comes to amendments, I would respect the will of the committee in that regard, understanding that those conversations—I'm not a member of the committee. Obviously, if colleagues on your side, the independents and the government benches wish to have that consideration when it goes to clause-by-clause, that's key. It's going to be important to

hear from the stakeholders over the next couple of days and hear if that's a glaring omission that they might see in that regard, before that happens. But I definitely understand—

Ms. Sandy Shaw: Before you take my word for it.

Laughter.

Mr. Sam Oosterhoff: Well, I wouldn't say it that way—but just to hear from this space, as well, with regard to that.

Ms. Sandy Shaw: I understand.

Mr. Sam Oosterhoff: We'll definitely look forward to hearing those presenters. I think it is absolutely critical that those voices are included, even in that consultation piece, to ensure that that consistency adequately addresses pediatric needs.

Ms. Sandy Shaw: With the time I have left, I just want to make a comment, because I don't think I have time for a question, and it is that mercifully, the numbers of children—

The Vice-Chair (Mr. Mike Schreiner): Sorry, MPP Shaw; we're out of time for this round.

We'll now turn to the government members. You have six minutes. MPP Wai.

Mrs. Daisy Wai: This is something very dear to my heart as well, especially because my mother-in-law is in long-term care, and she is just recently turning to palliative care.

This is so important, not only for the patients but also for the family members. I would also, as you say, like to have very clear and detailed information so that the patients and the family members understand and know how to respond to it.

0950

I understand that PA Oosterhoff has been working on this idea for some time and put a similar bill forward in the previous Parliament—and then moving Bill 3 forward in this Parliament.

Can you outline for us some of the stakeholders that you have reached out to over the years, and what their reactions are to this proposed legislation?

Mr. Sam Oosterhoff: We have had very good reaction from within this space. I'll speak a bit about a few of the stakeholders who have indicated their support. You'll also be hearing from some of them.

As well as from a significant number of hospices and individual doctors, we have received support from:

- the ALS Society of Canada;
- the Alzheimer Society of Ontario;
- the Alzheimer Society of Niagara Region;
- the Canadian Hospice Palliative Care Association;
- the Canadian Society of Palliative Care Physicians;
- the Catholic Health Association of Ontario;
- Hospice Palliative Care Ontario, which is the umbrella network for hospices across the province;
- the Ontario AIDS Network;

—and most importantly, the Ontario Caregiver Coalition, which includes 171 members, including CAMH, Parkinson Canada, the Multiple Sclerosis Society of Canada, Home Care Ontario, St. Elizabeth, and the Ontario

Association of Community Care Access Centres—when they were around more.

We've had support from the Ontario Medical Association, the Registered Nurses' Association of Ontario and the Registered Practical Nurses Association of Ontario.

So it's a substantial number of stakeholders who have indicated support for this in one way or another. That, I think, just speaks to the universality of, again, we're all going to die, we all know people who have died, and we all know that everyone we know will die. That sounds so stark to say, but that's just a reminder of our squeamishness, as a society, to talk about death, unfortunately. That does indicate just how many groups recognize this need. There are various proposals, suggestions and caveats, perhaps, to those endorsements, so I'm looking forward to hearing a bit more of that over the next coming days. I don't want to say that they wrote a blank slate or anything like that. Obviously, they all have a unique perspective to bear when it comes to this, as we all do. We all have lived experience, we all have various personal experiences—as well as various people we know who would have particular perspectives on this.

Of course, recognizing that it's a private member's bill, I can't force the government to spend and I can't bring forward a financial allocation as a result of this, as much as I would enjoy to be able to do that. But I do recognize, as well, that there is significant buy-in from the Ministry of Health. They really took their time in going over this before it came back to committee, to make sure that it was tangible, doable and practical, so I very much appreciate that.

I'm confident that we'll see for many on these groups that this legislation will make their jobs easier.

Mrs. Daisy Wai: I'll pass my time to my colleagues.

The Vice-Chair (Mr. Mike Schreiner): I recognize MPP Bailey.

Mr. Robert Bailey: Thank you, PA Oosterhoff, for bringing this private member's bill forward. I know something about private member's bills, certainly, and where they can come and go.

I do want to get on the record that I'm very fortunate in Sarnia-Lambton that we've got a great hospice system here. I had no idea, when I first got elected—I helped turned the sod 13 years ago for our St. Joe's hospice, and I assumed that everyone had access to a hospice throughout Ontario; I've realized since that they don't.

The Vice-Chair (Mr. Mike Schreiner): One minute.

Mr. Robert Bailey: I did want to get on the record about Dr. Glen Maddison who runs the operation there. It's a 10-bed hospice. Also, we have hospice care at Bluewater Health, a major hospital. They also provide, through Dr. Maddison and his associates, home care for a number of people. I know a number of people have preferred to stay in their home, with assistance from their family and home care, and receive pain management. It's very well-supported in my riding by the community. We have to raise about \$1 million a year over and above the money we get from the government, from the health ministry. One of the things they do there is the Granfondo, and it raises anywhere from \$300,000 to \$500,000 a year. It's a major

bicycle race. So it's very well supported. My sister is a volunteer there. I have a number of family and friends who have passed through St. Joe's hospice, and—

The Vice-Chair (Mr. Mike Schreiner): I'm sorry, MPP Bailey. That's all the time we have for this round.

The final round will go to the official opposition. I recognize MPP Gélinas.

M^{me} France Gélinas: I would like to thank the member for bringing this very important bill forward. I remember when you brought it forward for the first time in 2017. I agree with your description that there is a huge amount of support among the MPPs who were there then and the MPPs who are here now to move forward with palliative care.

I'm torn a little bit; your party has been in power now for over two and a half years, and very few concrete steps have improved our palliative care system. Are you confident that this is the key to getting them to walk in that direction and improve care? What are your feelings about that?

Mr. Sam Oosterhoff: I believe that the minister is committed to improving palliative care, from the conversations I've had with her and her parliamentary assistants and deputy ministers. They understand that need, and there is funding that has been allocated. But there is always more to do.

I would hesitate to say that this is the key. When I have constituents come to me and they speak about issues, I always say, "I wish I could wave a magic wand and fix that. I can't. But I can guarantee to advocate for it." I think with this legislation, as well, it's going to be a component of fixing and creating impetus for knowing where those dollars have to be allocated, knowing where those supports have to be put in place, knowing what data needs to be in place. I would hesitate to say that we're going to have a flawless system as a result, specifically, of this legislation. I think we all have to work towards perfection while also recognizing the need for the good on the way there. I hope that this will be a contribution towards that.

M^{me} France Gélinas: You and I were both there when medical assistance in dying was being debated. A lot of people came forward and told us that if Ontarians had access to good, strong palliative care—the statistics speak for themselves: Thousands of Ontarians are choosing medical assistance in dying right now. I'm sure you've heard, just as much as I have heard, that access to palliative care is not there for many, many Ontarians—Ontarians I represent in northeastern Ontario.

Even with what we hear from experts, we're not able to get the government to move faster and invest a little bit in access to palliative care.

You're not giving me much hope right now.

Mr. Sam Oosterhoff: No, I absolutely agree with you. Around MAID as well—we had the member for Ottawa Centre speak about the needs, just recently, in the community of those with disabilities.

I know the minister is committed to improving and also using this as a tool to know where to put those funds and resources. I'm very confident that we'll see improvements as a result of this.

What I can't do, as a private member, is say, "Yes, there's going to be exactly this much in this and this place, for this amount of years, with this amount of capital and this amount of operating cost." That's just not within my purview. As a private member, I can't bring forward government bills.

I understand that the minister wants to see improvements made, and has been advocating for that, also, within ensuring the allocations are there.

But I think you're absolutely right; there's a moral and ethical imperative to have in place substantive, meaningful palliative care for end of life, especially as we've seen the increase in the use of MAID.

M^{me} France Gélinas: We've just had a budget, and there is nothing in the budget that guarantees us that there will be money available to move forward with greater access to palliative care. I'm disappointed in this. Do you share this disappointment?

Mr. Sam Oosterhoff: I think we have understood that there is another budget coming in the not-too-distant future, obviously, in the next few months, and I hope to see continued investment and increased investment, as I have with every budget. I've been advocating for it since I came here in 2016, and I'm going to continue to do that. I know in all my conversations, both with the Minister of Health and with her team, that they want to see continued investment in palliative care and increased investment.

As mentioned earlier, even in the letter of the Canadian Society of Palliative Care Physicians, there is also a growing impetus with an aging population—and by 2024, we're seeing that really beginning to crest. Over the next couple of decades, that's going to be a huge need.

I think you've also raised important points with regard to MAID—I know the legislation that the federal government is looking at right now would include it, even to the extent of same-day access for certain segments of the population.

The Vice-Chair (Mr. Mike Schreiner): One minute.

Mr. Sam Oosterhoff: So we need to make sure that there's access. Again, there's going to be a delicate balance around what that looks like. I don't want to see 100%-funded palliative care, bluntly, because I know that's not what the sector wants to see. They don't want to see the government come in and take over every aspect of palliative care. They want to ensure that there are supports and that there are also meaningful supports right now for operating costs. I understand that has been something that there are ongoing conversations about, even as recently as the last couple of weeks.

M^{me} France Gélinas: I would say, from what you shared with us, that you agree with us that investment needs to be made in palliative care if we want to make sure that Ontarians, no matter where they live in our province, will gain access. The barriers that exist for the people I represent, for the First Nations I represent, are real barriers that lead to life-and-death decisions. The only way to make this fair for everybody in Ontario will require investment from the government.

The Vice-Chair (Mr. Mike Schreiner): I'm sorry, MPP Gélinas; that's all the time we have today.

I want to thank you for your presentation, and I want to thank all members for participating.

This committee is now recessed until 1 p.m.

The committee recessed from 1001 to 1300.

The Vice-Chair (Mr. Mike Schreiner): Good afternoon, everyone. The Standing Committee on General Government will now come to order. We will resume public hearings on Bill 3, An Act providing for the development of a provincial framework on palliative care.

The remainder of our presenters today have been grouped in threes for each one-hour time slot. Each presenter will have seven minutes for their presentation, and after we have heard from all three presenters, the remaining 39 minutes of the time slot will be for questions from members of the committee. This time for questions will be broken down into two rounds of 7.5 minutes for the government members, two rounds of 7.5 minutes for the official opposition and two rounds of 4.5 minutes for the independent members as a group.

Are there any questions?

MS. MAHOGANIE HINES

HOSPICE VAUGHAN

HOSPICE PALLIATIVE CARE ONTARIO

The Vice-Chair (Mr. Mike Schreiner): I will now call on Mahoganie Hines. You will have seven minutes for your presentation. Please state your name for Hansard, and you may begin.

Ms. Mahoganie Hines: My name is Mahoganie Hines. I would like to take a moment to thank each of you for taking the time and consideration to be here for this discussion. I am a registered nurse who has the distinct privilege of working with people both directly and indirectly, delivering and educating on palliative care. I'm a very active member of the palliative care nursing community, and I sit on the Palliative Care Nurses Interest Group executive for the RNAO. I also sit on the executive of the Canadian Hospice Palliative Care Association nurses' interest group, and I am the vice-chair of the Palliative Care Consultants Network.

I am employed as a palliative pain and symptom management consultant, a PPSMC, by Hospice Niagara, and I work throughout the region of Niagara. I also work in a casual capacity as an RN bedside in both of our local hospices, and I have been doing this even more since the pandemic began.

In my role as a PPSMC, my mandate is to build capacity by educating, training and supporting those who are providing palliative and end-of-life care. I work collaboratively with my fellow PPSMCs in all 33 of our long-term-care homes throughout the region of Niagara.

I am here today because as an RN in Ontario, I have the responsibility to my community health care providers, as well as to the patients and families we all serve, to demand better care for all.

Excellent palliative care is a right; it's not a privilege. It should not continue to be a postal code lottery, where it depends upon where you live to get excellent, accessible and comprehensive palliative and end-of-life care. Palliative care is everyone's business.

I've experienced first-hand the inequities that exist in our health care system. When my grandmother was dying in October of this year in long-term care in another region of Ontario, the staff were not equipped for the complexity of her care when she turned from stable to actively dying, with a greater complexity of care needs. Had I not been there and known what was happening, the situations that arose would have been incredibly stressful and even potentially traumatizing for myself and my family. I saw nurses unable to give necessary medications due to lack of knowledge and ability; treatments that are not best practice being offered; limited discussions on goals of care and advance care planning; and poor communication all around.

Let me be clear: I do not blame the staff for this, for this is the culture of Ontario health care that I see every day. I attribute this to many of the systemic inequities, such as a lack of education and support in developing palliative care skills and knowledge, that currently exist in Ontario health care. We have an opportunity to change this by passing this bill. Every health care provider, including health care students, should know what palliative care is and how to implement these approaches. Currently, I regret to inform you that that is not the case in Ontario.

The Ontario Palliative Care Network, OPCN, has established consistent palliative care standards, guidelines and best practices in all hospice settings. I would like to see this approach extended to all other areas of health care, including and not limited to university and college health care provider education programs, long-term care, community care, group homes, jails and hospitals—essentially, anywhere someone is living with a life-limiting illness. They should also extend across the lifespan. One of my colleagues mentioned that her patients receiving palliative care have spanned from people aged as young as 21 weeks old to 109 years old, and everything in between. Terminal illnesses do not discriminate. As health care providers, we have a responsibility to know how to care for all ages and stages of life.

Palliative care is an issue of the public's health. Palliative care is about living and dying well. It requires a team approach. Many amazing professionals and people make quality palliative care a reality, from physicians to nurses, PSWs, psychosocial bereavement clinicians, social workers, occupational therapy, physiotherapy, dietary, speech-language pathology, spiritual care workers and volunteers, to families, friends and communities. Everyone is essential and everyone has a role.

We also have an accountability to continue to learn and grow our health care models to be inclusive, accessible and culturally sensitive to all our priority populations, including and not limited to our Indigenous communities, our LGBTQ2+, our incarcerated, our differently abled, our francophones, our structurally vulnerable, our racialized communities and our new-to-Canada populations, as well

as our children and anyone else I may have missed who falls between the cracks of the system.

I am persistently using the term “ours” so as to identify the unique fabric of the Canadian landscape, where we are all citizens and we should all have equitable access to palliative and end-of-life care. We have to do better. The passing of this bill is a step in the right direction, but it cannot be the end of our progress. We need to ensure that we are continuously listening and learning. Much amazing work is already being done starting conversations about advance care planning, as I'm sure you will hear in our following presentations, but this work also needs to continue to be instilled into our health care providers.

Another intrinsic part of palliative care is loss, grief and bereavement. The fractures in our health care system, specifically around grief and loss, have become even more illuminated as the pandemic continues. Palliative care should be care from the time of a life-limiting diagnosis through to bereavement. I've personally and professionally experienced dying, death and grief over the course of the last seven months. I have experienced cumulative losses in the past four weeks, some professional but many personal. I am left to ask, where is the support for health care providers who experience compound losses and then are expected to continue to work through and support others in their loss? Hospices in Ontario have been doing much of the heavy lifting in this area, but we need more supports. Who takes care of the people who provide care? Many health care providers do not have the skills to tend to their own grief, much less tend to other people's grief in their care. Palliative care remedies this. Excellent palliative care equips health care providers with the skills to understand—

The Vice-Chair (Mr. Mike Schreiner): One minute.

Ms. Mahoganie Hines: —and begin to work through their grief and losses, as well as teaches them how to support others.

I want to thank you for making the time for this very necessary conversation.

I will leave you with a few last thoughts. We are going to die one day, hopefully not soon. When you are at the precipice of your life, who would you want to be caring for you or your loved one? Someone who has little to no understanding of palliative care, or someone who does?

A nursing student expressed to me that when her father was dying, they received excellent palliative care. She stated that the experience of the right kind of care can be incredibly healing and powerful. All we want is to ensure every one of Ontario's inhabitants have the opportunity for such an experience, regardless of who or where they are.

The Vice-Chair (Mr. Mike Schreiner): Thank you for your presentation.

I will now call on Hospice Vaughan. You will have seven minutes for your presentation. Please state your name for Hansard, and you may begin.

Ms. Belinda Marchese: Good afternoon, everyone. My name is Belinda Marchese. I'm the executive director at Hospice Vaughan. I'm truly honoured to be part of the public hearing on Bill 3, the Compassionate Care Act. A

warm thank you to you all, and especially to MPP Sam Oosterhoff, for this special invitation.

Hospice care at home, in local communities like here in Vaughan, has been occurring for well over 25 years. With the compassion and love of the incredible hearts of our citizens, we've created generations of ambassadors and volunteers, with a small group of staff, to create impact on the lives of thousands. Over the past decades, our visions have been driven by what we see and what we hear from our community, the aging population, and the voices of the sick and the distressed families. Joining an incredible alliance of palliative care, community and health partners, we have a strong voice to convey.

Hospice Vaughan is very proud to be opening our doors in early 2021. It will include a centre of excellence, a hospice palliative care hub and 10 private hospice resident suites—a love story for our community and one that is responding to the needs that we've seen.

One might ask: How does this happen? It's a simple term I often say: Hospice is about the community, from the community. Generosity, our government and how we move forward to make sure that we can do more—we impact the lives of thousands. Our families, the voices—we need to continue to do more.

Home hospice provides wellness counselling and bereavement services. We have trained professional volunteers and a small group of staff. We create capacity for the health care system and for the home care service providers. Like all hospices, our services are offered at no charge to our community, and as you can imagine, have high demand.

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COVID-19 has impacted the world, as we know. The sick and the dying—we know that, but we sure don't know pandemics. Never would I have imagined that palliative care would need to shift so quickly to help the newly isolated and be by the bedside as someone wished to say goodbye to their loved one, pray, sing—and that has not always been possible.

I have to say, truly, I've never dealt with so many crisis and distress calls, from families, from schools, from victim services, and from mental health and community partners, to say the least. The pain in their voices is something that will sit with me.

I often reflect on what we could do better and more. One Saturday, I got a call—a 47-year-old woman was dying. Her husband was sobbing. He has been her primary caregiver, with their two adult sons. It was time to transition, and they needed a residential hospice. All I could say was “breathe” and help him make that connection.

Families are burned out. They're doing the heavy lifting day and night, and all they want for their loved ones is not to see the suffering, and to make sure that they can journey with their loved ones—because at the end of the day, they're just living their lives like you and I. I have so much respect for these families.

For all of those who are part of this hearing, our partners and our friends who will speak before and after me: We have to do more. The reality is, what drives us is all very

personal in this sector. We all know we will die; we don't know when. We might see that journey coming; we might not. Allowing natural death—AND, “allowing natural death.” How will we support that dying process while we're living? We're not defined by our illnesses. Our families, our friends, our communities are here to respond. The hands that care, the eyes that watch—including our children, the lay caregivers, the professional caregivers, our volunteers, our neighbour's friend. It's a community-development approach. It has existed from the beginning of time. From a new immigrant family like mine that came here, who didn't have family—we create that family network within our community. We have to do more.

In the book, *Twelve Weeks in Spring*, June Callwood writes about a sick and dying friend, Margaret Frazer, and how a community comes together with a local hospice to do more. That was a time when formal community supports and visiting doctors weren't even happening much. We still have a long way to go.

I'm going to reflect on a personal journey. Hospice palliative care started in my life from the day I was born. Not too many people know this: My twin sister died. After that, I had many experiences from a young age. My mom was diagnosed with cancer when I was a new mom. Later on, I had a younger sister and an older brother also face their cancer journey, only a few years later to find out that my older brother was dying from a disease we didn't even know touched our family. Can you imagine? It's not so uncommon.

My family, your family—this is what drives us in hospice. We see it. We feel it. We know it. We have to prepare. The population is aging—and those examples I've just shared have nothing to do with old age.

Today, I'm a caregiver to my dying stepfather. It's horrible—you shouldn't have talked to me yesterday, to be honest with you. He's suffering. He's dealing with all his losses: his friends dying around him, him being in pain, and us now needing to support his transition—my sisters and I, who are devoted to make sure that his dignity and quality of life, and comfort, is first and foremost. This summer, he was in hospital for five weeks. We couldn't see him because of COVID-19, but when we finally did—horrible fact: his toenails were curled under his toes. He couldn't even walk. My sisters and I, we will cut his toenails; we will cut his fingernails; we will make him comfortable.

The Vice-Chair (Mr. Mike Schreiner): One minute.

Ms. Belinda Marchese: We have to do more.

Imagine an 83-year-old gentleman, who raised four children like his own, slowly facing his mortality.

Yes, this fuels my passion, and yes, this will be the way forward for us to continue to find ways to improve hospice palliative care for those in our communities and those in our families.

My hope and dream is to have a system that responds at a local level, and that also integrates with the formal and the informal system. People will reach out, often, to people before they're even picked up by the system itself—that neighbour who picks up their food, that person who drives

them to their appointment, that family who speaks to their spiritual or religious leader because they need that support.

We need to do more, and together, I truly believe that we are on our way, with Bill 3. We are prepared, as individuals, as families and as those in hospice and palliative care.

I sincerely thank you for giving me this opportunity. I'm in my own journey, and I know that we can do more together.

The Vice-Chair (Mr. Mike Schreiner): Thank you for your presentation.

I will now call on Hospice Palliative Care Ontario. You will have seven minutes for your presentation. Please state your name for Hansard, and you may begin.

Mr. Rick Firth: My name is Rick Firth. I'm president and CEO of Hospice Palliative Care Ontario, which I'll refer to as HPCO for the rest of my presentation.

Thank you, Mr. Chair, members of the committee and members of the Legislature, for your ongoing support of HPCO, and to MPP Oosterhoff for tabling Bill 3, the Compassionate Care Act.

What we know is that, with the aging population, the demand for quality hospice palliative care is rising rapidly. With the right commitment, prioritization and funding allocations, we can meet that demand, we can end hallway medicine, and we can deliver a meaningful patient and caregiver experience and measure outcomes in terms of well-being and quality of life, all while lowering overall health care costs. That is hospice palliative care.

This bill provides the impetus for our government to deliver on what is explicitly recognized under the human right to health by the World Health Organization. Palliative care is an approach that improves the quality of life of adults and children facing end of life or life-threatening illnesses, and their families. It's a support system helping patients live as actively as possible until death. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial, spiritual, or grief and bereavement. While the bill calls for a definition, this is the globally accepted definition in practice throughout the world, including Ontario.

HPCO has the most stringent standards of care and comprehensive accreditation processes for hospices, which contributes greatly to a quality of care recognized by the Auditor General in 2014, and caregiver surveys reporting a 98% overall satisfaction rating for hospice care. The Auditor General's report identified that while there is high-quality care, there is not enough access or capacity to meet the demand.

Similar to the definition, many parts of the bill are already in place, thanks to a sector that has been working collaboratively for years. In 2010, HPCO brought together a team of 80 individuals from across the health care sector, along with the ministry and the LHINs, to develop a declaration of partnership to advance high-quality, high-value palliative care in Ontario. Since then, a coalition led by HPCO and made up of representatives from more than 30 front-line health care organizations has been working

voluntarily to achieve many of the declaration's objectives. The year 2021 will mark the 20th anniversary of the declaration, and we will be reporting on the progress.

The creation of the Ontario Palliative Care Network was an offshoot of the declaration. In 2018, the network delivered on section 1 of this bill with the Palliative Care Health Services Delivery Framework, common competencies for all settings and regional leadership to support local implementation. This is one of a number of frameworks already in place, including one for long-term care.

The bill calls for identifying the training and education needs of health care providers and caregivers. Identification is done. What we need is further implementation. HPCO developed an online hospice palliative care training platform that has trained over 7,500 volunteers in the last three years. The platform can be scaled up for use with a broad range of health providers, and it would be exceedingly helpful for the government's initiative to hire and retrain resident caregivers for long-term care. HPCO is launching similar modules for personal support workers, and we also have free online training for family caregivers.

Research and data collection needs to be strengthened. HPCO has a metrics platform capable of measuring patients' experience in real time to simultaneously inform immediate bedside care and overall quality improvements. While we are using this to measure and maintain quality of care in hospices, this platform can be readily and inexpensively scaled up and used in many care settings. We're seeking very modest funding from the ministry to expand the platform. The basis of this platform is to shift away from measuring activity to measuring outcomes of well-being, quality of life, comfort and dignity. Dying is not a medical event. It is not a procedure. It is a life event that calls for compassionate care—the ultimate measure of the system.

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With regard to consistent access, the funding formula for residential hospices needs to be amended to improve access and capacity throughout the province, including in rural and remote areas. Residential hospices are currently funded, on average, 50% by government. They are the only health care facilities that must fundraise for clinical costs. HPCO has asked government to fund 100% of clinical costs in residential hospices, as they currently do for patients in hospitals. Covering all of the clinical costs would significantly ease fundraising pressures and enable more communities to support hospice.

Visiting in-home hospices are the largest provider of grief and bereavement supports, which are only funded by donations. The demand for these services was already growing when the pandemic caused a sudden spike—in some cases, up to 500% more.

Grief and bereavement services support the mental health and well-being of people, keeping them out of the health care system.

We've asked government to provide funding to meet the growing need.

We also know that more must be done to support marginalized and vulnerable populations, pediatrics and First

Nations communities. These areas need prioritization and funding.

The Vice-Chair (Mr. Mike Schreiner): You have one minute.

Mr. Rick Firth: As for consultation, HPCO is an enabler, connecting and facilitating an effective partnership between government and communities, and will continue to do so.

Given all the work that is under way, HPCO recommends that the committee consider an amendment to Bill 3. Five years is a long time to ask the people of Ontario to wait for a progress report on something that is explicitly recognized as a human right. We recommend that progress be reported to the Legislature by the minister every two years.

Nothing can halt the growing demand for hospice palliative care. This bill, if passed, will touch every single person, either when we're on the deathbed or beside it.

Thank you to MPP Oosterhoff for this bill, which provides impetus and accountability to ensure that we're delivering truly compassionate care, and that we are a truly compassionate society.

The Vice-Chair (Mr. Mike Schreiner): Thank you for your presentation. We will now begin questions. We'll begin with the official opposition.

Ms. Sandy Shaw: I want to thank all of you for your presentations. Your work is truly on the side of the angels. We all have our personal experiences. I just want to thank you so much for this.

Bill 3 is an excellent start to address palliative care in the province. But our role here is to improve legislation—and so, to begin with, I appreciate, Mr. Firth, your offer of an amendment, because we're here to make good legislation better.

To that end, I wanted to ask you, Mr. Firth, some questions about people who are “falling through the cracks.” That's an expression that has been used a lot this morning. You mentioned Indigenous and First Nations communities and pediatrics. I suppose, if you're familiar with my private member's bill, which is the Nancy Rose Act, specifically addressing the need for pediatric care in the province—and you did refer to the Ontario Palliative Care Network's framework for pediatrics. Unfortunately, this framework specifically excludes the needs of children and their families as out of scope. If you could speak to me a little bit about your understanding of the need for pediatrics, and if you have any suggestions as to ways we could amend this legislation further to ensure that palliative care children and their families are not excluded from this legislation—or, to put it another way, are included in this legislation.

Mr. Rick Firth: We recognize that there are two levels of pediatric palliative care. The three facilities that we currently have deal with everything from neonatal right through to early adulthood. The regular hospices have a capacity to support younger children, but they're not equipped to do the specialty neonatal. So what I see as enabling more access to pediatric palliative care is an ability to link the hospices around the province with

tertiary care centres and to provide access to individuals who want to go back to their own communities—the parents want to bring the kids home for their supports.

I think we've got models in place where this is working. Maison McCulloch in Sudbury is doing this in partnership with CHEO in Ottawa. So I think recognizing that pediatric care does require specialty training, and, in some cases, special support services that are outside the scope of the normal funding formula for hospices—we need recognition and ways to deliver that additional care and have it funded by government.

Ms. Sandy Shaw: Do you think that Bill 3 would be an appropriate place to start to address the specific requirements and needs of pediatric palliative care?

Mr. Rick Firth: I think it can be. I think the OPCN framework didn't include pediatrics because there's parallel work going on with the Provincial Council for Maternal and Child Health to look at those issues. But I think this bill should include pediatrics. It should be all one system and not a separate system built out for specific populations.

Ms. Sandy Shaw: You mentioned working with Indigenous and First Nations communities. As we in this room all know, there are so many First Nations communities that have boil-water orders, that don't have access to clean water. Neskantaga comes to mind.

Can you describe a little bit of your experience and understanding of what kind of palliative care we're delivering to Indigenous and First Nations communities and ways that we could be doing better?

Mr. Rick Firth: What I'm aware of is that in many communities they've had to adapt existing services in order to provide palliative care. It might be a community that has only a visiting nurse coming in occasionally, but maybe there are support workers who are present in the community—training them up with the necessary skill set. Improving telemedicine and also working within First Nations—because many of them have their own ideas and plans on how to do this. The Chiefs of Ontario prioritized hospice palliative care two years ago. Where there's a willingness, I think the system has a responsibility to provide support.

My organization has provided copies of our standards and access to working groups for First Nations that are trying to address delivery. We've partnered with the northern school of medicine at Lakehead to support some of the training that they're doing within local communities to utilize the resources they have available to deliver the care.

The most important part of addressing the First Nations need is that it has to be done in their own cultural context. They have to define what they need, and I think we have a role to support and provide as much information and knowledge transfer as possible.

Ms. Sandy Shaw: I'm going to pass to my colleague MPP Gélinas for the minute that's left.

The Vice-Chair (Mr. Mike Schreiner): MPP Gélinas.

M^{me} France Gélinas: Thank you, Ms. Hines, Ms. Marchese and Mr. Firth, for coming here today via Zoom to talk about palliative care. I have been here for a long

time, and we don't get to talk about palliative care very often, so I really appreciate you taking the time.

I have questions for all three of you, but I will continue with you, Mr. Firth. You've talked a lot about lack of access. When was the last time your association received a significant increase in the operational funding for hospice palliative care?

Mr. Rick Firth: The last base funding increase was in 2016.

M^{me} France Gélinas: That was four years ago. What has happened since then?

Mr. Rick Firth: No increase in the base funding. It has been a consistent formula for the residential hospices. And the visiting programs—there was some money that flowed in 2018, but it really wasn't sufficient enough to provide any change. They're not keeping up with the needs.

M^{me} France Gélinas: We don't have access everywhere in the province. Do you know of communities that would be ready to move on with the standard hospice that we know—the 10-beds?

The Vice-Chair (Mr. Mike Schreiner): One minute.

M^{me} France Gélinas: Are there communities out there that would be ready and willing to go if they had the money?

Mr. Rick Firth: Yes, there are. Not only 10-bed—but from one bed through to 10.

M^{me} France Gélinas: How many communities would you say are ready?

Mr. Rick Firth: There are about 25 communities that are working on hospices of different sizes. Some of those have received a funding commitment; others have not. Importantly, about 55% of the sites are now in rural Ontario, and that's an area that we continue to look at for alternate models, such as co-locating one-bedroom suites in rural hospitals so that they have access to hospice.

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M^{me} France Gélinas: In the last—

The Vice-Chair (Mr. Mike Schreiner): Thank you. That's all the time we have for this round.

The next round of questions will be for the independent. You'll have 4.5 minutes. I recognize MPP Fraser.

Mr. John Fraser: Thank you very much, Mr. Chair. It will be easier to speak through you now because you're right in front of me.

I want to thank Ms. Hines, Ms. Marchese and Mr. Firth for presenting today and for all the work that you do in your communities—and, Rick, with your association.

I want to direct my first questions to Mr. Firth. I want to follow up on Madame Gélinas's line of questioning.

You talk about the clinical costs being fully covered by the government, and we recognize that—hospice is a community-based solution. There has always been this tension between keeping community in it and having government support that.

How much would be left for the hospices to raise if the government went to supporting clinical costs?

Mr. Rick Firth: The formula varies by the number of beds, but it would mean that hospices would continue to raise between 28% and 30% or 32% of their budget.

Mr. John Fraser: You spoke about visiting home hospice and the increase of about 500% with bereavement this year, which is not surprising, given the current situation with COVID-19 and some of the excess mortality that we're seeing related to that.

What are the kinds of things that HPCO is recommending for bereavement and visiting home hospice right now?

Mr. Rick Firth: I think the most important thing is that the bereavement services are 100% fundraised. We're asking for government to start funding those services, both to stabilize them and to meet the increasing demand.

We know that we're the largest provider of bereavement services. We're in 450 communities. We support well over 10,000 intake bereavement clients a year, plus all the family who surrounds them. There's an ability to scale it up, but to do that, we will need dedicated government funding. We can't continue to expect communities to fundraise 100% for those services.

Mr. John Fraser: We spoke earlier this morning, when MPP Oosterhoff was presenting at committee, about compassionate communities and how hospice palliative care is something that requires capacity inside a community. You have to have the leadership. You have to have the people. You have to pull together what you have. And it may be different in every community.

I'd just like your thoughts on compassionate communities and how that can play a role in communities moving forward in this framework that the bill is describing.

Mr. Rick Firth: Compassionate communities is an important initiative that we launched a number of years ago. It brings the informal parts of the health system and non-health care providers together—the Rotarays, the social service clubs, church parishes—to basically train neighbours to support neighbours early on. It gives isolated people and the vulnerable connection so that the social determinants which often make their situation worse will be better, and when they do become ill and they require the palliative support, they will have a system around them already. The idea is to keep people out of institutional settings, out of hospital, and support them at home. The hospices in the province are using their capacity to recruit and train volunteers and to network locally to build these collaboratives in communities.

The Vice-Chair (Mr. Mike Schreiner): One minute.

Mr. John Fraser: I heard your comment with regard to not measuring quantity but quality. Quality is definitely important to get this right—I know we've talked about this before—but when I look at the bill, I still think we need some metrics. We have to say, "What do we report back to say this is how much we've advanced in the number of hospices or people served"—or just three or four data points that will help us, and quality points as well. I don't know what your thoughts are on that.

Mr. Rick Firth: I agree. The health system excels at measuring what we do, but not the outcomes, which is why we're emphasizing that.

In terms of big-dot indicators, the number of people who are getting quality hospice palliative care—

The Vice-Chair (Mr. Mike Schreiner): I'm sorry; that's all the time we have for this round of questioning.

We'll now go to the government side. I recognize MPP Oosterhoff.

Mr. Sam Oosterhoff: Thank you to the presenters for appearing today, for speaking to this legislation, and for all of your service in the community as it pertains to hospices.

Belinda, it was a real privilege to tour your gorgeous facility. I hope it's getting close to completion now. It's going to be truly, truly remarkable—the way it backs onto that natural space there.

Mahoganie, it's always very good to see you. I appreciate all your work in this space. I hope Holly is doing well.

Rick, it's very good to see you, my friend. I appreciate all the advocacy that you've been putting in for years and years on this file, and also on related issues.

Mahoganie, we've talked a lot about this in the past—some of the shortages in health care professionals and, specifically, the unique type of person it takes to be involved in palliative care on the front lines. When we were talking this morning, there was a lot of back-and-forth on, “Thank you to this politician for bringing it forward. Thank you to this politician”—and we had to stop and say that at the end of the day it's the front-line providers who are really the ones who provide this care and who need our thanks more than ever, and I think in the middle of COVID-19 we've really seen that.

Mahoganie, could you talk a little bit about what supports you would want to see in place for front-line palliative care providers? The reason I say that is because we need to ensure that we have that training available so that people who—maybe they've thought about it, but it's so intimidating, it's so scary, perhaps, for them to be involved in that. What can we do to provide that support, and how can that fit into this bill?

Ms. Mahoganie Hines: Thank you so much for your introduction. And thank you for bringing forward this bill. I think it's incredibly important and timely.

I think the other piece of it is that every single health care provider should know how to do palliative care. Regardless of whether or not they're a specialist in this field, we all have a responsibility to be able to take care of people throughout every stage of their life.

In palliative care, of course, we need additional supports. I do think that it would be very nice for us to have additional grief and bereavement supports specifically for health care providers, which are currently relatively limited because of the fact that we obviously can't speak about our patients because there are acts that protect people's health information. So there are complexities in that.

I definitely think that as far as education goes—and I do educate; half of my job is providing formalized education for palliative pain and symptom management, across the spectrum—we really need to be placing an

emphasis specifically in long-term care. I think long-term care needs a lot of support—and being able to support their staff in going for education and implementing it and integrating it into their regular practice. The other piece of that, from a long-term-care perspective—and I work predominantly with long-term-care homes—is that they're overworked, they're understaffed, they're tired, and then the media hits them with everything that has been going on specifically with the pandemic. They need formalized supports for debriefing, especially for grief and bereavement, because we're dealing with multiple compound, complex loss. That's really challenging when you're a health care provider, because we're still human beings. I know people like to call us angels or heroes or what have you, but we're workers and we're doing our job. We have a responsibility to do our job, but we're also human beings and we need additional support.

Mr. Sam Oosterhoff: You touched on something important right at the end there, this almost—I don't want to call it the myth of the tireless front-line worker, because that's not right. You are incredibly dedicated and all of your colleagues are, as well. But like you've said, at the end of the day, you're human beings. You have needs, as well, and we need to make sure that you're being supported in that. You have to still be able to get a good night's sleep in order to be able to do that work, and be provided with the supports you deserve. Thank you for sharing that.

I want to go to Belinda and ask a little bit more about capital. I understand, of course, that you went through that process fairly recently.

Earlier this morning, the member for Kitchener–Conestoga, MPP Harris, spoke about having to advocate for unlocking some of the capital funds for his local hospice.

How is that process to access capital funds? We want to make it more streamlined, but we also want to make sure we're actually allocating those funds to the areas that need it most and having consistent access to capital projects. Could you talk about your organization's story and how that went?

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Ms. Belinda Marchese: I think it's a big strain for communities to think about raising \$10 million to \$12 million for a 10-bed residential hospice. The community has been extremely generous. I'm just going to say we already have to raise 88% of our operating expenses for our community programs. On top of that, now we're raising funds for capital—and we know that capital expenses never go quite in the same direction.

While we're extremely grateful that the government was able to implement and we were able to benefit from the \$2 million for our facility, the costs and the exorbitant fees and even the COVID-19 delays have put a huge strain on us. And now there are going to be many other implications to come for new hospices around some of the criteria and the enhancements for infection control. So for communities that are smaller or that might not have the capacity of the generosity as we've had in Vaughan, it continues to be a big strain for hospices to take.

Fun fact: When I came to Vaughan just under four years ago—and I've been at other hospices for 15—I said, “Don't ask me to raise \$10 million. I'm not your girl. I'll come to the table to build the capacity within the community development model and to build a network.” To raise that kind of money in a community has a huge impact.

I don't know if all sectors really have to fundraise for their capital like hospices do. I think that's an important story to start to look at. As you start to look at the capacity—and one of the earlier questions was about the beds. Remember, we're keeping people at home well before they get to that end stage for those beds, so those community programs need to be supported so they can stay at home and then they can shift into a residential hospice bed.

The Vice-Chair (Mr. Mike Schreiner): One minute.

Ms. Belinda Marchese: I think the strain of raising that amount of capital in many communities, including even in our own, that are extremely generous has a huge impact for us. We want to respect our donors and our supporters, and we really need that support to have that continuity and build a resiliency of us doing this important work.

Mr. Sam Oosterhoff: Thank you so much, Belinda, for all of your organization's work.

Rick, there are a little over 400 hospice beds in the province of Ontario, between hospices and other settings. How many beds should a province the size of Ontario have?

Mr. Rick Firth: Ontario should have 814 beds to meet the demand that exists today.

Mr. Sam Oosterhoff: I know there are 200 or so coming on-board over the next few years, but, even so, we're still substantially under that number where we want to be—

The Vice-Chair (Mr. Mike Schreiner): I'm sorry; that's all the time we have for questioning.

This next round will begin with the independent member. You'll have 4.5 minutes. I recognize MPP Fraser.

Mr. John Fraser: I'd like to direct my question to Ms. Hines.

Thank you for all the work that you're doing in long-term care.

I've often believed that long-term care is actually like a big hospice, because everyone is on the trajectory—maybe not end of life, but on the way, getting close to end of life. If you look at the next step, in terms of the numbers of people dying, I think about 17% of Ontarians die in a long-term-care home every year.

What are the measures that you think need to be in place to make sure we do palliative care better in Ontario's long-term-care homes?

Ms. Mahoganie Hines: That's a really big question, but I thank you for it.

Mr. John Fraser: Just a tiny one.

Ms. Mahoganie Hines: I really appreciate it.

Just to clarify, I don't work in long-term care; I work with long-term care. I'm a secondary-level provider, so I work in building capacity among the health care providers who work in long-term care.

As far as measures go, I think the best measure that we can look at, besides our typical indicators of ER diversion, is how people are doing. Our question should always come back to how the people are doing within our care and how they identify good quality of life—because we're not the ones who are supposed to be identifying quality of life; we are the ones who are supposed to get them to wherever quality of life is for them, as they identify.

Also, making sure that we integrate the care with the families—and trust that the families really are the experts on that person. The person and the families are the experts on them; I'm the expert in the way that care is delivered. So we need to work together, as a collaborative team.

As far as measures go, the dead don't come to tell us if we did a good job, in my experience, so we really need to do a better job at finding out what those measures are before they die and how to get there, and then review and say, “Did we hit these? This is what they identified.”

Mr. John Fraser: I think one of the most important things is the entrance interview or the first family interview that's followed up on. Having been through that a couple of times as a family, I know that doesn't happen everywhere. That's something that should be consistently across the board in all 626 long-term-care homes.

I do understand that you're a second-party provider building capacity, but you're in and out of a lot of different homes, so I'm sure you see a lot of different things.

Ms. Mahoganie Hines: I do.

Mr. John Fraser: One very interesting thing: I was at a private home in Ontario, and they provided a \$500 bursary for anybody who wanted training. The actual palliative care team lead was a PSW, which I found really interesting. Sometimes you have to find the leadership, whether you're in a community or a long-term-care home or a hospital, to make sure you pull the team together. That's the work that you do, too, I'm sure, every day, when you go in to help long-term-care homes get better.

How much time do I have, Chair?

The Vice-Chair (Mr. Mike Schreiner): About a minute and 20 seconds.

Mr. John Fraser: Thank you very much.

Ms. Marchese, it's nice to see you again, even though it's on video. Thanks for all the work that you're doing there.

I'm going to ask you a related question: In terms of your community programs, what are the things that we could do to make sure that they're stronger?

The Vice-Chair (Mr. Mike Schreiner): One minute.

Ms. Belinda Marchese: That's a wonderful question.

I think what makes our community programs stronger is listening to the people in the community. They guide us to what we need.

One of the things we've realized over the last few years is that we've had a lot of parent loss, parents who have lost children to illnesses, to tragedies—homicide, suicide, car accidents. One of the things our community programs did was not only provide that grief and loss and trauma work with those families, but we also found a mechanism to bring those individuals together. Rick mentioned that

before—the grief and bereavement and the trauma work that happens, that often comes to the community because there’s nowhere else to go. What we do is—by building the capacity within the community, they’re able to support each other. We have to find a way to be resilient through natural processes of death and loss, but even through trauma, because when you can have that network where you’re able to build that community together with those who have a shared experience—

The Vice-Chair (Mr. Mike Schreiner): I’m sorry; that’s all the time that we have for this round.

The next round will go to the government. You have 7.5 minutes. I recognize MPP Bailey.

Mr. Robert Bailey: I want to thank Ms. Marchese, Ms. Hines and, of course, Mr. Firth for the great work that they do.

I’ve been listening intently here. Hospice care and palliative care is something I’m very fortunate—I live in Sarnia–Lambton. Mr. Firth, especially, will probably know Dr. Glen Maddison in Sarnia–Lambton. We’re very fortunate.

One of the first things I did when I got elected a number of years ago was turning the sod for the St. Joe’s hospice in Sarnia. At the time—I’ve got to be honest—I had no idea, I had no knowledge, of palliative care or hospice care. I assumed that everyone in Ontario had access to what we built in Sarnia. It has been going now for 11 or 12 years. We’re very fortunate we have the palliative care at St. Joe’s hospice. We have 12 beds, and then at Bluewater Health, which is our major hospital in Sarnia–Lambton, there’s also hospice care there. Dr. Maddison, among others, is the lead in hospice care. We are very fortunate.

In the county, in the more rural part of Lambton, there’s also palliative care available in the home. I know a number of families who have taken advantage of that and how grateful they are.

I did want to mention my own hospice and how fortunate people in my riding and county are. So I certainly support this bill and would like to see this same type of possibility available to other communities across Ontario.

If this bill is passed, the Ministry of Health will be tasked with the development of a provincial framework in consultation with hospice palliative care providers like you, other affected ministries, the federal government and many other persons, or any of these that the ministry would consider appropriate.

How do you believe that the palliative care sector can best support the work and advice to the ministry? That can go to whoever wants to jump in there.

1350

Ms. Mahoganie Hines: I think Rick will answer.

Mr. Rick Firth: Thanks. We’re a sector that has been at the table since the very beginning, and we have an amazing group of people who are dedicated to this work, because most of us are also clients of the palliative care system. We’ve had the losses of family members. So we can bring a wealth of individuals with very diverse experience to the table to work with government as partners in crafting the way forward.

You said “other ministries,” and I want to emphasize the importance of that. Hospice palliative care sits at the intersection of not only government and grassroots, but health care and social services. Many of the things that we do are not expressly a health care service, but they’re bundled in as part of the care that’s needed for people who are experiencing end of life, and their families. Bringing together different ministries that support children and youth and mental health and addictions and social services is important to bring that holistic, wraparound care to people.

In communities like Sarnia, where you have a very active compassionate communities program, along with the hospice, we’re seeing that connection of people before they actually need the formal health care system, and they’re being connected with supports and neighbours who are there for them.

So I think that you have to bring it together across government, the community and the various parts of the social sector. We can do that. We can bring the people to the table, and we have been doing that for years.

Mr. Robert Bailey: Do either of the ladies want to comment? Ms. Marchese has her hand up.

Ms. Belinda Marchese: Just a quick piece to validate Rick’s point: The social determinants of health guide the wellness wheel. What does that look like? We have a local food bank here in Vaughan. The leader of that, Peter Wixson—I dropped off some food to him, and he and I were talking about a gentleman who was dying, who was sleeping in his car in a Walmart plaza. We talked about what that could look like. Hospice can go to a car. Hospice can make that difference, to transition. We might think that in Vaughan there is no one suffering from insecurities such as housing and food, but that’s happening—the lineups were long before COVID-19 and since COVID-19.

So I think Rick’s point and your point around—that inter-ministerial component has to align, because people are accessing things, even around hospice and end of life, in the most creative areas that I hadn’t experienced until I worked in Toronto and I saw it first-hand.

Mr. Robert Bailey: If Ms. Hines doesn’t have a comment, I have another question I’d like to get on the record. This is something I’m really excited about in Ontario.

I don’t know how much time I’ve got, Chair, but—

The Vice-Chair (Mr. Mike Schreiner): One minute and 30 seconds.

Mr. Robert Bailey: Okay.

This is more of a statement than a question.

Ontario is in the process of transitioning to a new model of care, to Ontario health teams. We just had one announced in the Sarnia area. It’s going to be called the Sarnia-Lambton Ontario Health Team. I’m very excited about that. It’s going to deliver more integrated care and palliative care services, I hope, here locally.

Does anybody have any ideas on how we can better connect hospice palliative care resources with other parts of the system through the transition?

Mr. Rick Firth: If I may, the Ontario health teams have a great opportunity to work with the existing hospices, which are really hubs in their communities. They’re

already connected throughout a community. Supporting the hospices with their clinical costs will strengthen them—

The Vice-Chair (Mr. Mike Schreiner): One minute.

Mr. Rick Firth: —and it will enable the hospices to become regional assets, or regional resources, for those Ontario health teams. Collaboration has always been the core of hospice palliative care, and I think Ontario health teams will strengthen that.

Mr. Robert Bailey: Ms. Marchese? Sorry, Chair.

Ms. Belinda Marchese: And just break down the borders. It's not about the borders and the lines of the street and what side of the street you're at. Follow the person and make it seamless. People are often connected before the formal system comes into play. It's a really important piece—that we have to break that barrier down—and our Ontario health care teams are a perfect vehicle for that.

The Vice-Chair (Mr. Mike Schreiner): Ms. Hines? Go ahead. You have 10 seconds.

Ms. Mahoganie Hines: Really, all I wanted to say is just to echo what Belinda and Rick have already mentioned: that collaboration and—

The Vice-Chair (Mr. Mike Schreiner): I'm sorry; that's all the time we have for this round.

We will now go to the official opposition. You have 7.5 minutes. I recognize MPP Gélinas.

M^{me} France Gélinas: Please finish your comment.

Ms. Mahoganie Hines: Thank you. My comment was just that we need to follow people across all barriers, every barrier that's currently in the health care system. We work collaboratively with every partner, even if they don't consider themselves to be a palliative care expert or provider. The reality is, they are a provider; they just may not call it that.

M^{me} France Gélinas: Well said.

My first questions will be to Ms. Marchese.

In your presentation, you talked about home hospice, where there is no charge to the client or family, and very high demand.

When was the last time we saw an increase in the operating budget of home hospice services, if at all?

Ms. Belinda Marchese: I love this question.

Rick and I have this conversation on a regular basis. We've seen a slight few pennies over the last four years that I've been here in Vaughan. Part of the challenge that we have in community hospices is, we're not funded the same in our area. I can have a hospice north, south, east or west of me that gets more money than I do even though I might have the same measures or outcomes. So I think we have to look at how we build the capacity to the proper baseline and how we fund so we can have the professional services and build the volunteers.

Honestly, family members, caregivers, our volunteers—they all come from their hearts to make the capacity more dignified for a person in their journey. So the funding model needs to be looked at, really, at a grassroots level. How do we build that capacity? Our donors in the community are trying. We've been doing this for 25 years. At the end of the day, through COVID-19 and other stressors, our demand goes up, but we don't have the funding. I'm

so fortunate that I have a community that wants to make it happen.

I, myself, am a donor to my own hospice, so I'm prepared to also live my truth and make sure that we can continue to grow our services.

Let me be clear: Once our building opens, all we're going to do is get more in the community. My beds are only going to flow so many people—so the support has to be before. People can die at home with supports, with the formal and the informal systems. I truly believe the beds are key and vital, but so is the support in the home. People are aging, and the community wants to provide that support where a person wants it—and people want to stay at home.

My stepdad wants to be at home, and right now he's in hospital. So I'm going to need a whole army of people to make his dying wish possible.

M^{me} France Gélinas: Agreed.

Have any of the hospices—and I'll open it up to all of you—asked for funding for home hospice palliative care?

Ms. Mahoganie Hines: Yes.

M^{me} France Gélinas: What has been the answer?

Mr. Rick Firth: At present, there are 84 visiting hospice services. I think at least 65 or 70 of those are funded, but the funding is based on formulas that were put in place in 1994, and it really hasn't adapted to reflect the current demand. The funding originally was to train volunteers, but now there are the psychosocial supports, wellness programs—a whole myriad of services that the communities need.

We're trying to build capacity across the system with standardized baskets of services. We've been asking for investments to fill that capacity, but under the current system, the money is frequently filtered and interpreted through the LHINs, who then assign it to their own priorities—so in a \$3-million allocation, a visiting hospice might get \$500 and another might get \$60,000. So we're not really allocating the funds to close the gaps and meet the needs. We need a more significant investment. The psychosocial supports alone need an investment somewhere in the neighbourhood of \$13 million net new—in order to meet the needs that I was talking about with grief and bereavement support programs.

M^{me} France Gélinas: Did I hear you right? The formula is based on the formulas from 1984?

Mr. Rick Firth: From 1994, when the first funding was announced for visiting hospice services.

1400

M^{me} France Gélinas: That's a long time ago.

I take it that you have done the math. You say 13 million net new dollars—is this the number that would bring visiting palliative care at a level that can provide quality care throughout Ontario, or is this for the 84 existing visiting palliative care sites?

Mr. Rick Firth: That's for the existing sites, to both sustain their grief and bereavement supports and also expand to meet the demand.

M^{me} France Gélinas: I take it that you have asked for this money. It was not in the last budget that was tabled

two weeks ago. Are you hopeful that it will be in the new budget coming out at the end of March?

Mr. Rick Firth: We're very hopeful that it will be in the March budget, because, honestly, I don't know how many of the hospices will be willing to sustain the programs with fundraising. COVID-19 has really tapped their ability to fundraise.

M^{me} France Gélinas: Not only for hospice, but for everybody else in between.

The bill is focused on developing a framework, but from what I understand, OPCN already has a framework in place, and you're more focused on delivering that framework than rebuilding it. Am I right?

Mr. Rick Firth: Correct.

M^{me} France Gélinas: Would you be open to making amendments in the bill that talk about delivery—

The Chair (Ms. Goldie Ghamari): One minute.

M^{me} France Gélinas: —not just talk about doing the framework, but focusing on the delivery?

Mr. Rick Firth: Yes, absolutely. I think we've done the frameworks. We know what we need to do. We now need support to move forward.

The \$13 million we need for grief and bereavement—that's pre-COVID-19. We estimated we needed at least \$25 million to meet the spike in demand because of COVID-19.

M^{me} France Gélinas: Yes, I could see this.

When you answered the questions before—you've put the number of beds that Ontario needed at 814 beds. Has this number changed because of COVID-19, or are you still comfortable at that number for the province?

Mr. Rick Firth: We're still comfortable with that number for the province at this point.

M^{me} France Gélinas: But the focus in increased help would be for the grieving and bereavement delivered through the home—

The Chair (Ms. Goldie Ghamari): Thank you very much. That concludes this round of questioning.

I want to thank the presenters for their very informative presentations. You are now released, and you may stand down.

MCNALLY HOUSE HOSPICE

DR. PAUL-ANDRÉ GAUTHIER

PROVINCIAL PEDIATRIC PALLIATIVE
CARE STEERING COMMITTEE

The Chair (Ms. Goldie Ghamari): We'll now call upon our next set of presenters. We have representatives from McNally House Hospice, we have Paul-André Gauthier, and we have the Provincial Pediatric Palliative Care Steering Committee.

At this point, I'd like to call upon McNally House Hospice. Please state your names for the record, and then you may begin our presentation. You will have seven minutes.

Ms. Pamela Blackwood: Good afternoon. My name is Pamela Blackwood. I am the executive director of McNally

House Hospice, a six-bed residential hospice which opened nearly 13 years ago in the region of west Niagara.

I am honoured to be here today to speak to our support for Bill 3, the Compassionate Care Act. Our thanks go to our MPP, Sam Oosterhoff, for not only introducing the bill but taking the time and effort from his very first early days of office to fully learn and understand the palliative care needs of Ontarians. My thanks also go to the MPPs from all parties who have welcomed me and my colleagues from across the province, during our hospice palliative care Queen's Park meeting days, to learn more about and support the hospice sector.

If you ask people where they would like to die, most will tell you, "At home." That isn't always possible or realistic, but the excellent community hospice palliative care services in Ontario are making that ever more possible.

Hospice palliative care came into existence nearly 40 years ago in Ontario as a grassroots community initiative that trained volunteers visiting patients in their homes. The community visiting hospice services have expanded to include residential hospices with in-patient beds, providing a comfortable, home-like setting for the last weeks of life when the need for care exceeds what can be provided at home but an acute-care hospital is not required.

That's how McNally House in Grimsby, in MPP Oosterhoff's riding, came to be. McNally House was the realization of a growing awareness in west Niagara that, despite good health care and community palliative care services, not everyone was dying well, and too many people who had wished to remain home were ending up in hospital at end of life.

Like any community who has seen and heard this need—the McNally build was the caring response from our community. In fact, the World Health Organization states this clearly: Dying well, wellness no matter what your end-of-life condition is, is a basic human right. Opening a residential hospice for those who could not manage at home and offering the wide range of services that McNally House now has was and is, to my view, the right step to attending to this basic human right.

Hospice palliative care is an approach to providing care for people with life-limiting illness and at end of life as well as providing support for their families. At the end of life, there are physical, psychological, spiritual, social and practical aspects of suffering. Hospice palliative care addresses each of these needs, providing pain and symptom management and a host of other supports that help to maintain quality of life even at the very end of life. The care can be provided in any care setting: at home, in a residential hospice, in long-term care or in an acute-care hospital. What we hear over and over again is that once someone receives hospice palliative care, the suffering is eased—physical, mental and emotional—and the family and loved ones can focus on each other once again and share an important last chapter of life.

I would like to introduce Stephanie Ryckman. Stephanie had the experience of accompanying two of her family members as they journeyed through end of life here

at McNally House. I cannot think of a better way to demonstrate the need for greater and consistent access to palliative care for all Ontarians than to hear from a family's first-hand experience.

Stephanie?

Ms. Stephanie Ryckman: Thank you, Pam.

I'm Stephanie Ryckman. I'm really privileged to share our story. As a family, access to residential hospice has had a significant impact on our lives.

Our experience at McNally House began in 2017 with our mom, Maureen. Despite in-home assistance, help from family and the Herculean efforts of our dad, as Mom's health continued to deteriorate and her needs increased, we knew that her hope of dying at home would not be possible. Hospice had been in our discussion, but in our ignorance, we thought hospice was just a place you go to die. What we came to realize is that hospice is so much more than that.

A bed had become available, and we had to act quickly. Dad was still undecided, as were we, and a visiting nurse shared her thoughts as she watched us struggle with the decision-making. She said, "Think of it this way: Hospice can provide the opportunity for you to be a family again." We realized that we were so wrapped in her medical needs that we had abandoned our regular roles out of necessity.

Mom's stay was short. She wasn't aware of her surroundings. We knew we didn't have long with her. But in those short hours, not only was Mom comfortable and pain-free; we were, too. The staff and the volunteers were amazing, welcoming us with a meal, kind words, answers to our many questions—even the ones that we were super uncomfortable asking—and, most of all, reassurance that we had made the right decision. We felt safe and supported, and we were quickly able to resume our family roles at Mom's bedside, comforting her, saying goodbye, holding her hand while the team focused on her physical needs.

Our experience didn't end with Mom. In January of this year, our dad, Murray, spent his final days at McNally House too. Our experience with Dad was much different than Mom's. Faced with the certainty that he would not recover from his illness, our family physician suggested it may be time to look at hospice care for Dad's end-of-life journey. Dad was part of the decision-making and agreed that McNally House was the right choice, and he was ready.

Although his body was shutting down, his spirit was in full swing. His last two weeks were spent surrounded by friends and family, sharing time, memories, meals, live music and even bubble baths. He joked with the nurses. He flirted with the volunteers. He gave the PSWs a run for their money. And he even had singalongs with the spiritual adviser.

He was comforted by the fact that he knew we could focus on our time together, being present and in the moment. He never liked being cared for or doted on. He was always more comfortable in the role of caregiver, and he didn't love being a patient. He eventually gave in to the fact that it was his turn to be taken care of. We were able to bring in family photos, his favourite art—

The Chair (Ms. Goldie Ghamari): One minute left.

Ms. Stephanie Ryckman: He knew his time was limited, but he never lost the joy of life, affecting those around him in a positive way. He, too, passed peacefully, with us by his bedside—no tubes, wires or beeping machinery; just peaceful and supported by care providers who ensured that he was comfortable and we were, too.

Without the opportunity of hospice, I think our good-byes would look much different. As both Mom and Dad's conditions quickly deteriorated, the focus would have been on asking ourselves, "How much can we do before calling for help?" There would have been loss of dignity, around-the-clock caregiving, time away from our families as we focused on the physical needs of our parents, and likely, death in hospital. Unquestionably, we would not have experienced the peaceful end we were so blessed to have.

1410

The role of hospice and palliative care has been life-changing in our family. We realize how fortunate we were that a bed was available when we needed one.

We're hopeful that sharing our story will help open the doors to difficult conversations, raise awareness, and provide others with the opportunity to experience the same compassionate commitment to care hospice has provided our family.

I truly appreciate the opportunity to share our story.

The Chair (Ms. Goldie Ghamari): Thank you very much. You will have more time during the questions and comments to share your experiences. I'm sure everyone will want to ask you questions.

We'll now turn to our second presenter, Paul-André Gauthier. Please state your name for the record, and then you may begin. You will have seven minutes.

Dr. Paul-André Gauthier: I'm Paul-André Gauthier from Sudbury.

Thank you for the invitation to present on Bill 3. Merci de l'invitation pour présenter pour le projet de loi numéro 3.

I want to mention that I have no conflict of interest in presenting today because I'm not paid for my palliative care services. I do volunteer my time and my services to palliative care people, as an expert.

Offhand, definitely, I have to say that we need to improve palliative care. I've been involved in palliative care in Ontario for the past 35 years. I began in Timmins, then I moved to Sudbury after that. I have completed two clinical masters in palliative care. I was a nursing professor for 30-some years, teaching theory and teaching in the clinical environment. My expertise in palliative care goes from the theory to the practice.

One of the things I have done over the years is continue being involved in palliative care with the clients, the residents, the patients, the families, and also the health care professionals who are providing care to the people who are terminally ill. With my expertise, I can work with the people from the beginning, from the diagnosis, until the end, when they're dying. I can attend while they're dying and help them through that difficult challenge.

First of all, I will talk probably more from a general perspective.

We are short of health care professionals who are educated in palliative care. We need more of them. We also need specialization at the master's level to educate people in the clinical expertise at the advanced level, such as I have done in my case, in Montreal, in both master's programs.

We also need to train and educate health care professionals on-the-job, because quite a few things you cannot only learn in theory; you need to learn and look at it while you're practising.

We need to assess, treat, care for and also "accompany" the terminally ill—that word is not often heard. We need to help the person to go through the process they're going through and not push them through the process. There's a big difference there.

We also need qualified health care professionals to provide counselling to the people who are terminally ill, and counselling to the staff, to help through the process—because when you work with kids who are terminally ill, there are a lot of things that are quite different from elderly people, when you do the work with these individuals, and the parents also need quite a bit of help.

We also need continuous, supervised learning. The staff in palliative care are quite busy doing their work, but they also need to be having ongoing, continuing education in the clinical environment, not only conferences and this and that—because quite a few people cannot go to conferences because it's quite expensive, number one. Number two: In our case, in northern Ontario, we have to go away in order to be able to attend these conferences.

We also need to develop more effective teams in delivering palliative care. We're doing good, but we need to be better at it. We need to be improving. Over the years, there are improvements that have to be done.

We also need full-time staff for continuity of care, because when we have part-time staff, they move back and forth, and then they don't get to know the clients, the families and the residents. We need continuity of care.

Also, we need to keep the staff. I'm talking about full-time staff. We need to keep these nurses—the RNs, RPNs—and PSWs on staff full-time. Once they acquire expertise and knowledge, we want to keep them. We don't want to lose them—because sometimes they move on if they get a job somewhere else that pays much better. So we need pay equity with the hospital environment, because when nurses—for example, registered nurses are paid \$10 to \$15 an hour less than the hospital. It's not good. It's the same with the RPNs. So we need qualified staff who are paid well who will not be leaving us when they get a good deal somewhere else.

Also, one of the things I have noticed over the years is that a lot of hospices and palliative care services have to do fundraising. To me, this is annoying, because they spend a lot of time to raise between half a million dollars to \$1.5 million every year in order to be able to provide the care. They should not be spending time and energy in doing fundraising while they should be providing care, so

there should be something done by the government about that, in order to help them to focus on the things they should be doing.

The bio-psychosocial-spiritual assessment that needs to be done for the residents and the families needs to be done appropriately. Also, the plan of care has to be developed in accordance with the needs of these individuals and these families.

Also, they need to have counselling about the issues and the concerns that the people are experiencing. These are individuals; we never know until we do the assessment and we work with them what the issues are that they are dealing with and how we can help them. We cannot leave them alone and say, "Okay, deal with that." It doesn't work.

The Chair (Ms. Goldie Ghamari): One minute left.

Dr. Paul-André Gauthier: My clinical expertise is about the things we need to do to make sure that we are becoming effective. We need to stabilize palliative care services and hospice services in order to provide a higher quality of care.

In summary, we need full-time nursing staff, we need more qualified staff in palliative care, we need better salaries for nursing staff, and we need to deal with the issue of fundraising to avoid them spending too much energy and time on this and not focusing more on the care of the people.

The Chair (Ms. Goldie Ghamari): Thank you very much.

We'll now turn to our third presenter, Provincial Pediatric Palliative Care Steering Committee. Please state your names for the record, and then you may begin. You will have seven minutes.

Dr. Adam Rapoport: Thank you very much. It is my pleasure to start by introducing myself as well as the others who are accompanying me today.

Dr. Greenberg, I'm going to ask you to start sharing your screen, if that's okay, for the presentation.

My name is Dr. Adam Rapoport. I am the medical director of palliative care at the Hospital for Sick Children and the medical director of Emily's House children's hospice in Toronto. I am here speaking today as the co-chair of the Provincial Pediatric Palliative Care Steering Committee.

I will also take this time to quickly introduce my co-chair, Dr. Mark Greenberg, as well as the two individuals who will be speaking immediately after me, Julie Drury and Valerie McDonald, the co-chairs of our family advisory council.

I'm going to assume that it is an accepted premise that any effort to ensure Ontarians have access to high-quality palliative and hospice care must do so for citizens of all ages, including infants, children and adolescents. With that in mind, my focus will be why it is crucial that Bill 3 specifically acknowledges that a distinct pediatric framework and oversight body are necessary—and I will do so by highlighting three important points:

(1) Pediatric palliative and hospice care is something different. Nearly half of our patients are less than a year of

age, and the vast majority are not capable of making important medical decisions for themselves. Clinicians need to be able to communicate with each child in a developmentally appropriate way to help them grapple with serious illness and death. The relationship is never just clinician-patient; it's always clinician-family. Pediatric palliative care addresses the needs of the patient, the parents, the siblings, and sometimes even the extended family, friends and classmates. The majority of adults referred to palliative care have cancer; less than one quarter of our patients do. The majority have severe neurologic problems, are often technology-dependent and medically fragile and have uncertain prognoses.

1420

(2) Ensuring that all of Ontario's pediatric patients and their families have access to high-quality palliative care requires a unique model. We are talking about a relatively small cohort spread out across a large geographic area. But no matter where they live, parents will always ensure that their child is getting the best medical care possible. Imagine that your child needed a serious operation. Would you want a general surgeon who has done it a few times, or a pediatric specialist who does it every day? For that reason, children with palliative care needs will almost always receive care at one of the five regional pediatric academic health sciences centres in London, Hamilton, Toronto, Ottawa and Kingston. While there are very skilled palliative care clinicians working in almost all communities across our province, most are extremely uncomfortable caring for children and received little, if any, training to do so. An effective pediatric palliative care framework in Ontario must embrace a regional hub-and-spoke model. Palliative care teams affiliated with the five children's hospitals must be those central hubs. These teams have access to the patients. They are trusted by the referring teams and the families, and they have the knowledge and expertise. However, children and families should be able to access high-quality palliative care wherever they live, particularly at the end of life. This can be accomplished when pediatric palliative care teams build bridges with community providers, adult palliative care clinicians and pediatricians and provide them with 24-7 support.

(3) It is not enough to simply state that a provincial framework must apply to Ontarians of all ages, including children. This has been the approach by the province for decades, and it does not work. Those who must set priorities understandably look for opportunities that will have the biggest impact. For palliative care, that means that the adult system will always be the priority, and because yearly budgets don't allow us to address all challenges at once, pediatric issues never make the cut. It was for this reason that our Provincial Pediatric Palliative Care Steering Committee was first created. Only when there is a dedicated framework and body focused on addressing the palliative care needs of children, with appropriate resources and funding, will there be improvement.

Julie?

Ms. Julie Drury: To illustrate how pediatric palliative care can be such an incredible asset and benefit to a family, I want to share with you the story of my daughter, Kate. Kate died five years ago, on November 30, 2015, at the age of eight. We chose for her to die at home after she was treated for a bone marrow transplant at a Montreal children's hospital and we were told that nothing else could be done for her.

The Chair (Ms. Goldie Ghamari): One minute left.

Ms. Julie Drury: We chose for her to die at home. The reason we made that choice and were able to make that choice is because of the incredible support we received from Roger Neilson House, a well-known pediatric palliative care hospice and facility in Ottawa located on the grounds of CHEO. Because of our long-standing relationship with the pediatric palliative care team there, they were incredibly able to support Kate and our family, including her sibling, her older brother, Jack.

We chose for Kate to die at home with her stuffies and her bears and her princess dolls. The team were available to support us 24-7, day and night. They were able to support me as her mother, through her medication management, and for our family to be at her bedside.

If we did not live in Ottawa or any other part of the province where this care would be available, Kate likely would have died in a hospital, in an intensive care room with limited access to her family, her friends and her loved ones.

Roger Neilson House is also able to support bereaved families of pediatric children and their siblings in a way that is 100% supportive, wraparound care—

The Chair (Ms. Goldie Ghamari): My apologies. I'm sorry for cutting you off. I'm sure you'll have—

Interjection.

The Chair (Ms. Goldie Ghamari): Continue? Okay.

The government side has agreed to allow you to finish your presentation using up government time. Please continue.

Ms. Julie Drury: Thank you; I have about 15 seconds left—allowing her brother to be at her bedside and to fully participate in the end of life of his sister. Again, this is not possible in a hospital setting in the way that it is in a pediatric palliative care design, either in hospice or at-home care.

I'm very fortunate and well aware of how fortunate our family is to have received this type of care.

Children are not mini-adults, as Dr. Rapoport has shared. I urge this committee to consider including a pediatric palliative model within this bill. Thank you.

The Chair (Ms. Goldie Ghamari): Before we go to the government side, I just want to thank you for sharing your experience with us. Being an Ottawa-area MPP, I have visited Roger Neilson House a couple of times as well, so I understand the impact.

We'll now turn to government. You may begin. You have six minutes, 55 seconds.

Mr. Sam Oosterhoff: I think one of the benefits of the committee is being able to hear from family members. All of us have unique stories. In politics, in organizations, in

governance and all those things, at the end of the day, these sorts of changes come down to people. Hearing these stories, I think, puts a real point on what we're trying to accomplish. So I just want to thank you for sharing, because I know it's difficult. I know, having gone through that—I can see within your eyes the courage and also, of course, that pain still being relived. It's very meaningful to hear this depth of personal connection with palliative care, and I think it's very important for all members of the committee.

I want to return to Pam and Kristi and Stephanie from McNally House—my home hospice, if you will; the closest to my area, just a few minutes away. I want to first of all thank them for coming and for their steadfast support since 2016, when I was just elected and had a tour and was blown away. We spoke about the importance of making sure these services were more widely available and about some of the areas.

I also want to acknowledge Denise Marshall—an incredible force of nature at McNally House and a wonderful woman who is honoured and respected by so many within the community, and more broadly, for her advocacy.

I'm wondering if you could talk a little bit about the importance of something that the member from Ottawa South has talked about: compassionate communities. I talked about it this morning. We want to make sure that that community engagement piece doesn't disappear, that we have that buy-in from the community that makes it special—the volunteers, the people who come and make sure there's always a bowl of soup ready, homemade soup on the oven, and lots of those types of amazing pieces. Can you talk about how we can ensure, as we move forward with a framework, that we're integrating various government agencies to provide support, but also maintaining that network, that framework, that community aspect, and how important that is?

Ms. Pamela Blackwood: Yes, absolutely. One of the biggest goals for us in bringing the hospice to west Niagara is our compassionate communities work. Our work is not within just the hospice itself, as Sam alluded to, supporting not only our residents but their family members—and when we talk about family members, it's usually around five family members, or friends and family, who we support in other ways. Some of our greatest work has been in our compassionate communities work of bringing education to the community about death, dying, loss and grief, to normalize death, dying, loss and grief and to create a death-positive society.

Our work has been brought to our high schools, where we are spending time with our high school students, talking about what is on their bucket list, their hopes for their future and their understanding of death, dying, loss and grief, and the importance of bringing that conversation to them. We have done work with our communities in having what we call dialogues, having those difficult conversations in a coffee shop, with a dozen people asking those difficult questions about what death and dying means to them and their plans for the future.

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That work, along with incorporating education into our local businesses and employers about how they can support a family member who is going through a loss, or a person who is actually dying—that is work that we need to be doing, in educating employers in how they can support their employees.

We've done everything from art museum displays, with artists in our community sharing their grief stories through art, to having library support groups, where we have book clubs and movie clubs where we discover and discuss death, dying, loss and grief.

Mr. Sam Oosterhoff: To build on that, could you talk about a best practice that you would want to see extrapolated across the province that you've seen as extremely successful within McNally House, or a characteristic that might be unique but that would be good to see in other areas? We have a number of different hospices that are on the witness list—we've already heard from a couple—so it would be great to have an idea of what an absolutely essential best practice would be that you could share.

Ms. Pamela Blackwood: I think one of the most essential best practices is the supports for bereavement and psycho-spiritual supports. We do very well in supporting our residents in the hospice with the dollars that are provided through the Ministry of Health and with our fundraised dollars. But what is not funded, and should be, is bereavement and psycho-spiritual supports.

There is a huge impact to the family as they go through not only the journey of walking their loved one home, but also the bereavement. What we do well is to reach out to those families and support them. We tell them that once they are part of our McNally family, they are always part of our McNally family.

The Chair (Ms. Goldie Ghamari): One minute left.

Mr. Sam Oosterhoff: I want to make sure I get to the Provincial Paediatric Palliative Care Steering Committee. An amendment to this legislation—what would you want to see in the wording around that, exactly? Would it be an addition of a subclause indicating the development of—fill in the blank. How would you want that worded? This I to anyone on the steering committee.

Dr. Adam Rapoport: We are looking specifically for language that acknowledges that a separate framework, as well as a body, is required to provide oversight and guidance so that we can have excellent palliative care—

The Chair (Ms. Goldie Ghamari): Thank you very much. That concludes this round of questions.

We'll now turn to the independent member. You have four—

Interjection.

The Chair (Ms. Goldie Ghamari): Oh, sorry.

We'll turn to the official opposition. You have seven and a half minutes. You may begin.

Ms. Sandy Shaw: Dr. Rapoport, would you like to complete your answer?

Dr. Adam Rapoport: Sure. I pretty much finished, but thank you.

I just want to make sure that there is a separate and distinct framework and body overseeing pediatric palliative care.

As mentioned earlier, the province's approach over the last 10 years has been to acknowledge the needs of children—which is terrific; I think that's wonderful. But when we do that and that alone, we never get our kick at the can, so to speak. There are always more pressing—and more numbers and more money behind the adult issues. It is only when we have our own distinct framework and body that we are actually going to be able to ensure that children and families everywhere across this province have access to equal and high-quality palliative care.

Ms. Sandy Shaw: Thank you, Dr. Rapoport.

I would like to address my question to Dr. Greenberg. I would like to begin by thanking you for a personal connection. I want to thank you for mentoring me in understanding pediatric palliative care.

I would like you to share with the committee your expertise and why pediatric palliative care is so unique.

I welcome the discussion that we're having about amending Bill 3; that would be wonderful. The Nancy Rose Act, as you know, does provide for the development of a provincial pediatric palliative care strategy, but if all of the wisdom and the work that went into the Nancy Rose Act and that you have done over the years—and if the provincial pediatric palliative care could be included in Bill 3, that would be fantastic.

Dr. Greenberg, share with us your wisdom and your experience.

Dr. Mark Greenberg: Thank you very much for the invitation.

Dr. Rapoport has outlined why it is a fundamentally different exercise, but let us begin with the idea that everybody, without doubt and without exception, will acknowledge that our future is our children. In every other context, child health care and child comprehensive care are identified as discrete and have their own resources and pattern of practice and organization. That is not and should not be different for children in need of palliative care. Palliative care is a complement to every other dimension of child care.

One of the big pluses that has occurred in palliative care is to move palliative care to the front end. I'm an oncologist by training, and we became very aware that the palliative care service has things to offer our patients from the time of diagnosis. Whether they live or not, they live a better life when palliative care is offered at the front end. That is also true at the back end, where palliative care steps in to help us to guide a child and a family through life.

That entity of child and family—I understand full well. Let me acknowledge fully I have been through this exercise myself and so talk from both sides of the gurney, so to speak. What is fundamentally different is that while family members are part of the death of an adult patient, a child cannot die without their family. A child can't transit the kinds of things that they have to transit without a family. It's not only about decision-making; it's about communication, connection, love, want and holding.

Palliative care is uniquely placed to do that. They probably do it better than I as an oncologist and my colleagues the gastroenterologists.

Finally, the option of dying at home must be an option for children. But in order to achieve that, we can't simply rely on adult providers or even pediatricians, who probably will only see one or two children die in their entire practice life. We have to set up a system. That system has to have the hub and spokes that Dr. Rapoport has described. We can do that. We have it set up. But we need funding, and we need to have it enshrined in the act.

Ms. Sandy Shaw: Dr. Rapoport has talked about the distinct framework and oversight body that are so necessary—and need to be distinct, discrete, identified. Can you discuss some of the work that has already gone into this? We heard that the OPCN already has a framework for delivery of palliative care, and it seems to me that the Provincial Pediatric Palliative Care Steering Committee also has done work on an actual delivery framework. Could you explain that to us, either Dr. Greenberg or Dr. Rapoport?

Dr. Mark Greenberg: Go ahead, Adam.

Dr. Adam Rapoport: Sure. As we've already alluded to, we do have a Provincial Pediatric Palliative Care Steering Committee that is well-represented by various factions across the province. We have leadership from the five major academic health sciences centres. We have an extremely strong family advisory council, represented by Val and Julie, who are here. They are the co-chairs. The members of that family advisory council who guide us in the work we do are represented from across the province in all five regions—urban and rural—some of whose children are still alive but with palliative care needs and some who are bereaved. We have representatives from the Ontario Palliative Care Network; we are working in partnership. Each region has formed a regional implementation working group with members from the community, both hospice and palliative care physicians and clinicians, pediatricians in each region.

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The Chair (Ms. Goldie Ghamari): One minute left.

Dr. Adam Rapoport: So we have a very strong committee that exists, that works in concert together with the Ontario Palliative Care Network.

Again, just coming back to that point that I made earlier: The OPCN has a mandate to address the needs of children, but they recognized right away they didn't have the skill to, so they turned to us and they asked us if we would guide them in their efforts. We are proud to do so, proud to work together with them and proud of the steering committee that we formed that has representatives from across all five regions.

Ms. Sandy Shaw: Thank you, Dr. Rapoport. We're out of time, but I would like to say, for Kate, for Nancy Rose, for Jessica, I'm certainly hoping the government is listening and will include distinct recommendations for pediatric palliative care.

The Chair (Ms. Goldie Ghamari): Thank you. We'll now turn to the independent. You have four and a half minutes.

Mr. John Fraser: Thank you very much to McNally House, Dr. Gauthier and the Provincial Pediatric Palliative Care Steering Committee for your presentations today and for taking the time. Seven minutes is not a lot of time; I know it's really hard.

I first want to say to Julie, who I know, thank you very much for sharing your family's story—stories are important—and for all the work that you do every day not just here, but in other ways, to support families in the health care system.

I have to go upstairs to speak shortly, so I may miss my second round, but I did want to ask Ms. McDonald if she had a presentation. If you want to use this time to give your presentation, please do.

Ms. Valerie McDonald: Thank you very much. I'm co-chair of the family advisory council along with Julie, but I'm also speaking to you today as primary caregiver of my daughter, Natalie, who died of cancer at age nine, and also my father-in-law, Bill, who died at 92. As caregiver to both adults and children, I would argue that children and their families have very distinct needs that must be recognized in this act.

When my father-in-law's illness became incurable, it was very sad for him, and it was sad for us and for my children to learn that he was going to die, but it was not unexpected.

When Natalie relapsed after more than two years of treatment, everyone was shocked and unprepared. Many of the medical staff actively avoided us because they didn't feel equipped to help her die. On occasion, I had to comfort weeping home care nurses before they could do their jobs and take care of my daughter because they lacked pediatric training.

When my father-in-law stopped active treatment for his cancer, his medical team was very experienced and comfortable with providing compassionate care and, as Dr. Gauthier recommended, accompanying him on his journey. As an adult, he understood what was happening and he was able to express his wishes and make choices about his care.

Put in contrast to her grandfather, Natalie needed support to continue to learn, to develop and to try to understand what was happening to her. She worked with the hospital's teacher to keep working on math and reading, and she found ways to express herself by working with a therapeutic clown and a music therapist.

As a family, we needed support from professionals with a deep understanding of the needs of children in order to help us make good decisions on her behalf, but also to find ways to include her in making her own choices. It was a pediatric psychologist who prepared me to be able to answer the question when Natalie asked me, "Mom, am I going to die?"

After my father-in-law died, we missed him; after Natalie died, we had to rebuild our lives. Our family con-

tinued to need support to grieve and to rebuild our relationships with each other. Her death has had a lifelong impact on her sisters, on my husband and on me.

I can't stress enough how important it is to include a distinct framework for pediatric palliative care within this act.

I'm very grateful to you for allowing me to make this statement.

The Chair (Ms. Goldie Ghamari): One minute left.

Mr. John Fraser: I'm glad you were able to make your presentation, and thank you very much for sharing that.

I know that we had the good fortune, in 2018, to support perinatal hospice in Ontario, which I think is really important, too. There is a great loss that exists there. It's something we have to continue to support and continue to grow, and it does intersect with child and maternal health. I don't know if anybody has 30 seconds to add anything about that? That's okay.

I hope I can get back down for my next round of questioning. I have to go upstairs and speak.

I want to thank you very much just in case I don't get back down here. I really appreciate your presenting it. We got the message about making sure that it's in this bill, and I'm sure there are ways that we can find to do that.

The Chair (Ms. Goldie Ghamari): We'll now turn back to the government for seven and a half minutes of questions. MPP Kusendova, you may begin.

Ms. Natalia Kusendova: Thank you to all of our presenters today. The topic of death and dying and palliative care is often considered the elephant in the room—and I actually brought the two elephants that were gifted to us by the Ontario palliative care association that comes every single year to talk to us about this very uncomfortable topic. It is indeed the elephant in the room.

I am a registered nurse, and I work in the emergency room. Every single death is tragic in the emergency room, but when it comes to the death of a child, it's even more tragic. I can tell you that throughout my nursing studies, we didn't talk about palliative care. This was not part of the curriculum. Furthermore, once I started working in the emergency room and we had instances of children dying, we didn't have bereavement for health care providers. We didn't have these kinds of sessions. This speaks to a systemic issue that we are experiencing in the province of Ontario.

I represent Mississauga Centre. It's the third-largest city in Ontario. I was shocked to learn, when I got elected, that a city like Mississauga does not have a single palliative hospice care bed. This was quite shocking, so I started to do some research and connected with my local hospice organization, Heart House Hospice. What I found out is that the hospice has to fundraise nearly 90% of its cost to build capital. So this is not something new. This is not something that our government started. This is a systemic issue when it comes to palliative care.

As a registered nurse, I feel that this bill couldn't come sooner. It's much needed, because we seriously need to start addressing these issues, especially with the uncertainty that is at the federal level with Bill C-7.

Today, I want to thank you for your bravery—especially the family members. I cannot imagine what you have gone through—it’s simply a lack of words. So thank you for your bravery, for sharing that with us.

What I want to ask: If you were to envision a robust and appropriate palliative care network for children, what would that look like? As PA Oosterhoff has alluded to, the government is open to amendments to this bill. This is for any members of the palliative pediatric steering committee.

Dr. Mark Greenberg: I think there are two elements to this. One is the conceptual and framework structure that we have created. The other is the implementation side, and the implementation side requires the spoke-and-hub mechanism that we have alluded to.

One of the ways that the hub can handle the spokes is to have the right kind of resources—that consist of an expert palliative care physician and an outreach nurse practitioner or equivalent, who can both resource the people in the community who are willing to undertake provision of care but are uncomfortable doing it. If you’ve never watched a little child die, it is horrifying. Those of us who have done so have become accustomed to it and can guide people through it.

So that whole notion of tapping into the community resources that exist within the regions and providing the 24-7 coverage that enables them to have expert backup is what needs implementation. This whole undertaking is a drop in a bucket fiscally but is critical to being able to ensure the option for children and their families to die where they need or want to die, and to implement palliative care from early in the diagnosis of life-threatening or chronic disease. We have the format; we need funding for the oversight body, the resources and the direct providers.

1450

Ms. Natalia Kusendova: My next question I would like to address to Paul-André. We know each other from work at the Registered Nurses’ Association of Ontario.

I spoke a little bit to the need for better training, especially in the nursing curricula, and frankly, all health care providers should have palliative care training.

For me, it’s not unusual in the emergency room to actually palliate a patient, which is absolutely not the appropriate place for a person to pass away, especially when the death is expected or is from a chronic illness.

Paul-André, can you talk a little bit about what that might look like?

Dr. Paul-André Gauthier: One of the things we notice in the schools of nursing, for example, or other health care professionals is that there’s so little on palliative care. In my case, my students were fortunate because I was able to talk about it. Not only that, but when I went to clinical, I was also talking and helping the students to learn about individuals who have terminal diagnoses like one kind of cancer. We need more of that.

Also, in order to palliate them—because there’s so much education that health care professionals need in order to begin their practices. We need master’s programs in palliative care to work with adults and also with pediatrics, because pediatrics—I worked a bit with kids. That’s a different challenge. Some of my colleagues said,

“Oh, we can start pediatric palliative care, right?” “No,” I said. “You have to work at it.” You have to look at what is needed not only for the clients and the families, but also for the staff, because a kid who is dying is different from an adult or elderly person who is dying, and the support and the counselling are really different.

The Chair (Ms. Goldie Ghamari): One minute left.

Dr. Paul-André Gauthier: So we need specialized master’s programs, clinical master’s programs, in order to help the families with the basics, the bio-psychosocial aspects, but also the counselling aspects, because these two elements cannot be separated. When I do some work with families, I can tell you, I don’t separate myself. I go in and I say, “What is the need? How can I help? What can I do?”—and not only that for the family, but also for the staff, because if you don’t support your staff who have to deal with death all the time, you’ll lose them. We lose these people who have a lot of experience—then we start over with other people who have less knowledge and less expertise. This is a bit stressful, to say the least.

Ms. Natalia Kusendova: Absolutely.

Thank you for your testimonies today.

The Chair (Ms. Goldie Ghamari): Before we turn to the official opposition, I want to confirm—MPP Schreiner, you have joined us virtually. Can you please confirm that you are MPP Schreiner and that you are present and in Ontario?

Mr. Mike Schreiner: Yes, I am present. and I’m in my Queen’s Park office.

The Chair (Ms. Goldie Ghamari): Thank you very much.

We’ll now turn to the official opposition. You have seven and a half minutes.

M^{me} France Gélina: Merci. J’aimerais commencer avec une question au D^r Paul-André Gauthier.

I’d like to thank everybody from McNally House Hospice for being here and everybody from the Provincial Pediatric Palliative Care Steering Committee. I’ve learned a lot listening to your presentation and probably will come back to you.

Première question, Docteur Paul-André Gauthier : tu as parlé beaucoup; tu as présenté pour nous dire qu’on avait besoin de retenir les professionnels dans le domaine des soins palliatifs. Est-ce qu’il y a des incitatifs qui existent en ce moment et qui fonctionnent, ou si vous aimeriez en voir? Vous pouvez répondre en français ou en anglais.

Dr. Paul-André Gauthier: Merci beaucoup, France, pour la question.

As you know, I can speak both languages, and I provide the service fully in French or in English when I work with individuals. But I’ll answer in English to give an opportunity for everybody to hear my answers.

Yes, we need more elements to help stabilize the staffing in hospice and palliative care services, either at home or in hospices or at the hospital.

I worked in various institutions when I was teaching nursing, but also after, as a volunteer consultant. One of the things I find is that if people are not full-time, it’s hard for us to have the continuity of care. In some environments, it’s even worse, because when you have a staff who

is the lead on the nursing units who has one or two years' experience—this is not much. We need staff who have been there for a long time, with acquired expertise and knowledge. Then they can help the new ones to gain and develop the expertise. So we need full-time staff. We have only a few full-time staff once in a while. And then during COVID-19, do you know what happened? The ones who got better-paid jobs, because they had to pick one place to work, left. So what's going on? This is nonsense. Educate them in palliative care and pay them full-time—these are two elements that are key. Provide them support, because when you go through difficult times—I know, in my case, when I'm around, I'm also helping the staff a lot, sometimes more than the clients and the families, because they are the ones who are providing the service. If I can help them, they can continue providing the service, but if we lose them, we have to start over. That can be a nightmare.

M^{me} France Gélinas: So are you telling us that you would like us to add to the bill to make sure that the framework looks at the staffing side of palliative care, to make sure that things that you suggested, like full-time work, like decent pay, like—

Dr. Paul-André Gauthier: Pay equity.

M^{me} France Gélinas: —pay equity with the hospital.

If I focus on the north—because you're the first one from northern Ontario to join us—what type of support would be useful right now to attract students and caregivers to the field of palliative care in northern Ontario, specifically?

Dr. Paul-André Gauthier: That's a good question.

I can tell you one thing: When the students graduate, one of the things they do is, they go for a full-time job in order to pay for their four years of education. The field doesn't matter; they need to pay for their education. So if they are paid \$10 to \$15 less an hour, that doesn't help. Also, if you work part-time, you may not have benefits; in some places they do, but in some places they don't.

We need people to recognize that expertise is needed—and also have people who will be able to support them through their work in order for them to continue. Like I said, when you go through little bumps, when elderly people are dying, that may not be too bad, but when somebody of their age is dying, even adults—well, the staff is getting quite a bit perturbed. So we need to help the staff and say, “How are you doing? What's going on?”

We find in northern Ontario that we don't have too many people who are experts who can provide the support to the residents, the patients, the families and the kids who are dying and to the professionals. I know a few psychologists who can work with people who are terminally ill, but their workload is full. They cannot take too many people because they are swamped—and it's private and it's in the community, so people have to pay quite a bit of money in order to see them. So we need experts who can provide more support, and these experts cannot be paid less than in Toronto.

M^{me} France Gélinas: The Provincial Pediatric Palliative Care Steering Committee is promoting a hub-and-spoke model, and no matter where you are in Ontario, you would be connected. You and I both know that we have a

palliative care home in Sudbury, but for the rest of my riding, whether you live in Gogama or Bisco or Foley or Mattagami, there is zip, nothing. Do you think that this model could also be used for adult palliative care in northern Ontario?

Dr. Paul-André Gauthier: Definitely. People living at home outside of the Sudbury region or outside of Timmins, for example, and outside of Hearst—I work in different hospitals in northern Ontario, so I know some of the challenges we're having. People in small communities lack services, so when they are at home dying, they have challenges with pain and symptom control—then, for the families who have to help them, it's 24 hours a day. They are burning out. So what happens is, they end up going to the hospital because the family cannot cope anymore, or family members die before the patient dies. We are often seeing that. People end up in crisis, so they call the ambulance. They bring them to emergency, or they resuscitate them when they have a DNR. Things sometimes don't make sense. In Sudbury, we're fortunate to have the hospice here that helps in community care. But outside of Sudbury, that's quite a challenge.

The Chair (Ms. Goldie Ghamari): One minute left.

Dr. Paul-André Gauthier: And pediatric is needed, by the way.

M^{me} France Gélinas: To McNally House Hospice: You talked about wanting support for bereavement and psycho-spiritual. Is this something that exists and just needs to be funded? Or is this something that we don't have quality procedures for yet?

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Ms. Pamela Blackwood: We certainly have had bereavement and psycho-spiritual work in our community since 2009, a year after we opened, but all of it is funded through fundraised dollars. There are no dollars supported through the Ministry of Health or any other organization. This comes completely off the fundraising efforts of our community.

Now, more than ever, COVID-19 has put a focus on the importance of quality at end of life. This year, our bereavement program—

The Chair (Ms. Goldie Ghamari): Thank you. I'm sorry to interrupt. That concludes this round of questioning.

We'll now turn to the independent member. You have four and a half minutes. You may begin.

Mr. Mike Schreiner: I'll just let you finish your remarks that you were working on there.

Ms. Pamela Blackwood: Thank you so much. I appreciate it.

I just want to highlight the need for bereavement supports and psycho-spiritual supports, especially this year, during COVID-19. We've had to pivot our services to provide supports virtually so that no one in our community was left to grieve alone this year. We created five different support groups. Our psycho-spiritual program was expanded to support loved ones who were unable to visit due to social distancing restrictions. And our virtual caregiver support groups have gone through the roof as we've started to provide those supports to alleviate

caregiver isolation. So those supports for bereavement and psycho-spiritual are much needed and completely underfunded.

Mr. Mike Schreiner: I appreciate you saying that.

I want to follow up on those comments. I've had a number of bereavement organizations reach out to me pre-COVID-19, but especially during COVID-19, saying that they need additional financial support to provide services. Do you have a sense of what type of funding is needed and how that would enhance bereavement support?

Ms. Pamela Blackwood: Simply put, pivoting to virtual has added significant costs that we haven't covered. We do have bereavement and psycho-spiritual clinicians on-board, and we have a shared agreement with our hospital that we share these supports, because neither one of our organizations can afford full-time bereavement and psycho-spiritual supports.

For COVID-19, because we've had to pivot to online, the supports of simply laptops and cameras—and even Zoom for health care is much more expensive than Zoom for the average joe, where we have to have security. It's \$300 a month for Zoom for health care. It's a significant cost to the hospice, especially when it's put on fundraised dollars. The ability to reach out to our caregivers, of providing some of them supports both within the hospice and in-home, of having tablets for them or providing supports for them to be able to reach out and speak to a bereavement clinician or a psycho-spiritual clinician—all of those costs are what we have taken on as a hospice.

Mr. Mike Schreiner: We know how hard this has been on families. Can you comment on the effects on staff?

Ms. Pamela Blackwood: That is an excellent question.

It has had a huge impact on the staff. We pride ourselves on the way that we support our families and our residents, and having to limit the number of family members coming in and limiting the access of our own staff to those family members—we're used to having conversations around the kitchen table with our volunteers and our staff and with these family members who are grieving or going through the loss.

The Chair (Ms. Goldie Ghamari): One minute left.

Ms. Pamela Blackwood: We no longer can do that, so our staff have taken on that burden of how they're no longer able to provide palliative care as they have in the past. We've had to look at other ways to support those families.

Mr. Mike Schreiner: Chair, I think I'm almost out of time, so I'll yield the rest.

The Chair (Ms. Goldie Ghamari): At this point, I'd like to thank the presenters for their time today and for appearing before the committee. You may step down.

CANADIAN CANCER SOCIETY
DR. BOB KEMP HOSPICE
PALLIUM CANADA

The Chair (Ms. Goldie Ghamari): We're now going to call upon our next set of presenters. We have the

Canadian Cancer Society, Dr. Bob Kemp Hospice and also Pallium Canada.

I'd like to call upon the Canadian Cancer Society to state their names for the record and then begin. You will have seven minutes.

Mr. Stephen Piazza: Good afternoon. My name is Stephen Piazza. I'm manager of advocacy for the Canadian Cancer Society. With me today is my colleague Daniel Nowoselski, senior coordinator.

Thank you to the members of this committee for allowing us to speak today and for bringing forward this important legislation.

The Canadian Cancer Society is the only national charity that supports people with all cancers in communities across Ontario and Canada. With nearly one in two Ontarians expected to develop cancer in their lifetime, it is vital that we work together to strengthen our efforts to reduce the cancer burden in Ontario and support people across the cancer continuum. We offer a range of services available to Ontarians that address the emotional, physical and practical needs of those impacted by cancer from the date of diagnosis through survivorship and end of life.

We fully support the implementation of the Compassionate Care Act and a palliative care framework for Ontario.

Palliative care was largely developed for and is still largely delivered to support patients with advanced cancer. In Ontario, past estimates indicate that over 80% of patients receiving palliative care are patients with cancer. These estimates are further supported by the prevalence of palliative care inquiries to our Cancer Information Helpline, a toll-free hotline where trained professionals answer cancer-related inquiries from the public. Cancer Information Helpline data from 2018 shows that over the past five years, palliative care was logged as a topic in nearly 3,000 inquiries nationally. Bereavement was logged as a topic in over 1,000 inquiries. The 2018 Ontario data shows that palliative care represented nearly 29% of all inquiries.

CCS looks to be a partner of the Ontario government as it develops and implements a palliative care framework in Ontario. While the COVID-19 pandemic brings the need for alternatives to acute care to the forefront, limited access to palliative care in a preferred setting of choice was an issue long before the pandemic began. Actions must be taken to improve access to palliative care now and long after the pandemic is behind us.

To strengthen the Compassionate Care Act, the bill should include a clear, expansive definition of palliative care beyond just hospice palliative care. While there are many different operational definitions of palliative care in Canada, it can be understood as care that focuses on the quality of life of patients with progressive life-altering illnesses. This definition refocuses palliative care conversations from just end-of-life care to discussions on relieving suffering and improving quality of life for patients and their families at all stages of the illness. This may include expert pain and symptom management; skilled psychosocial, emotional and spiritual support; and comfortable living conditions with the appropriate level of

care, whether at home, in a hospital or any other setting of a patient's choice.

Along with a more expansive definition of palliative care, the Canadian Cancer Society requests that sufficient funding accompany the implementation of a palliative care framework, to ensure guaranteed, timely access to palliative care in a patient's setting of choice. When quality palliative care is available for people in their communities and homes, patients are less likely to be in emergency departments, intensive care units and acute care, which are more costly and not designed for patients whose primary needs are palliative.

In a 2014 Ontario Auditor General report, costs of palliative of care during the last month of life ranged from a high of \$1,100 per day in an acute-care hospital to just \$460 per day in a hospice bed and as little as \$100 per day in the home. Increased access to appropriate care outside the hospital setting will result in not only preferred care for patients, but also a more efficient use of our health care dollars.

I'm now going to ask my colleague Daniel to speak about improving indicators for palliative care.

Mr. Daniel Nowoselski: To echo some of the points made by Steve: We support the Compassionate Care Act's promotion of data collection in the hospice palliative care setting, but we feel that we should be extending this effort to improve data collection on palliative care across all settings where one may receive palliative care, including hospitals, long-term-care facilities and at home. For one, we feel that in an ideal palliative care system, people would begin receiving palliative care before they enter a hospice setting, and starting data collection earlier would ensure that Ontarians have a more holistic picture of the gaps in the palliative care across our health care system.

To this end, we need a comprehensive set of indicators that are relevant, evidence-based, measurable, feasible to measure in a timely manner, actionable and easy to interpret. These indicators should address the structure and process of care, access, training and education, management of pain and symptoms, psychosocial aspects of care, caregiver supports, goals of care and decision-making in setting out care and place of death. We will be including what we feel is a comprehensive set of these indicators that reflect these criteria in our written submission.

1510

While there is no research consensus on what the number of palliative care beds, specialists and associated health care providers ought to be to adequately support a given population, other provinces, such as Alberta and Quebec, have established benchmarks for themselves. We feel Ontario can and should undertake similar efforts to establish minimum benchmarks as part of this framework.

We are pleased that the training is included as part of the framework in the Compassionate Care Act. There certainly is a documented need for additional specialized palliative health care professionals. Again, we feel this needs to go beyond just ensuring there are enough palliative care specialists in the hospice care settings and include training and continuing education opportunities for all

health care providers on palliative care in all settings, even if it's just to ensure that they know when a patient ought to be referred to a palliative care specialist.

Lastly, caregivers are a critical part of every health care team. They should have a presence in assisting to develop this palliative care framework, and the supports that they need, be they additional financial, respite, psychosocial and other supports, should be captured within this framework.

The Chair (Ms. Goldie Ghamari): One minute left.

Mr. Daniel Nowoselski: In conclusion, the Canadian Cancer Society is proud to support the Compassionate Care Act. The development of a framework regarding hospice palliative care would be a positive step forward for our health care system. However, we would suggest that if the government is going to take the steps to develop a framework for palliative care, it should be one that is comprehensive of all settings to ensure all Ontarians have access to the quality palliative care that they deserve.

Thank you very much for your time and consideration. We look forward to answering your questions.

The Chair (Ms. Goldie Ghamari): Thank you very much.

We'll now turn to our second presenter, Dr. Bob Kemp Hospice. Please state your names for the record, and then you may begin. You will have seven minutes for your presentation.

Ms. Clare Freeman: My name is Clare Freeman. I'm the executive director at the Dr. Bob Kemp Hospice. With me, I have Danielle Zucchet, a senior leader with us at Dr. Bob Kemp Hospice, who will share her personal experience of end-of-life care; and the chair of our pediatric committee here on our board, Doug Mattina.

I'm going to turn it over to Danielle to first give you her presentation. Danielle?

Ms. Danielle Zucchet: I would like to start by first of all thanking you for allowing us this time to tell our stories.

My name is Danielle Zucchet, and today I am speaking to you as a bereaved parent.

My son, Keaton, was diagnosed with a rare form of cancer, and after three years of extensive chemotherapy and radiation treatments, he passed away on December 4, when he was seven and a half years old.

As you can imagine, this experience changed the lives of myself, my spouse, our daughter and our whole family. My lived experience with a seriously ill child who has died, as well as meeting other families along the way with similar situations, is why I gave up my previous career. I'm now focused on making a change and enhancements in pediatric palliative care. Today, I'm a proud senior member of the Dr. Bob Kemp Hospice team.

Our family was affected by Keaton's diagnosis on so many levels—financially, as one or both of us were off work to care for him; and emotionally, as a family unit, we were in constant crisis, as we really didn't know what the next day would bring.

At his end of life, our only option was the hospital or home. Hospice was not an option for us.

I believe that families of seriously ill children deserve the same options as adults—by offering specific pediatric hospice palliative care to our families.

My family is simply one example out of thousands of what Ontario families look like, and in many ways, we are privileged. These days, it's hard enough for Ontario families to stay united. Imagine what happens to husbands, wives, sisters, brothers and grandparents when a child is diagnosed with a serious illness and the impact that that has on the family. Despite living in Ontario with a health care system that is world-class, I'm here to testify that navigating the system upon finding out the seriousness of your child's illness is profoundly complex and, in many ways, inefficient.

I'm also here to tell you that the journey after Keaton's passing was and is far from over. The bereavement supports for my spouse, my daughter and our families were some of the most crucial services throughout the journey. One of the supports that I was connected to was another group of families who had also lost a child, and the experience with them made me feel a little less alone in my grief.

I want to thank the committee for your time today. In working with Dr. Dave Lysecki and on the Nancy Rose Act, I know that supporting these initiatives in the Compassionate Care Act will be a step forward for Ontario families who have a seriously ill child, and a beacon that lights the way for parents like me.

I'm going to turn the floor over to Clare now.

Ms. Clare Freeman: Thank you so much, Danielle.

I'm here as the executive director and, if you want to call it that, the operational expert of a hospice. I'm here for two reasons. The first is to give you my personal and my organization's full support to the submissions put forth by Hospice Palliative Care Ontario. You'll hear tomorrow from Dr. David Lysecki, pediatric palliative care expert, in support of passing the Compassionate Care Act. The second is to be so bold as to go a step further and encourage continued leadership and innovation toward hospice palliative care approaches, especially for seniors and the most vulnerable seriously ill children and their families, by supporting this act and also collaborating with the Nancy Rose Act to enhance pediatric palliative care and bereavement services here.

In six years as the operational leader for the hospice, I have learned some important lessons. Number one is, there are some people who think that hospices are boutique services—and I want to be really clear: They are not; they are required throughout the journey. As my colleagues have spoken to before, we need to get services to people earlier on. When end of life is near, people need to have options. When they're delivered in a coordinated and efficient way, they not only impact the direct personal experience of an Ontarian, but they offer the most effective impact for the Ontario taxpayer. Ontario residents, especially seniors and our most vulnerable children, deserve the level of coordination and person-centred compassion, and high-quality outreach, respite, end-of-life and bereavement care.

I know the cost of delivering health care services for people with life-limiting illness towards the end of life. As we develop more medical care that prolongs life, this increases the cost to the medical system. Hospice palliative care can and does reduce unnecessary ER visits. It improves quality of life for the caregivers and for the patients living in the community—

The Chair (Ms. Goldie Ghamari): One minute left.

Ms. Clare Freeman: —and it reduces complex mental health issues along the way.

We are in uncertain times and profound changes here in Ontario, and I want to commend this committee for being bold and forward-thinking in its endeavour to do more for Ontarians, especially as we move forward to improve our health care system with the Ontario health teams. Pediatric palliative care and palliative care need to be forward in our development of those teams.

I want to reiterate what my colleague said about caregivers needing support. We need to have training that goes beyond just palliative care folks. We need comprehensive advance care planning as part of that education.

We do need to do indicators, and I completely support that these indicators need to be comprehensive.

There was a caregiver voice survey that was done by McMaster here in Ontario around experiences, and we know that families rated hospice palliative care much higher than they did hospital care—

The Chair (Ms. Goldie Ghamari): Thank you very much. My apologies; that concludes your time.

I'd now like to turn to our third presenter, Pallium Canada. Please state your names for your record and then you may begin. You will have seven minutes.

Mr. Gérald Savoie: My name is Gérald Savoie. I am chair of the board of Pallium Canada.

Mr. Jeffrey Moat: Good afternoon. My name is Jeffrey Moat. I'm the chief executive officer of Pallium Canada.

We all live in an aging country, and as we all know, Canadians are living longer, but they're not always living better. For many people, living longer means a struggle with poor health caused by chronic conditions, degenerative diseases or cancer. Thanks to improved medical treatments, declines in health are now more gradual, but this can also draw out the process of dying.

When this happens, palliative care can help to improve the quality of life for people of all ages with life-limiting illnesses by relieving symptoms, enabling a peaceful and dignified death, and providing support to families through the dying and grieving process.

1520

If the palliative care approach was widely adopted, we would see a health care system that supports earlier interventions, better use of hospice care, fewer emergency room visits and hospitalizations, and less use of ineffective interventions in the last days of life. There is a large and growing body of evidence that palliative care, especially when initiated earlier, alongside treatments to control these illnesses, results in better quality of life for patients

and better treatment decisions, including more judicious use of new technologies and medications.

Despite the benefits imparted by palliative care, many Canadians are either unaware of what palliative care is and what it means, never get to benefit from it or receive it too late. Multiple educational, financial and system barriers prevent equitable access to palliative care for far too many people. It's estimated that between 15% and 30% of Canadians have access to palliative care services.

Palliative care, in its very essence, is compassionate care. It will touch every single Canadian and therefore must be seen as being everyone's business. Canadians expect nothing less. And this right is supported by the Canada Health Act, which calls for continued access to quality health care without financial or other barriers. The fact is that almost 90% of Canadians who die might have benefited from a palliative care approach. The vast majority of Canadians who pass each year and their families do not receive any palliative care support, or they receive it far too late.

While we know that medical assistance in dying is law and a right bestowed to all Canadians, the same cannot be said for the availability of palliative care. Canadians have a legal right to die, but they also have a right to live. Palliative care is not yet considered a fundamental health care right for all Canadians. To ensure that the palliative care approach is available to all Canadians, a focused effort is required to significantly expand the number of health care professionals who are educated and trained on the palliative care approach, to reach a critical level that would allow Canadians to reap the benefits of a system-wide approach.

Caregivers and community members must also be included in the continuum of care. Mobilizing and equipping community members with tools, training and resources helps to create a wraparound effect to better support the patient and family dealing with a diagnosis pertaining to a life-threatening or life-limiting illness. Benefits will include improved patient and family outcomes, improved quality of care, improved transitions in care, reduced unnecessary use of emergency departments, and reduced hospitalizations and hospital deaths.

Training, development and workforce preparedness are key tenets of Bill 3, which "identifies the hospice palliative care training and education needs of health care providers as well as other caregivers." The good news is that evidence-based solutions that have already been funded by Health Canada, fully paid for by taxpayers, already exist and are ready for large-scale deployment to help address the disparity in the availability and calibre of care available to Canadians.

Since 2000, Pallium Canada, with its accredited LEAP courses, which is an acronym for "learning essential approaches to palliative care," has been educating tens of thousands of health care professionals on the palliative care approach across different settings of care and in different speciality areas. This has helped ensure that all professions share a common understanding and language relating to palliative care. They see opportunities for

seamless care across different settings and across the illness trajectory, and initiate a palliative care approach earlier in the illness. These LEAP courses also promote inter-professional learning and collaboration.

When it comes to palliative care, as I mentioned a few moments ago, the health care system is only part of the equation. Compassionate communities are members of the community who are moved by empathy to take compassionate action to respond to local community needs and provide important physical, emotional, social, spiritual and practical supports to families, patients and the caregivers. Since 2015, Pallium has been helping accelerate the creation of compassionate communities by developing resources that meet people where they are, whether that's in a place of work, within their faith communities or right where they live. We empower communities with practical tools that are easy to access and easy to implement.

Our approach builds primary or generalist-level capacity by providing palliative care education and support materials to health care professionals who, in the course of their work, are involved in the care of patients with advanced cancer or non-cancer diseases. These professionals include pharmacists, nurses, family doctors, specialists, social workers, PSWs and paramedics working in a variety of settings such as community, family health teams, home care, long-term care and hospitals as well as emergency services. It also introduces these professional learners who participate in these LEAP courses to local palliative care specialist-level providers, setting the stage for closer collaboration.

By equipping these professionals with these primary or generalist-level skills, they're able to identify patients much earlier who could benefit from a palliative care approach. They identify the physical, social, psychological, religious and spiritual needs and start addressing them. They engage in timely and effective advance care planning and goals-of-care discussions and identify those patients with complex needs who require the intervention of specialist palliative care. We've trained over 30,000 health care professionals.

The Chair (Ms. Goldie Ghamari): One minute left.

Mr. Jeffrey Moat: In Ontario alone, we've delivered over 819 LEAP courses and have trained 13,500 health care professionals. Despite this progress, the percentage of health care professionals who work in fields and settings of care for patients with serious illness and for whom it would be appropriate to learn about the palliative care approach is still only about 3%. So there is considerable opportunity for growth if we're to reach a tipping point where the knowledge, skills and training becomes commonplace and expected of all health care professionals.

In support of Bill 3, appropriate investments must be made to scale and spread evidence-based, proven solutions to train and support health care professionals and community leaders to relieve pain and suffering and to improve a person's quality of life whether at home, in hospice, in hospital or in a long-term-care home.

I'm going to pass it over to my colleague Gérald to wrap things up.

The Chair (Ms. Goldie Ghamari): Twenty seconds left.

Mr. Gérald Savoie: Well, as you can see, the main emphasis here is on education. All parts of the system need this education. Physicians and others do not get the training at the beginning—we're talking about before they become professionals and provide care—and I think that's a core element here, in terms of changing—

The Chair (Ms. Goldie Ghamari): Thank you very much. At this point, I do have to cut you off. That's the time we have.

There is currently a vote that is happening, so we're going to recess the committee. I will ask that members return as soon as possible when the vote is done. We will be resuming in 30 minutes at this point—based on what the vote says.

Interjections.

The Chair (Ms. Goldie Ghamari): If we're all good with resuming—okay. So we will resume, let's say, in about 10 minutes.

Mr. Mike Harris: Madam Chair?

The Chair (Ms. Goldie Ghamari): Yes, MPP Harris?

Mr. Mike Harris: I believe there is going to be a second vote after this vote, as well. Are we taking that into account?

The Chair (Ms. Goldie Ghamari): If there is a second vote, then we can adjourn and come back, unless the members would like to wait until the second vote is done.

Mr. Mike Harris: The only reason I ask is because for some of us, logistically, it's going to take us a few minutes to get back to our computers from the chamber.

The Chair (Ms. Goldie Ghamari): How much time do you need, MPP Harris?

Mr. Mike Harris: I'm probably going to need 10 to 15 minutes—but it depends on others, as well. If we have to run back and forth multiple times, it may delay proceedings a little bit longer.

The Chair (Ms. Goldie Ghamari): If that's the case, then let's say we'll resume in 45 minutes, assuming that gives—

Interjections.

The Chair (Ms. Goldie Ghamari): Sorry, at 3:45. We'll take a 15-minute break. We'll resume at 3:45. Thank you.

The committee recessed from 1528 to 1545.

The Chair (Ms. Goldie Ghamari): The Standing Committee on General Government will now resume.

We'll go to our first round of questioning, beginning with the official opposition. You have seven and a half minutes.

M^{me} France Gélinas: I would like to start by thanking the Canadian Cancer Society, the Dr. Bob Kemp Hospice, as well as Pallium Canada for your presentations.

I will start my questions in reverse order, with Pallium Canada. I was truly impressed with all of the training that you have done and some of the stats that you have presented. Where does your money come from to do this?

I understand that you're a not-for-profit organization. Do you get any provincial funding to do this important work?

Mr. Gérald Savoie: Over to you, Jeff.

Mr. Jeffrey Moat: Thank you very much for that question.

Pallium is funded in part by Health Canada, and we derive the other portion of our revenues from the sale of our coursework.

M^{me} France Gélinas: Coming back to the Dr. Bob Kemp Hospice: First, thank you for sharing the story of your son Keaton with us. That was very, very moving.

From the administrative side of the hospice—are you in the same situation as all others? When was the last time that you got an operational budget increase? And what percentage of your budget is actually paid for by the government versus what you have to fundraise or other sources?

Ms. Clare Freeman: Well, 49% of our operational budget is provided through the LHIN and the government, and then 51% is community-fundraised. In Hamilton, in particular, we have two other hospitals in our community. We have hospitals that are fundraising, then asking a tiny organization to fundraise \$1.4 million to operate both its community-based services, its residential hospice and our bereavement programs.

I can tell you that our staff are not paid at the premium levels of their sectors. We have such compassionate people that that is why our costs are lower, as well.

M^{me} France Gélinas: Of the total budget of your hospice, how much of it goes toward providing care versus paying hydro bills and that kind of stuff? How much would you say goes to paying staff to provide care?

Ms. Clare Freeman: I would say that 80% of our budget is front-line services, either bereavement support, outreach support and then our nursing staff for our 10-bed residential. The other portion, the 20%, is turning on the lights, doing all the other things that we have to do. If you look at administrative costs, they are about 10%.

M^{me} France Gélinas: My next question is, how did we end up there? No other health care provider is asked to fundraise to provide care. We live within medicare. Care is based on needs, not on ability to pay. It is the provincial government's responsibility to pay for health care. Why is it that we don't pay for palliative care, that we ask you to fundraise to provide care?

Ms. Clare Freeman: Originally, Dr. Kemp was a strong advocate that actually got hospices funded in the first place across the province. Partially, it was that we were not part of the health care act or the hospital act here in Ontario. We weren't part of the long-term-care act. So nobody really knew where to put us. But that has changed. That act has changed, so there is no reason, I think. We are a comprehensive part of the medical system and the community system, so I do think, deeply, that we should be fully funded, in many ways.

M^{me} France Gélinas: You say that you presently fundraise for \$1.4 million a year? I don't know how you do this as a small organization, but kudos to you.

How much money would you need to be able to meet the needs of your community?

1550

Ms. Clare Freeman: That's a big question because we know there are greater needs than what we are already offering. In particular, my colleague Pam Blackwood was talking about the need for bereavement support. I think that is a driving need, and it goes beyond palliative bereavement. We know that there are lots of folks who are dying through opiate loss, sudden loss. There is a deep need, and we have the experts who are trained in bereavement, as well as a plethora of volunteers.

How much would we need? Well, certainly the \$1.4 million would be a great place to start, but if we are talking about meeting all the needs, I think it would be larger. But we would be happy just getting what we need right now.

M^{me} France G elinas: The last budget was tabled a couple of weeks ago. There is no new money for palliative care in the budget. We're now talking about a bill that would set up a framework. I can guarantee you that we all agree that this is a step in the right direction, this is a good idea and this is something we will support, but I'm a little bit worried that if we wait for the framework to be developed, another year or years will go by and you will have to fundraise \$1.6 million just to keep what you have. Am I the only one who's worried?

Ms. Clare Freeman: No, I'm certainly worried. But I would also say that we are in these times of changing the health care system, and I think the Ontario health teams really offer—

The Chair (Ms. Goldie Ghamari): One minute left.

Ms. Clare Freeman: —an opportunity to collaborate stronger and find savings where we can in systems. I do think that there are important needs to pull some of the ways in which we do things into the community. I think there are ways that we could offer more and reduce our fundraising cost by having more collaboration as we move forward with the health teams.

M^{me} France G elinas: And you're not afraid that you are the very small player on the team, that there's a Goliath on your team who sometimes gets really hungry and angry?

Ms. Clare Freeman: Yes, I fear that we don't get the voice that we need at the table, and I would applaud anybody who would allow small organizations such as ours a larger voice, particularly around palliative care. We've been doing it for 25 years, and I know we have the research to demonstrate both the cost-effectiveness but also—if you ask families what they love about hospice care, it's that it feels like home, but also their bereavement process is so much more integrated into their life after their loved one passes.

The Chair (Ms. Goldie Ghamari): That concludes this round of questioning.

At this point, we'll turn to the independent member. MPP Fraser, you may begin. Four and a half minutes.

Mr. John Fraser: I want to thank the member from Guelph for sharing his time with me all the way through

the day. We'll be sharing time right now, and then he'll be continuing on for the rest of the day.

Everybody from the Canadian Cancer Society, the Dr. Bob Kemp Hospice and Pallium Canada, thank you for being here. I know many of you, so I'm not going to pick you off one at a time—other than one person I haven't seen in a long time, Gerry Savoie. I'll just say hi. I haven't seen you in about five or six years.

That's actually where I want to direct my question first, so it can be either to Gerry or Mr. Moat. What are you looking for in this bill? Are you looking for anything in particular? What are you looking for from the Ontario government?

Mr. G erald Savoie: What do we want? Number one is leadership—I think the committee has already demonstrated that through the different readings and approvals and so forth.

What we've seen across Canada and other provincial jurisdictions is, where they have a solid framework, things build on that and it brings palliative care to the next level. But I also agree with comments that were made earlier, that if we wait until the framework is fully in place—we're into the most significant crisis at the moment. COVID-19 demonstrates all of the gaps that occur at the moment. A lot of that can be alleviated through education. It's not just trying to sell a bunch of programs; we need to get rid of the root cause of this in terms of support, and that is getting to the universities and colleges—to professionals—in terms of educating them on the basics of palliative care, integrating this across the continuum of the system, getting people faced with life-threatening challenges outside of the emergency department out of beds, unless it's specialized care that's absolutely required, into hospices, into the community, linking that to the family health teams and so forth.

All of those various professionals are used to working in a departmental specialized sense, and when you try to bring it all together, they really don't have the same commonality and understanding and education and so forth. So education is the key here, and we want to look at both ends, those who are already in the profession and so forth. We've done huge webinars this summer with the Canadian Medical Association, many of them in Ontario. We're talking about tens of thousands of health care professionals sharing what they need to share.

Long-term care is a good example. We're reinventing long-term care. We're giving more focus to that. When you take a look at long-term care, the vast majority of that could be looked at as being of a palliative nature. We're talking about chronic diseases. We're talking about illnesses, end of life. And the personal support workers—who are probably the most influential in terms of numbers of caregivers who are there, in with the family member and the family and so forth—have little or no training at all. That, I think, is very evident. Training and education is not a small thing. It doesn't cost that much today, because we've pivoted and we do have everything online. It is evidence-based. It is Canadian-made.

The Chair (Ms. Goldie Ghamari): One minute left.

Mr. Gérald Savoie: A lot of this initiative was pioneered in Ontario as well, and we're very pleased to be part of the solution.

Mr. John Fraser: Dr. Bob Kemp Hospice, can you give me a brief description of your pediatric program?

Ms. Clare Freeman: We were excited—because Hamilton has a children's hospital, and what we were profoundly affected by is the fact that we don't have a pediatric hospice in our region. We serve 2.3 million children, so what we've started is a day wellness program, just like we started under Dr. Bob Kemp Hospice when he started us 26 years ago. We started a visiting volunteer program and a day wellness program. These are fundamentally supported through volunteerism in our community. We have a partnership with Hamilton Health Sciences, the LHIN and all children's services that support seriously ill children. We have brought them all together.

The Chair (Ms. Goldie Ghamari): That concludes this round of questions.

We're now going to turn to the government for seven and a half minutes. MPP Harris, you may begin.

Mr. Mike Harris: This is a general question for everybody, and if a couple of you could touch on this from your respective organizations over the next—

The Chair (Ms. Goldie Ghamari): Sorry; actually, I'm going to stop you there, because I think there's a vote that's going to be happening. It's 4 o'clock, so the votes are going to happen.

Interjections.

The Chair (Ms. Goldie Ghamari): So 4:10—10 minutes—is that enough—

Mr. Mike Harris: I know that MPP Wai is—

The Chair (Ms. Goldie Ghamari): She'll have to go back?

Mr. Mike Harris: I think she's potentially out of the building. I was planning on going back to my office, as well, and there may be a couple of others.

The Chair (Ms. Goldie Ghamari): So let's say 20 minutes. Or let's do the entire duration, then?

Interjections.

The Chair (Ms. Goldie Ghamari): Okay. The bells are going, so we're going to recess and resume in 15 minutes.

The committee recessed from 1559 to 1614.

The Chair (Ms. Goldie Ghamari): We're now going to resume the Standing Committee on General Government. At this point, the government has the floor. MPP Harris, you may begin.

Mr. Mike Harris: Thank you very much—and sorry about that, to our presenters. I think that should be our last interruption of the afternoon.

I'll throw this out to anyone, and we'll just open up the floor when the time come. I mentioned this to MPP Oosterhoff this morning, when he was going through some questioning on the bill that he has brought here and sponsored today. I represent a largely rural riding. About 40% of my riding makes up southwest Kitchener and the other 60% is what we like to call the "W townships" of Wilmot, Wellesley and Woolwich and does sort of an

upside-down horseshoe, if you will, around Kitchener-Waterloo and then down towards Cambridge.

We have, as far as I know, two hospices in Waterloo region—actually, one hospice in Waterloo region; the other one is slated to be opening within the next couple of months. They're both located within the actual city centres—one in Kitchener and one in northeast Waterloo. But we don't have any that represent our townships. And to my knowledge, I don't think there's any hospice or palliative care in any of our rural areas that are anywhere between Guelph, Waterloo region, and down to Brantford on the south end, and then the west end, moving out towards the Woodstock-Ingersoll-London area. They're all pretty centred right within the urban centres. Several of us here are from rural ridings, and people who have presented today have also talked a little bit about it. I believe it was Mr. Gauthier in, the last round of speakers, who was talking about northern Ontario, where I'm from originally—North Bay, not too far down the road from MPP Gélinas.

My question to you is, how do you think this type of framework and trying to bolster hospice and palliative care in the province can lend itself to seeing more of this type of care in rural communities where, obviously, people have a different way of life? They think differently. They maybe have a deeper sense of roots and family tied to some of those regions. I'd like to get your perspective on what this would mean for people of those communities.

I'll just open it up to anyone who would like to answer.

Ms. Clare Freeman: Our hospice is on the upper part of the Hamilton Mountain. We're not part of the super-urban core of Hamilton. As you know, Hamilton is close to Six Nations, Caledonia and Simcoe, so we do also service a very rural area, but not remote like the Far North, absolutely.

With outreach palliative care teams that are centred within a hospice that might be in an urban centre, you can get that hospice palliative care approach in people's homes, which is really key. And those who actually want to be in residential end-of-life care—oftentimes, they're going to be pushed into a centre core anyway, because their options are going to be hospital or home. If the hospice palliative care approaches cannot be supported in the home, then there usually is a hospice close by, like a residential centre.

So I absolutely think that the approaches that we have, because they're so movable in a lot of different ways, can work in other urban centres. It's the collaboration that's key.

I know we're collaborating with Simcoe and with Six Nations though Brantford's hospice.

I'll let others speak now; sorry.

Mr. Jeffrey Moat: I'll be chime in.

One of the things that we've had great success with is moving information rather than moving people. Part of the success has been identifying key hubs in key parts of the country that identify the local needs and the learning, education, training and development needs, and then funneling that back to us to help curate content and information—not just information that we develop, but content

that we have access to that we can then serve up to these different rural and remote parts of the country through these hub locations. It's a very efficient and effective way of, as I said, developing, curating, getting content out to health care providers to ultimately build capacity in those rural and remote regions. We have years of experience doing that; in fact, that's where we started as an organization—so I'd just like to underscore that this need and the role of hubs and spokes in helping build local capacity, especially in rural, remote and Indigenous communities, has been a very effective tool for us. I think that's something we could spread and scale.

Ms. Clare Freeman: If I could speak quickly about the pediatrics: Dr. Lysecki will be speaking tomorrow. Again, it's such a small part of our population. There's no way we could build enough individual hospices to serve the small amount of children in different areas. The Hamilton Health Sciences children's hospital serves the Kitchener-Waterloo area and the remote areas. The approach that Dave Lysecki and our team is looking at is doing a regional pediatric.

Again, the hub-and-spoke model, I think, works well in adult care, but it's especially important in pediatrics.

Mr. Mike Harris: How much time is left, Madam Chair?

The Chair (Ms. Goldie Ghamari): One minute and 30 seconds.

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Mr. Mike Harris: All right.

Maybe you could quickly walk us through what it might look like to have your hospice or palliative care at home, because that is something that, when you're talking about that hub-and-spoke model, obviously lends itself a little bit better to that in some more rural or remote areas.

Ms. Clare Freeman: Hospices have associated outreach teams. Here in Hamilton, we have a palliative care outreach team. McNally House Hospice, beside us, also has an outreach team for a rural area, because they're in Grimsby. Niagara has one, as well.

I think attaching an outreach team to hospices—certainly, we'll continue to have the expertise that we're looking—

The Chair (Ms. Goldie Ghamari): One minute left.

Ms. Clare Freeman: Pallium is a big part of our process, as well, in terms of education.

Mr. Mike Harris: Does anybody else want to comment on that? Okay.

Madam Chair, I'll cede my time.

The Chair (Ms. Goldie Ghamari): Thank you very much. We're now going to turn to the official opposition.

Given the breaks that we've had throughout the day, in order to make sure that we're not cutting from presenter time, presenters will continue to have seven minutes each; however, the round of questioning for each group will be shortened by two minutes.

The official opposition may begin. They will have five and a half minutes.

Ms. Sandy Shaw: I want to address my questions to Dr. Bob Kemp Hospice. I have the privilege and pleasure of working with Dr. Bob Kemp Hospice in Hamilton.

I want to ask specifically about bereavement supports. We have talked a lot about the importance of grieving and bereavement supports. I know, Danielle, that you touched on them, but could you talk about how important it would be to specifically identify the need to address bereavement—the need for bereavement supports, the need to fund them, the need to put that in a framework—and how that would not only impact the lives of the families directly involved, but their extended family, like the siblings, the grandparents and so forth?

Ms. Clare Freeman: If I can speak to bereavement in general—we have expertise in end of life. We know that when you're bereaved, you don't necessarily need mental health training; you need to feel, as Danielle spoke about earlier, connected with other people who have walked where you walk.

Bereavement is not supported anywhere, and the reason it needs to be is that people are dying every day—but they don't just die through palliative illnesses. They die from sudden loss and other kinds of losses. In Canada, between 250,000 and 300,000 people die each year. That means that we have anywhere from three million to 15 million people grieving in a given year. Why aren't we supporting that grief? We know that if people don't have their grief needs supported, it can turn into more complex mental health issues. It certainly is a need that hasn't been focused on long enough.

I do think that because hospices have built up that kind of expertise and we have such a strong volunteer base, it is really the place to expand bereavement services.

Ms. Sandy Shaw: I'm going to pass it to my colleague MPP Gélinas now.

M^{me} France Gélinas: Bonjour. Une petite question pour M. Savoie : ça fait longtemps qu'on ne vous a pas vu, monsieur Savoie, mais ça me fait plaisir de vous revoir. Je me demandais si dans le travail que vous avez fait avec Pallium, vous aviez identifié les meilleures pratiques pour offrir des services de soins palliatifs en français en milieu minoritaire? Et si vous l'avez fait, ça ressemble à quoi?

On ne vous entend pas.

M. Gérald Savoie: Est-ce que vous m'entendez? OK, merci beaucoup.

Merci de votre question. Oui, le développement au niveau de Pallium, nous avons autour de 20 différents programmes maintenant offerts en français, non seulement face à face, mais aussi de façon numérique. On est capable d'offrir nos programmes à distance en français. On va travailler étroitement avec la Société Santé en français sur le plan national et aussi avec divers réseaux à même l'Ontario. Nous offrons une solution qui touche non seulement les régions éloignées et moins peuplées, mais la francophonie comme telle, avec une sensibilisation au niveau de la culture et la langue, que ce soit pour les Autochtones, les Premières Nations, les francophones, peu importe qui.

Notre offre de service est robuste. On est capable de développer une capacité à même le milieu, comme on avait déjà démontré. Je donnerai juste un exemple qui été fait—bien, par plusieurs en Ontario, évidemment. Les paramédicaux : nous offrons un programme, « Les

essentiels de l'approche palliative », pour les paramédics. Aujourd'hui ils ne résident plus dans un service d'urgence, à côté d'une civière. Ils sont à la maison, à domicile en train de donner des traitements, injections, un soutien à la famille, et redirigés vers la communauté, etc. On a diminué les visites dans les différentes urgences, par exemple, dans différentes provinces de l'ordre de 30 % à 50 %.

En Ontario, les néphrologues avec les lieux spécialisés—on a offert un cours spécialisé juste pour eux. Ils ne voulaient pas un cours de trois jours, évidemment. On a pu réduire l'utilisation des lits de soins intensifs de l'ordre de deux tiers, 66 %, de réduction. Ces réductions en coût devraient être redirigées, selon moi, dans la formation, dans ce continuum géant qui existe, dans une collaboration. Mettre ensemble les forces du milieu : par exemple, les équipes de santé—

The Chair (Ms. Goldie Ghamari): One minute left.

M. Gérald Savoie: —les hospices, etc. Alors il y a beaucoup de développements en français.

M^{me} France Gélinas: Vous nous avez dit que vous avez offert 819 cours en Ontario à 13 500 professionnels de la santé. Est-ce que vous êtes capable de me dire quel pourcentage de ça était des cours en français ou à des professionnels francophones?

M. Gérald Savoie: Pas au moment, à moins que Jeff les ait. Mais je pense que le point qu'on voulait faire ici, c'est qu'on investit très peu au niveau de la formation en ce moment. C'est à nous d'aller chercher de l'argent qu'on réinvestit. On est sans but lucratif.

Dans les provinces où on a commencé à investir beaucoup plus au niveau de cette formation, c'est là où on a vu le plus de bénéfiques. Je pense que ça, c'est un des points essentiels : les provinces qui ont adopté et développé ces éléments de base profitent beaucoup plus. Alors, la vraie question c'est, pourquoi on n'est pas en train de—

The Chair (Ms. Goldie Ghamari): Thank you. Désolée. That concludes our time for this round of questions.

We'll now turn to the independent Green Party member.

MPP Schreiner, before you begin, just a slight change: Instead of cutting your time by two minutes per round, we'll just cut it by one minute. It means we'll end at 6:05 instead of 6, but at least you won't have 50% of your question time cut. Having said that, you have three and a half minutes. You may begin.

Mr. Mike Schreiner: Thanks to all three presenters for taking the time to share your stories. It's a good thing I've taken notes, given all of the interruptions we've had.

I'm going to start with the Canadian Cancer Society. I can relate to all of your calls for palliative care. I grew up on a farm, and my dad, unfortunately, passed away at much too young of an age from pancreatic cancer. We were able to provide palliative care so he could remain on the farm, which was the place he loved. So I certainly appreciate the rural and remote—in this case, rural—palliative care that is provided.

You talked about the need to include an expansive definition of palliative care within the bill. There is a pro-

vision in the bill about the minister putting forward a definition. Were you suggesting a more expansive definition as something that should be included in the bill itself? Or were you providing that as advice to the minister, when the minister comes forward with a definition?

Mr. Stephen Piazza: Thank you for the question.

In our written submission, we'll have a preferred definition for palliative care that could be either implemented by the minister or inserted directly in the bill.

What we wanted to get across in that conversation was really understanding palliative care outside of just end-of-life care. The rationale for this is, when we do that, we start to have conversations about earlier identification.

We've seen some success in Ontario in more patients receiving palliative care, but unfortunately, that's coming in their last month of life.

We really want to start to broaden the definition of palliative care to things like pain management so that people can include and incorporate palliative care into advance care planning earlier. That is, in substance, what we hope to get out of a more expansive definition.

Mr. Mike Schreiner: I'm going to shift gears and go to the Dr. Bob Kemp Hospice.

Danielle, I want to thank you for sharing your story and having the courage to share a bit of your grief.

The Chair (Ms. Goldie Ghamari): One minute left.

Mr. Mike Schreiner: I know that the member from Hamilton West—Ancaster—Dundas has the Nancy Rose Act around pediatric palliative care.

Would you like to see some mention of pediatric palliative care in Bill 3?

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Ms. Danielle Zucchet: Oh, 100%, I would love to see that. We're treated out of McMaster, which is a renowned hospital, but we are the only city that has a pediatric hospital and doesn't have a pediatric hospice.

So the inclusion of pediatric palliative care in this bill is of the utmost importance. I believe that children should have the same options as we do in the adult world.

Mr. Mike Schreiner: I'm probably out of time, right, Chair?

The Chair (Ms. Goldie Ghamari): Nine seconds—well, seven now.

Mr. Mike Schreiner: Okay. Thank you all for coming today.

The Chair (Ms. Goldie Ghamari): We'll now turn to the government for five and a half minutes. MPP Kusendova, you may begin.

Ms. Natalia Kusendova: I believe that MPP Wai had questions, but if she's not with us, I'm happy to jump in.

The Chair (Ms. Goldie Ghamari): She's not.

Ms. Natalia Kusendova: Okay.

Thank you so much to all our presenters. It's always great to hear from people who actually work on the front lines and from other stakeholder organizations.

Hello to the Canadian Cancer Society. It's great to see you again. I'm a huge fan of your work. We've had numerous discussions, especially on your program, Wheels of Hope, which is driving cancer patients to their appointments.

You've mentioned that about 80% of people who receive palliative care in Ontario are cancer patients. We know that right now, our palliative care network is a patchwork for end-of-life care. Our government, from day one when we got elected, wanted to create and transform our health care system to have a more integrated approach, such that patients would be taken care of holistically throughout the life continuum, which includes end-of-life care and palliative care.

In your view, what are some elements that would be necessary in a palliative care strategy in order to achieve that health care transformation?

The Chair (Ms. Goldie Ghamari): MPP Kusendova, can you please direct your question to a witness?

Ms. Natalia Kusendova: The question is to the Canadian Cancer Society.

Mr. Stephen Piazza: Thank you for the question, MPP Kusendova. It's excellent to see you again today, as well.

I think some of our key points to talk about in response to your question would be things like earlier access to palliative care with an expansive definition, along with funding of portions of the framework.

I'm going to hand things over to my colleague Daniel to speak more in depth about some of the indicators, as well, because I think that's an important piece of this framework that we'd like to see included.

Mr. Daniel Nowoselski: As we mentioned in our presentation, we have a list of indicators we'll be sending in our written submission.

We think access to care—particularly to MPP Harris's earlier point about geography, making sure that the access is a reasonable distance away or that you have reasonable access—would be an important indicator, as well as the number of specialists trained, but also the number of other health care professionals trained in order to support that.

As part of that overall discussion of indicators, we also want to see an expectation of a minimum standard that the government would be working towards in terms of the number of health care specialists they have available, in addition to the access to care along those lines.

Lastly, I think we'd want to see, in terms of bereavement supports but also supports for caregivers—incorporating them in terms of how we measure and how we deliver palliative care.

Ms. Natalia Kusendova: My next question is to Pallium Canada.

In fact, the government of Ontario has committed \$74.7 million a year to provide palliative and end-of-life care for Ontarians, which includes about \$36 million in capital funding to build more than 200 residential hospice beds across the province.

I'm happy that in my city of Mississauga, finally, we will have a residential hospice—only 10 beds, which for a population of our size—I would like to advocate for more. It's clearly not sufficient, but it is a good start.

Ontarians are currently receiving palliative supports in their homes, in hospitals, in hospices and in long-term-care facilities. Are there any settings that you feel should receive more attention or focus as part of a future provincial network, especially in light of COVID-19, when

perhaps in-home visitations or even virtual care might be something that Ontario patients find more effective?

Mr. Jeffrey Moat: Thank you for your question. I appreciate that.

Frankly, I think what's needed here, in what you've described, is a systems approach. We can't have one setting of care that is, for instance, trained up on the palliative approach and the other is not. What that leads to, ultimately, is a disconnection that is felt by patients and families. Take, for instance, a patient who is being seen by a specialist who is not trained on the palliative care approach, but the patient's family doctor is. You can see pretty quickly how a disconnect could happen when some information from the specialist is not aligned with what the family doctor is saying.

The Chair (Ms. Goldie Ghamari): One minute left.

Mr. Jeffrey Moat: It would be easy for me to say long-term care and home care. But the reality is, we need a systems approach. We need the palliative care approach throughout all settings of care: hospitals, long-term care, ERs. That way, a true holistic approach to palliative care would be administered by all health care professionals who treat patients with a life-threatening illness and their families—and including into the communities.

Ms. Natalia Kusendova: In my last 30 seconds—I want to say that volunteers also play a huge part in supporting families at the end of life. So I want to thank all the organizations for recognizing the role of volunteers and for training them and for supporting them, as they are key in supporting our communities at the end of life.

The Chair (Ms. Goldie Ghamari): I would like to thank our presenters for your very informative discussions. You are released and may step down.

CATHOLIC HEALTH ASSOCIATION
OF ONTARIO

CANADIAN HOSPICE
PALLIATIVE CARE ASSOCIATION

DR. DEBORAH DUDGEON

The Chair (Ms. Goldie Ghamari): I'd now like to introduce the Catholic Health Association of Ontario, Canadian Hospice Palliative Care Association and Deborah Dudgeon. Each presenter will have seven minutes for their presentation, followed by a round of questions.

At this point, I will call upon Catholic Health Association of Ontario. Please state your name for the record, and then you may begin.

Mr. Ron Noble: I'm Ron Noble. I'm the president and CEO of the Catholic Health Association of Ontario. Thank you for the opportunity to appear today and speak in favour of Bill 3, Compassionate Care Act. The Catholic Health Association of Ontario represents 29 health care organizations running approximately 40 sites across the province, including hospitals, long-term-care organizations, seniors housing and home care, as well as community service providers and hospices. We represent

approximately 15% of the institutional health care budget and provide a significant capacity to the health care system.

Through this diverse membership, CHAO represents a full continuum of the health care system. We see first-hand what can be done when the health sector works together and care is delivered in the most appropriate setting and at the most appropriate time. We see first-hand how important palliative care is. These organizations, including St. Joseph's hospices in Sarnia, London and St. Thomas, serve Ontario's rich and diverse population, regardless of religion, socio-economic status or culture.

Our members always focus where the need is greatest, often working with the frail elderly and those with chronic diseases, mental health issues, and palliative care. They play a leadership role in hospice palliative care through a number of initiatives in Ontario that deliver these much-needed services. These initiatives are consistent with the Palliative Care Matters consensus statement that was endorsed by the Conference Board of Canada. Additionally, at the national level, health care organizations initiated Palliative Care Matters and are members of this important group.

This topic of hospice palliative care is an emotionally difficult one. It's not always an easy topic to discuss or consider, but it is critical to do so. Dying is a part of life, and as legislators and policy-makers, you must ask yourselves what can be done to ensure that Ontarians receive the best palliative and end-of-life care possible. We believe Bill 3 provides part of that answer. By establishing a provincial palliative care network, the government will begin to draw the attention that is required to this necessary, if sometimes difficult, issue.

While people now have access to medical assistance in dying, there are still many barriers to palliative care services, and it is a topic that is rarely discussed or fully understood. Because of that, along with introducing a framework, it is important to raise the public's awareness of palliative and end-of-life care, and help people understand that palliative care is not just about helping people die in comfort; its goal is to help people who are living with life-limiting illnesses to live as comfortably, with purpose, and as long as possible.

Together, we must address the stigma that is associated with the term "palliative care" and build a system that can start to provide palliative care services earlier, which will improve the health and lives of palliative care patients. Along this continuum of care, palliative care is a quality-of-life decision, while medical assistance in dying is an end-of-life decision. It is important for society to understand that they have a broad spectrum of choice.

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Additionally, we must build stronger linkages between primary care providers, home care providers and palliative care. Primary care physicians have a unique role in the health care system and must be better trained on the hospice palliative care services in their areas. At the same time, home visits from physicians, as well as home care providers, can greatly reduce the time and stress that comes from travel for patients, help reduce unnecessary

visits to the hospital or emergency departments, and assist in ensuring that capacity remains in our acute-care sector and care can be provided in the home and in the community for this population.

Committee members, we applaud the MPP from Niagara West for drafting this bill, and we strongly encourage you to send it quickly for third reading. Thank you.

The Chair (Ms. Goldie Ghamari): Thank you very much.

At this point, we'll turn to our second presenter, from the Canadian Hospice Palliative Care Association. Please state your names for the record, and then you may begin. You will have seven minutes.

Ms. Sharon Baxter: My name is Sharon Baxter. I'm the executive director of the Canadian Hospice Palliative Care Association. I'm going to start the presentation and then turn it over to Laurel Gillespie, who is the director of the Advance Care Planning Canada initiative, and she'll speak for a few minutes.

I want to thank you, the committee, for having us come and present today in support of Bill 3, the Compassionate Care Act. This act grows the understanding and delivery of hospice palliative care through education and training, increased capacity, equity of access and an overall palliative approach to care in all settings, and will support the quality of life and well-being of all Canadians.

Support and funding for hospice palliative care and advance care planning in Canada is vital to making hospice palliative care accessible to all Canadians. Of course, as a national association, that is our primary goal—to try to get hospice palliative care available to all Canadians; at this point in time, it certainly isn't. Governments, health care associations and organizations all need to be partners in this.

Some of these stats you may have heard already, because you've had a number of great presentations today: Of the 270,000 Canadians who would die each year, 90% of them die of a chronic illness such as cancer, heart disease, organ failure, dementia or frailty. We've seen some of that with this COVID-19 pandemic in our long-term-care facilities. By 2030, seniors will number over 9.5 million Canadians and will make up 23% of all the population. Few Canadians—only 15%—have early access to palliative care in the community, as per the CIHI report of 2018. Many Canadians are living longer, but they're not always living better. We need to take steps to make sure they are living better.

The Canadian Hospice Palliative Care Association supports Bill 3 and is grateful to MPP Sam Oosterhoff for introducing it and to the MPPs of all stripes who support the bill and who have supported the hospice and palliative care sector in Ontario for many generations.

Our reporting framework will help ensure that our society is a truly compassionate one by ensuring that hospice palliative care is available to all people right to the end of life in all settings. This can be hospice residences, acute-care hospitals, in their home, in long-term-care facilities, and occasionally in shelters or prisons.

As our population ages, the number of people reaching the end of life inevitably grows, and we need to build on this capacity. We feel that this bill does that.

COVID-19 has put a poignant spotlight on the need for compassionate care at the end of life and a place and time for families to be together at the end of life. Having a legislative mandate to report back to the Legislature on palliative care would ensure that the government is moving forward. I think five years is likely too long, but there should be reports back in a timely fashion.

Bill 3 will lower overall health care costs; work towards ending hallway medicine and ER overcrowding, which we've seen in the last little bit; support mental, emotional and physical well-being; and deliver holistic care that is highly valued by patients, families and communities.

The recommendations that we want to make today to the Ontario government to make home care and palliative care more available across the province are specifically to:

- fund all the priorities in the national framework, which include palliative care education, training for health care providers and caregivers, including volunteers, communities and others;

- support research and systematic standardization of data collection on hospice palliative care, including formal and informal care for the grieving and bereaved;

- measure to facilitate equitable access to palliative care across Ontario, with a focus on underserved populations; and

- support a public awareness initiative around hospice palliative care that shows the benefits, like the National Bereavement Day.

Before I end, I will turn it over to Laurel Gillespie to speak further about the advance care planning initiative.

Ms. Laurel Gillespie: Thank you, Sharon. I'd like to echo your sentiments and thank the standing committee for allowing us to present today in favour of Bill 3. I'd also like to note that I am speaking from a national perspective, and that HPCO is a leader in hospice palliative care and advance care planning in Ontario.

The Canadian Hospice Palliative Care Association continues to advocate for increased awareness, public education and community-based advance care planning programs to help Canadians navigate the process of reflecting their wishes and their values about their future health care needs, and that access to advance care planning resources and information needs to continue to flow.

Advance care planning helps to ensure that care one does receive in the future is in alignment with their expressed wishes and, as an identified substitute decision-maker is named in that process, that they're in alignment with and prepared to communicate those wishes on the individual's behalf.

Advance care planning is really a lifelong process and not merely about end-of-life care. If you look at it, it's about the quality of care that you want to have up until the end of your life. Engaging in advance care planning can dramatically improve the quality of palliative care that is received when these important discussions take place in advance.

The Chair (Ms. Goldie Ghamari): One minute left.

Ms. Laurel Gillespie: Advance care planning as part of a palliative approach will reduce the suffering of not only the individual, but also health care professionals, in knowing what patients' expectations are and what their desires are for future care. It even reduces unwanted medical interventions that were maybe not even warranted or wanted by the patient in the first place. It also has a lasting residual impact on the bereavement and grieving process, when these advance care plans are in effect.

To give you a few numbers—just in the last few months, on our national advance care planning website, we've seen an increase of 44% of people looking into creating their advance care plans. While attitudes toward advance care planning are overall positive, the behaviour has not followed, so it's incumbent upon us to try to get people to move from thinking to doing and engaging in advance care planning. While eight in 10 Canadians have given end-of-life care some thought, less than one in five actually engage in a current advance care plan or advance care planning—

The Chair (Ms. Goldie Ghamari): Thank you very much. My apologies; that concludes your time, but I'm sure you'll be able to continue during questions.

I'd now like to call upon our final presenter, Deborah Dudgeon. Please state your name for the record, and then you may begin. You will have seven minutes.

Dr. Deborah Dudgeon: I'm Deborah Dudgeon. I'm the expert adviser for the Canadian Partnership Against Cancer. I was the inaugural head of palliative care for Cancer Care Ontario and the head of palliative medicine at Queen's University for over 20 years.

I'm sharing my screen.

CPAC hosts a palliative and end-of-life care national network. The membership of the network includes patients and families, representatives from Health Canada, all of the ministries of health of all the provinces and territories, provincial cancer agencies, the Canadian Hospice Palliative Care Association, Canadian medical and nursing associations, and other organizations that have a national interest and mandate within palliative care.

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The priorities of the palliative and end-of-life care national network are two. The first is integration of core palliative care competencies into curricula and standard practice for individuals providing palliative care. Health Canada, Pallium Canada, the BC Centre for Palliative Care and other partners have developed national competencies for nurses, physicians, social workers, personal support workers and volunteers that are adapted from those that were developed by Nova Scotia, Ontario, Quebec, Alberta and BC. We've developed self-assessments so that individuals, managers and organizations can look at their competencies and look at where the deficiencies are and what educational programs should be instituted to help meet those deficiencies. Health Canada and ourselves have also been in discussions with the Health Standards Organization and the Canadian [inaudible] around putting the competencies as a part of the accreditation processes for organizations, and in discussions with

the Canadian Home Care Association so that they can implement the competencies within the community sector.

The second priority of our network is performance measurement. As you know, data collection is vital for continuous improvement, and evidence is needed to address gaps and drive innovation. Currently, many studies and attempts to do surveys etc. have shown that largely the data that's available is reflective of end-of-life and acute-care settings and doesn't actually reflect what patients and families value most. One of the priorities is to promote the use of standardized person-reported outcome, screening and assessment tools across all settings of care. Patient-reported outcomes are outcomes where, basically, patients themselves are asked, with the primary goal of improving patient care so that you can monitor patient symptoms over time and across settings. This can lead to regional monthly progress reports which feed into quarterly reviews for regions and performance scorecards and give you the ability to compare common data across different regions, with the intent to improve the quality of care and learn from one another. It also provides data for researchers to look at innovations in terms of the care that we do provide.

CPAC currently and previously has supported the standardization and implementation of patient-reported outcomes across all of the provinces and territories except for Nunavut. This is largely within the cancer system but also, in the Yukon, the Northwest Territories, PEI and Nova Scotia, extends into the community in the non-cancer population.

Australia is the international leader in this work in palliative care. The Palliative Care Outcomes Collaboration have over 150 palliative care programs from across Australia submit results of standardized assessments, where information is analyzed, fed back to the different programs, compared with other services, and then the programs are coached about how to improve the quality by quality improvement advisers. This is an example of the dashboard that the different programs will get. You can see here that these are basically benchmarks. This particular organization wasn't meeting a benchmark in terms of the time that people were spending in an unstable phase. They weren't responsive enough in care, in that people's symptoms were remaining outside of the benchmark for longer than was shown in other areas and what the benchmark was. Basically, this is what is sent back to the different programs so that they can look at them, see where they fall short of the benchmarks in other programs and then have quality improvement coordinators work with them. Currently, the Palliative Care Outcomes Collaboration receives information from over 25% of all expected deaths in Australia, and they have demonstrated improvements in the quality of care delivery over time. We are in discussions with Health Canada, CFHI and their project partners currently to see if we can institute such a system in Canada.

I believe that the adoption of An Act providing for the development of a provincial framework on hospice palliative care would signal Ontario's commitment to address current gaps in care—

The Chair (Ms. Goldie Ghamari): One minute left.

Dr. Deborah Dudgeon: —and provide a structure to help to implement these sorts of improvements in care. Thank you.

The Chair (Ms. Goldie Ghamari): Thank you very much for your presentation.

We're going to turn to the independent member for three and a half minutes. MPP Schreiner, you may begin.

Mr. Mike Schreiner: Thanks to all three presenters for your presentations today. Hopefully, I'll have some time to ask each of you questions.

I'm going to start with the Canadian Hospice Palliative Care Association. You talked about the need for more timely reporting, and I'm just wondering if you have some recommendations on what reporting timelines you would like to see in the bill.

Ms. Sharon Baxter: Thanks for the question.

In the bill it said five years, and five years is a long time [*inaudible*] for the changes. In talking to our representative in Ontario, the Ontario Hospice Palliative Care Association, I think Ontario is ready in a lot of ways to implement and to get moving on some of these items in the bill. To keep people on track, because we are so far along in Ontario, two or three years seems fairer than five years. If you don't have reporting back to government for five years, things can get stalled. I think it keeps the eyes on people, and I think you're in a good position in Ontario compared to some of the other provinces.

Mr. Mike Schreiner: I want to direct a question to you, Ron, of the Catholic Health Association of Ontario. I think most of us agree that Bill 3 is a really positive step forward. In your presentation, you said it's an important part of the answer, but you suggested that there are more parts to the answer. I was wondering if you could elaborate on what you think some of the other parts are.

Mr. Ron Noble: Well, I think it goes back to what the gentleman from the Canadian Cancer Society spoke about: It's educating not only providers but the public on what they should expect and what our best-class service is in palliative care. I think a lot of society is not aware—a lot of providers aren't aware—of what the actual scope of services is that can be provided under palliative care.

Unfortunately, I think a lot of the public thinks that MAID is palliative care, and it is not. As I said, it's an end-of-life decision; it's not a palliative care decision.

The Chair (Ms. Goldie Ghamari): One minute left.

Mr. Ron Noble: I think that's a lot of public education. Use of advance care directives is a good tool to educate the public and engage them in that discussion.

Mr. Mike Schreiner: Deborah, you talked about the importance of data collection. Would you like to see a more expansive scope of data collection in the bill?

Dr. Deborah Dudgeon: Yes, I think it's really important that patient-reported outcomes are a part of what is in the bill, what's being collected. Right now, they are being collected within the cancer system, and some of the palliative care programs are collecting them as well, but they're not being collected in such a manner that they can be shared and that people can learn from them.

Ontario actually has a really good system within the cancer system. To expand that out into the palliative care community, I think, would serve everyone very well, because, again, it's asking patients what's important to them.

The Chair (Ms. Goldie Ghamari): That concludes this round of questioning.

We're going to now turn to the government for five and a half minutes. MPP Kramp, you have the floor.

Mr. Daryl Kramp: Thank you, Chair. And to all of our presenters today, thank you so, so kindly for coming here to provide us with your input, your thoughts, your guidance and your support. We certainly do appreciate it.

As we've all seen, this is a topic that knows no boundaries. Fortunately, it's not a partisan issue; it's everybody's personal issue.

I was formerly past president of our local cancer society, I've been involved in the creation of two hospices, and my wife is a caregiver, so I've seen first-hand the impact that hospice has and where it's going.

I was very impressed, Deborah Dudgeon; your dashboard was very, very important. I think it really gave us an indication of some of the challenges that we face and how we're going to have to track this.

1700

I'm in those "golden years," as they call it here now. The demographics are going to have a dramatic impact on where we're going. I'm worried about demand and capacity to be able to support. I know, my local ones, whether it's from Bancroft or Centre Hastings or the new one they're putting up in Belleville—as these baby boomers go through, there's going to be quite a significant demand, again, over these next eight, 10, 12, 15 years.

In your dashboard of that, in your projections, do you have any anticipated growth for the demands and needs that's over, above and beyond what most of us would [*inaudible*] on a daily regimen, Deborah?

Dr. Deborah Dudgeon: I'm wondering, Sharon, if you have the statistics. You might have them at your fingertips better than I do.

Certainly, there is going to be growth. I don't have those numbers at my fingertips. I'm sorry.

Mr. Daryl Kramp: Sharon, do you have anything?

Ms. Sharon Baxter: I don't have the exact numbers.

Because of the number of Canadians who are aging and the number of us who have hit baby boomer time, our end-of-life survey of care has changed drastically in the last 25 years. Where we used to die quickly of heart attacks and strokes, now we're living, on average, 25 years in that frame. Even though we're only hitting about 15% of Canadians who have access to hospice palliative care right now—it's looking pretty dismal unless we do something drastic.

That's where the whole palliative care approach has come in—that not every Canadian needs to have an acute-care hospital bed [*inaudible*] some Canadians in their own home.

We need to do a better job of providing a well-balanced approach to home care, residential hospice, acute care and long-term care.

Through the COVID-19 situation, we saw the cracks in the long-term-care settings, so we really need to pay attention to them. It's actually quite frightening right now.

Mr. Daryl Kramp: Well, there are a lot of suggestions as to how we can improve this legislation. Some of the amendments that have been suggested—one of them, of course, was a dedicated youth or infant palliative unit, which certainly is a whole different set of dynamics. There are a lot of great suggestions coming forward.

On the other side of the coin, maybe any of our guests could offer a suggestion on what we need to avoid. What should not be in this legislation, going forward? What would not be helpful? That's very, very important—to make sure that we don't fall into a pitfall, either unaware or unacknowledged. Do any of our guests have a suggestion as to a complete no-no that you don't want to see in this legislation? I'll open it up.

Ms. Sharon Baxter: I don't have a complete no-no. I think that all the different areas that have been talked about in the act are important, and I think it would be a mistake to put an overemphasis on one area and not any of the others. I think that a balanced approach in moving everything forward at the same time is where we need to go, and it would be a mistake to do otherwise.

The Chair (Ms. Goldie Ghamari): One minute left.

Dr. Deborah Dudgeon: I was just going to say, one of the things that I would suggest is that we need to be developing a system that's needs-based—it's not based on diagnosis and it's not based on prognosis, but rather it's based on the needs of the patients and families. So often, palliative care and the access to different things have been based on what prognosis—and physicians are all very poor at prognosticating. What we need to say is, "How do we identify what the needs of individuals are, and then how do we meet those needs most effectively?"

Mr. Daryl Kramp: Chair, how much time?

The Chair (Ms. Goldie Ghamari): You have 18 seconds—now you have 14.

Laughter.

Mr. Daryl Kramp: I'll leave it over to the next questioner, then.

Once again, thank you to all of our presenters today. It's much appreciated.

The Chair (Ms. Goldie Ghamari): Before we turn to the official opposition, I want to remind presenters that written submissions are due tomorrow at 7 p.m. So you are welcome to submit a more fulsome response to MPP Kramp's question or any question here today by tomorrow at 7 p.m.

We'll now turn to the official opposition. You may begin. You have five and a half minutes.

Ms. Sandy Shaw: I want to start with what my colleague MPP Kramp has said: that we've been hearing from witnesses about ways that we can improve this legislation. This is an important bill. We think it needs to be here. It's timely. We think that's the role here—to make suggestions to improve it.

One of the things that we're been hearing about quite a lot is the requirement to break out and very specifically identify the unique needs of pediatric palliative care.

You may or may not know, but I'm going to tell you anyway, that I have a private member's bill, the Nancy Rose Act, which is looking to create a pediatric palliative care strategy for the province.

Can you talk about the importance of the unique needs of pediatric palliative care? This is to the Canadian Hospice Palliative Care Association, because I know your organization was part of a report—the pediatric hospice palliative care guiding principles that your organization did in 2006. I think that your organization would be well-placed to speak to the importance of specific recommendations that are targeted to pediatrics.

Ms. Sharon Baxter: The Canadian Hospice Palliative Care Association actually hosts the pediatric palliative care network for Canada.

Right now, there are seven pediatric hospices in the country.

In Ontario, in the Hamilton region, where they have a children's hospital, they don't have a hospice. All the other pediatric hospitals have hospices.

Providing care for pediatrics is difficult. We have large parts of the province of Ontario where there isn't a pediatric hospital, and you need to be creative.

I think one of the things I've learned from the pediatric folks is that it's not implicit—we need to really name that we need to provide services for children. We tend to think of seniors, the elderly and those with acute diagnoses, and we tend to not think about [*inaudible*] and their needs. They are very different. Adults die after an episode, being a fairly quick manner, so to speak—some of them don't. But with children, the care that they need to receive can be up to 10 years. It can be very long, and it's very different than adult care. So we need to do that sort of thing.

We only have seven residential hospices for kids in this country. We have programs in a lot of the hospitals, but rural and remote Canada—because that's my bailiwick; it's all of Canada—struggles sometimes. It's long distances and sending people [*inaudible*] away. So I think we can do a much better job with pediatrics.

Ms. Sandy Shaw: I will say, you're right. There are only three pediatric hospices in Ontario. I've toured all of them. They do fantastic work, but we need to expand that.

The recommendation is not just to say the word “pediatric” in this bill, but to understand that it needs a distinct framework and even a distinct oversight body because of the unique expertise in this area. Can I have your comments on that?

Ms. Sharon Baxter: We had a pediatric webinar in October for the first-ever national pediatric palliative care day on October 13. We had 450 people [*inaudible*]. A small number of them were from the pediatric palliative care community. The rest of them were from the pediatric community, and they were saying that they needed to know more about how they would care for kids and their families at the end of their life. We were overwhelmed with the numbers. It was quite remarkable.

Ms. Sandy Shaw: Thank you for the work that you do. I appreciate that.

I'm going to pass my time to MPP Gélinas.

M^{me} France Gélinas: To Mrs. Baxter again: In your presentation, you mentioned that palliative care should be available to all in all settings, including in our jails.

Do you know of anywhere in Canada where palliative care is available to inmates?

Ms. Sharon Baxter: Yes, all the federal prisons governed by Corrections Canada have a palliative care program. Their availability of medication is different, and I don't want to get into the details of that because I'm not even that aware of the most recent areas—

The Chair (Ms. Goldie Ghamari): One minute left.

Ms. Sharon Baxter: One of the things we talk about is equitable access. It doesn't matter if you're on-reserve, you're in a big city or you're in a shelter; you should be able to get access to a palliative approach to care.

M^{me} France Gélinas: The federal government provides it. Do you know if it's provided in any of the provincial jails?

Ms. Sharon Baxter: It's a bit of a smattering of things. I am actually not aware of the Ontario situation. It's maybe something to be looked at. Maybe it needs to be looked into in the bill, because when we talk about equitable access, we should be talking about all people in Ontario.

M^{me} France Gélinas: So for some of them, obviously, it's not a hospice, but it's through outreach or through home care?

Ms. Sharon Baxter: One of the programs that is quite remarkable is the hospice for the homeless in Ottawa, where they treat unstably housed or homeless people who are at the end of their lives, and they do it through outreach programs.

There are some really creative programs. There are some great programs in Toronto. And there are some prison program organizations in Toronto. So I would encourage us to look a little further into what's going on in Ontario—

The Chair (Ms. Goldie Ghamari): Thank you very much. Sorry; that concludes this round of questions.

1710

We'll now turn to the independent member. You have three and a half minutes. MPP Schreiner, you may begin.

Mr. Mike Schreiner: I'm going to try to maximize my three and a half minutes, giving each one of you a voice. All of you have done a great job of talking about the importance of passing this bill and having a framework. Each of you have 30 to 45 seconds.

I'll start with the Catholic Health Association of Ontario and go in order. What would be your top priority, if you could say to government, “This is what we'd like to see in the framework moving forward?”

Mr. Ron Noble: Mine would be, quite honestly, equitable funding. Hospices are funded at about 50 cents on the dollar. It makes it extremely hard for them to fund-raise for the operating funds. Most donors want to contribute to capital and not operating. I would say that funding would be key to ensure that there's the full scope of service—not only nursing care, but social and recreational services for this population—and that it's equitably funded to other Ministry of Health programs.

Mr. Mike Schreiner: I'll give the Canadian Hospice Palliative Care Association a chance.

Ms. Laurel Gillespie: I'd say that funding is paramount to the success of any implementation of framework that you're going to put together.

Hospitals, fiscally, are ideally not the place to have end-of-life care be delivered. They're really good at fixing people; not so much on the end-of-life care delivery.

I'd also say, don't under-score the need for removing the barriers for those with disabilities in this country. If those of us who have capacity to make sound decisions for ourselves—what about those who have intellectual disabilities? Please don't forget about them, as well as underserved populations, such as correctional facilities and those who are homeless.

For me, as director of Advance Care Planning, what it comes down to is, normalize the conversation. People are still tremendously uncomfortable talking about what their wishes and values are. I think that to help with garnering support and some trajectory around implementing any plan, we have to make sure that people are educated about what palliative care is and is not, and what mechanisms can be put in place to give themselves a voice when they're facing their own end-of-life care or goals of care.

Mr. Mike Schreiner: Deborah, you have a few seconds, probably, to give your answer.

The Chair (Ms. Goldie Ghamari): One minute left.

Ms. Deborah Dudgeon: What's really important is that there's accountability—that the service providers are accountable for the care that they're giving, so that they're competent; that we've got a way of measuring their competence—as well as a system where we can get patient-reported outcome data, so that there are processes in place that make it easy for the people to collect this information and share it, so that we can use that to improve the care by comparing ourselves to one another.

Mr. Mike Schreiner: Chair, I'll yield the rest of my time.

The Chair (Ms. Goldie Ghamari): We'll now turn to the government side for the second round of questioning. Five and a half minutes, MPP Kusendova. You may begin.

Ms. Natalia Kusendova: Thank you to all of our presenters today.

My first question is for the Catholic Health Association of Ontario. I am a proud practising Catholic and a proud practising registered nurse. As such, I believe in the sanctity of human life, from conception to natural death. It feels good to say that out loud. That is why I strongly believe that there is a place in our health care system for the type of health care services that you provide, with that unique Christian lens.

In the absence of a robust palliative care network—and we know that we are about 400 beds short for a population of our size in Ontario—and with the looming federal Bill C-7, which removes some of the safeguards in place for medical assistance in dying, I fear that more patients may opt for MAID in the absence of appropriate access to palliative care, simply out of fear. That is why Bill 3 is needed now more than ever.

Does your organization share some of the fears I express? And how can we, as a society, ensure that there's enough awareness among terminally ill patients about palliative care as a viable option at their end-of-life journey?

Mr. Ron Noble: Well, I think it builds on what I spoke about earlier. The standard of care has to be developed at a provincial and national level, and this needs to be communicated to both care providers and the public, in terms of their understanding of what palliative care is and their rights to access that palliative care. So I think a standardized approach to what the scope of service of palliative care is, timing for access—it's not a last-minute decision; it's a decision that can be made early in the caring process—and, as I mentioned earlier, better education on advance directives, so that those discussions can be had between family, patients and their caregivers and their professional staff in advance, so that wishes are known and wishes can be acted upon.

Ms. Natalia Kusendova: My next question is for Deborah.

You spoke about the integration of palliative care competencies for health care professionals. I concur, because as a registered nurse who works in the ER—as I mentioned before, palliative care or end-of-life care was not part of my nursing curricula. With an aging population and people living longer and having way more complex health care needs, I think adding this competency for all health care professionals is very much needed.

You also spoke about the fact that data for end-of-life care is mostly available only from acute care. My question is, why do you think that is?

As you know, with our health care transformation, we are trying to integrate all aspects of health care in Ontario, which will also include end-of-life palliative care, under Ontario Health.

Do you believe that this transformation of our health care might lead to better data collection and, as a result, better palliative care planning for future generations?

Dr. Deborah Dudgeon: Well, I would hope that it leads to better data collection. I think that data is important in terms of creating a system that meets the needs of patients and families.

I think that the system has largely gone on the information that's available from acute care because that's what's available. We don't have a rigorous ability or system to collect data in the community or in long-term care, and therefore the data that we get is reflective of where the data is.

We have to set up a system where we can actually start to collect that information consistently within these other sectors.

Ms. Natalia Kusendova: My last question is for the Canadian Hospice Palliative Care Association.

I couldn't agree with you more that hospitals are not good at palliative care. We are good at fixing people, but we are not good at supporting them in their end-of-life journey.

For many families, there are a lot of struggles and challenges when they are trying to navigate that end-of-life journey with their loved one. So how can we make navigating this difficult time less difficult or less challenging for the patients and their families?

Ms. Sharon Baxter: One of the things that we have an inherent problem with is that people are not referred to the hospice and palliative care programs early enough. Particularly with—

The Chair (Ms. Goldie Ghamari): One minute left.

Ms. Sharon Baxter: —a cancer diagnosis, you may only get care for the last month or two. So it's really hard to support the patient, the family, the caregivers and all those around them. I think that the people working in hospice and palliative care do a yeoman's job in that area, but so much of the care that Canadians are getting is not actually provided by hospice and palliative care professionals.

I think we need to do a much better job in making an awareness of the programs and getting people to advocate on behalf of themselves and to advocate for others. I think having a strategy where we try to address caregiving in this country is an important thing to do. That would help a lot. But I think some of it just comes down to awareness.

The Chair (Ms. Goldie Ghamari): We'll now turn to the official opposition for five and a half minutes of questioning. You may begin.

M^{me} France Gélinas: I would like to thank all of you for sharing your thoughts—very interesting.

Mr. Noble, my question is a bit in line with the questions that MPP Kusendova was asking you.

I live and represent people in rural northern Ontario, where palliative care is not available to 90% of the land mass that I cover. There is nothing available. We do have a hospice in Sudbury, but if you live in Foleyet or Gogama or Biscotasing or Shining Tree—I can go on and on—there is none.

Has your association ever looked at the requests for MAID by people for whom palliative care is not available versus people who have access to palliative care?

1720

Mr. Ron Noble: Not to my knowledge. We would obviously prefer that we focus on palliative care in the communities that we serve and provide that scope of service. We do partner with organizations in the communities that we're present in for access to good palliative care, whether that be community-based or facility-based. So that is our approach.

Again, I go back to how I grew up in a rural community as well—and many of these services need to look to being community-based, because the institutional support isn't there. I think the comments made of getting good training, what's best practice, good awareness amongst all professionals and the accountability to care to that standard—in many ways, it starts with the college and university curriculum, as physicians and nurses and therapists, it's part of their core curriculum, and understanding that it is a significant component of care.

M^{me} France Gélinas: To the Canadian Hospice Palliative Care Association: Is there a province or a territory in Canada that has really made strides forward in the number of people or communities that have access to palliative care? Are we the norm, or is anybody else doing way better than we are when we look at access to palliative care?

Ms. Sharon Baxter: None of the provinces are doing what they need to be doing, to be frank. Ontario, Quebec, BC and Alberta likely are doing best, when we look at rural outreach. I know you're asking the question because you're from a rural community. I think that we have a long way to go.

It may not be in a hospital-based program—it might be a community outreach program, or it could be a volunteer-based program.

In Ontario, there are over 13,000 hospice volunteers who are actually not doing much right now because of COVID-19, which is another issue that we need to deal with.

There are things that we can learn from each of the provinces, but no, none of them are a great standard of care at this point in time. But there are some great observations from HPCO in Ontario.

M^{me} France Gélinas: If we look at the way it is structured in Ontario, where most hospices only get 50% of their operating costs funded and have to fundraise for 50% of their costs—is this standard across all of the provinces, that we don't pay for palliative care?

Ms. Sharon Baxter: You're talking about hospice residences, and yes, that's truly the way it is. PEI has 100%-funded hospice, and they have one. It's the only one in the country that is funded to that level. All the other hospice programs are funded between 35% to 60% of their clinical practice. So it really is the norm. The average hospice program needs to raise between \$2 million and \$3 million a year out of community coffers. It's crazy.

One of the things that HPCO in Ontario has been trying to get is for the Ontario government to consider 100% of the clinical funding. We would still fundraise for the other parts of the—

The Chair (Ms. Goldie Ghamari): One minute left.

Ms. Sharon Baxter: —programs. It would be a benefit if they looked at that model.

M^{me} France Gélinas: Dr. Dudgeon, if you really focus on accountability and competence—do you figure it is achievable in Ontario that every health care provider would graduate with a knowledge of providing palliative care? Do you know of jurisdictions that have done this?

Dr. Deborah Dudgeon: I think that it's not just people who graduate, but also those who are currently in practice. It's certainly a goal that that should be the standard.

I'm just trying to think of if there is any particular area where all different levels, including social workers, nurses etc.—I don't know of anywhere where all of them have that. I think that it's certainly achievable, but it's over a period of time that that could happen. I think that the—

The Chair (Ms. Goldie Ghamari): My apologies; this round of questioning is complete. But you will have an

opportunity to continue your comments with written submissions.

I want to thank the witnesses at this point in time for your insightful presentations. You are now released.

HOSPICE NIAGARA
CARDINAL THOMAS COLLINS
CANADIAN SOCIETY OF
PALLIATIVE CARE PHYSICIANS

The Chair (Ms. Goldie Ghamari): We'll now turn to our final set of presenters for the day. We have Hospice Niagara, Cardinal Thomas Collins and the Canadian Society of Palliative Care Physicians. Each set of presenters will have seven minutes.

We'll begin with Hospice Niagara. Please state your name for the record, and then you may begin. You will have seven minutes.

Ms. Carol Nagy: My name is Carol Nagy. I'm the executive director of Hospice Niagara. I want to thank everyone tonight for having this extremely important conversation. Also, I want to acknowledge Sam Oosterhoff, who brought this bill forward. It's an important piece of legislation. I also want to recognize all of the MPPs from every single party for continuing to support hospice palliative care in Ontario.

This bill has the potential to foster further excellence in hospice palliative care through education, training, increased capacity, equity of access and ensuring an overall coordinated palliative care approach across the province in every single community. If we get this right, it will move Ontario toward a truly modern, connected health care system that nurtures close partnerships between primary and community care, long-term care, hospitals, home and hospice, and ensure that every person receives the highest quality of care they expect and they deserve.

This comprehensive provincial commitment aligns with this government's priorities and will be strongly supported. I am sure that we can all agree that improving each person's and each family caregiver's experience must be our first priority. To better ensure that people requiring hospice care have equitable access to this kind of care, we need to work together to capacity-plan for hospice and palliative care services across the province.

Hospices have capital-built projects ready to go in many communities. Hospice care saves health care costs and provides end-of-life care that people often prefer. Annually, for example, Hospice Niagara cannot accommodate the over 350 to 400 requests from people wanting hospice care, due to the limited number of hospice beds in our community. We know that hospice capacity planning means that there should be at least seven to 10 hospice beds per 100,000 people in every community. The majority of funding for hospice capital projects comes from community donors who recognize the importance of this care.

Hospice builds are innovative, as we look to control costs through integrated models and building alongside health care campuses and long-term care. As long as we

continue to prioritize hospital beds without growing the number of hospice beds, people will most often die in hospital, in hallways and in emergency departments. This is expensive and does not serve our communities well. For this reason, the Compassionate Care Act has to provide better capacity planning to provide better health population outcomes.

We also need to work together to provide additional community palliative care team support to people at home. Palliative care teams work to prevent unnecessary hospital-based care. When receiving services and supports from Niagara's community palliative care team, people are 70% more likely to stay at home at end of life. For those people who cannot access this team, it is a 50-50 chance that they will die in hospital. Planning an investment in these teams delivers health care savings, while providing better population health outcomes.

Working in this type of care, we see first-hand the difficult but important role that family caregivers play in providing care to their loved ones at home. We know that family caregivers sacrifice a great deal to care, day in and day out, for their loved ones. They often put their physical and mental health at risk. We have to do better for them.

Realigning existing community home care services under hospices will increase support and help caregivers avoid burnout. Family caregivers, including young caregivers, are critical members of every home care team. We need to provide them with timely education, groups and wellness programs. We need to provide them with more alternatives for respite that are easy to access, flexible, safe and dependable.

With increased capacity, supported by the Compassionate Care Act framework, we can continue to evolve as a one-call organization that caregivers rely upon to receive seamless transitions across care settings and coordinated palliative care at home.

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Dying is not just a medical event; it is a physical, social, spiritual, psychological life event impacting each of us and our family members. Families need more access to fully funded grief and bereavement services. The grief that accompanies the loss of a loved one at times requires mental health support. It is real, it is palpable, and it can be debilitating if left unsupported. Hospices are providing this support, including information groups and counselling services for all ages. Our bereavement programs decrease incidents of mental health and stigma, and save health care costs and emergency care resources. These critical bereavement supports provided by hospices need to be recognized as mental health services.

Hospices play a central role in delivering critical palliative care and end-of-life care. Our services keep caregivers healthy and help people manage through grief.

The Chair (Ms. Goldie Ghamari): One minute left.

Ms. Carol Nagy: Hospice palliative care is not an add-on, an afterthought or nice-to-have services. These are services that are part of the health care continuum that everyone should expect to receive. By strengthening this

care through the Compassionate Care Act and with continued provincial government support, we—all of us—are improving health care and social care outcomes for our communities and people across Ontario. Thank you.

The Chair (Ms. Goldie Ghamari): Thank you very much.

We'll now turn to our second presenter. We have Cardinal Thomas Collins. Please state your name for the record, and then you may begin. You'll have seven minutes.

Cardinal Thomas Collins: I am Cardinal Collins, the archbishop of Toronto.

Good evening, and thank you for providing me with the opportunity to speak with you about Bill 3, the Compassionate Care Act. I'm very grateful to MPP Oosterhoff for bringing forward this legislation to develop a provincial framework on hospice palliative care in our province.

As the archbishop of Toronto, I serve as the spiritual leader for two million Catholics in the greater Toronto area.

In my allotted time, I would like to focus on three key points.

First of all, the need to highlight what palliative care is and how it can foster a culture of compassion: Palliative care is a great gift, and one that desperately needs to be promoted and magnified so that Ontarians can both understand what it is and have access to it. Studies show that those in their final days fear two things above all: loneliness and pain. Palliative care addresses both of these fears with compassion and love.

I personally spent a significant amount of time over the past four years speaking of the dangers of euthanasia in this country. While that is not the focus of this committee, it does have relevance. What started out as "mercy killing" has turned into "euthanasia," and then more recently has been referred to as "medical assistance in dying." That term is not correct when giving someone a lethal injection. The correct use of the term "medical assistance in dying" is actually what palliative care is and can be: assisting a patient compassionately, controlling their pain and surrounding them with love before they die.

I witnessed authentic medical assistance in dying—true palliative care—first-hand a few years ago as my sister entered into her final days as she was dying of pancreatic cancer.

My prayer is that this bill, in addition to requiring the Minister of Health to more formally develop a framework for the various aspects of palliative care available, will also present an opportunity to help educate the public on how palliative care can offer hope and comfort for those who are dying, to help the public understand what is available for those facing a terminal illness.

While it is not a goal of the bill, I encourage all members of provincial Parliament to speak about palliative care, highlight the incredible work being done by those in the field, and to consider opportunities or campaigns to educate Ontarians on how to access this critical service.

This leads to my second point: the critical need to expand palliative care as quickly as possible. At present, very few—maybe 30% of Canadians—have access to

palliative care, and far fewer in some areas. Despite promises from both federal and provincial governments to expand access, there has not been the political will to make this a priority. The development of a provincial framework that is called for in this bill will help push things along. Yet we need more than a framework; we need palliative care to be given priority by our elected members of provincial Parliament, and to assign aggressive timelines, funding and accountability for its expansion.

The provincial Ministry of Health website on palliative care reads, "Based on the experience of other countries, only a small number of Ontarians will choose to access medical assistance in dying. Patients with life-limiting illnesses will generally choose to access palliative care and other treatments."

There's no question that euthanasia has been a priority for the federal government, but if most people would choose palliative care if given the option, why hasn't it been a priority for us? If the energy and resources given to euthanasia had been devoted to palliative care, I believe every Canadian would have access to it at this time. I wonder how many of the 14,000 Canadians who have so far died by euthanasia would have made a different end-of-life decision had palliative care been available.

We also know that the arrival of euthanasia in our country has impacted palliative care providers. They're increasingly being pressured to provide euthanasia, something that most providers see as completely contrary to their mission. We also see doctors, nurses and other health care professionals being compelled to participate in euthanasia, with no conscience rights to protect their desire to do no harm to their patients. I ask that those creating this framework consider the dilemma that these palliative care workers find themselves in.

My final point is the need to draw on the example of proven palliative care providers. Throughout our province, we have a tremendous gift: Palliative care providers are quietly working each day to journey with people through the most challenging and vulnerable moments of their lives. I know that many of these groups will participate in these hearings, and that they are participating today. They should have our gratitude and admiration. In the Archdiocese of Toronto, we have the tremendous example of groups like Saint Elizabeth Health Care and Providence Healthcare. These and other groups provide some of the most robust palliative care in the country. I am pleased to see that the bill calls on the Minister of Health to consult with these providers. They have been engaged in this work for years. We should listen closely to their advice and ask them to be part of implementing the framework in this bill and to partner on a path to expand palliative care in the future.

In closing, I encourage the government to move as quickly as possible to fast-track the action items in this legislation as well as other initiatives to accelerate our palliative care framework, funding, resources and access through our province. I continue to be troubled knowing that only a third of Canadians have access to palliative care. It is no wonder that other, darker alternatives are

emerging in the absence of access to loving, personal and compassionate care.

I hope that all political parties will support this bill and champion palliative care in any way possible. Let Ontario be an example for the rest of the country and demonstrate that compassionate care for our citizens is not only achievable but must be accessible to all.

The Chair (Ms. Goldie Ghamari): Thank you very much, Cardinal Collins. You have 50 seconds left, unless that's the end of your presentation.

Cardinal Thomas Collins: No, that's it.

The Chair (Ms. Goldie Ghamari): Thank you very much.

We'll now turn to our third presenter, from the Canadian Society of Palliative Care Physicians. Please state your name for the record and then you may begin. You will have seven minutes.

Dr. Leonie Herx: Good evening. I'm Dr. Leonie Herx. Thank you for the opportunity to speak to this important bill, the Compassionate Care Act. I'm the immediate past president of the Canadian Society of Palliative Care Physicians, and I've been on the board of directors with their organization for the past eight years. I'm the division chair and associate professor of palliative medicine at Queen's University, and I practise in both adult and pediatric palliative medicine.

I'll make note of a couple of extra points, as I heard some pieces of the last session. I've been involved in developing a local and national strategy for palliative care for incarcerated persons, and I'm also a member of the Provincial Pediatric Palliative Care Steering Committee, one of their working groups. It may have some relevance for questions later.

Palliative care focuses on improving the quality of life and symptom management for those living with life-threatening conditions and their families. It does not intentionally end life and is internationally recognized as a practice distinct from MAID. Palliative care has been shown to reduce health care costs by reducing length of hospital stays, unnecessary diagnostic tests and inappropriate disease-targeting interventions, and decreasing the number of intensive care unit and emergency room visits. Studies show that the savings in direct health system costs are consistently around 30%.

It is estimated that approximately 70% to 94% of adult deaths would benefit from a palliative approach to care. However, less than 30% of Canadians have access to palliative care and even fewer, about 15%, have access to specialized palliative care. In Ontario, we see that less than 15% of patients receive publicly funded palliative home care services in their last year of life.

Whether you will get the palliative care you need depends on where you live, how old you are, what you are dying from, and how close you are to death. You are also less likely to get palliative care if you are poor, rural, Indigenous, homeless or incarcerated. Every Ontarian has a right to access high-quality palliative care regardless of their diagnosis, age or location, yet they do not have the same universal access to the care that is needed to address

their symptoms, contain their pain, maintain their comfort and allow them to die a dignified, natural death in their desired location of care.

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Ontario needs legislation that provides the infrastructure and necessary resources to implement the key priorities already outlined in the Framework on Palliative Care in Canada. The following two priorities are essential from our perspective: The first is to ensure that all health care professionals and caregivers receive education and training on palliative care; and the second is to ensure that all palliative care programs across the province collect and report using standardized, patient-reported outcomes to measure quality improvements in palliative care provision, which can then be evaluated and compared nationally. Together, this will allow equitable access to palliative care so all Ontarians can be assured of quality palliative care from appropriately trained individuals where and when they want it.

Delivery of palliative care is a shared responsibility among all health care professionals within all fields of medicine, as described in the Ontario Palliative Care Network's Health Services Delivery Framework. Most suffering due to serious illness can be relieved with support through primary palliative care services, with basic palliative care training and access to specialist palliative care when needed. Specialist palliative care teams provide care for those with the most complex palliative care needs and also mentor and provide education to support capacity-building for a palliative approach to care for all care providers.

As the Canadian Society of Palliative Care Physicians, our expertise focuses on physician education. However, education and competencies in palliative care are needed across all health care disciplines, as outlined in the Ontario Palliative Care Competency Framework and the soon-to-be-released Health Canada competency framework.

Specialized training in palliative medicine has been evolving since the 1970s in Canada, when it was first founded by Dr. Balfour Mount at McGill and Ontario pioneer Dr. Elizabeth Latimer. As of 2017, there are now two certification routes for recognition of specialist physician expertise: the Royal College of Physicians and Surgeons of Canada subspecialty in palliative medicine and the College of Family Physicians of Canada certificate of added competence. It is essential that these minimum standards for credentialing physicians providing specialist palliative care be recognized by the provincial ministries of health, with appropriate specialist billing codes for consultant-level work. This is currently not the case in Ontario. This is an essential step that should be included in the foundational work of the Ontario palliative care framework, in its implementation through Bill 3. Recognition of specialist physicians in palliative care is necessary to support workforce planning for Ontario, including the number of specialists needed and the number of funded training positions for palliative care residency programs. Specialist billing codes can also be used to

better track provision of specialist palliative care expertise at a population level.

Physicians working part-time or full-time in palliative care comprise about 0.28% of all Canadian doctors, compared to 0.52% of doctors in the US and 0.38% in Australia. More concerning is that only 25% to 30% of practising physicians in Canada feel comfortable providing any type of palliative care. We need provincial funding to increase the numbers of doctors being trained annually in specialist palliative care, to grow and educate our workforce, planned according to population need.

An increased palliative care physician workforce is also needed to appropriately train and provide clinical training opportunities for all undergraduate and postgraduate medical and other health care students to develop minimum competencies in providing a palliative approach to care. Together, these will ensure Ontarians have access to appropriate palliative care service where and when they need it. The funding needed for these positions would be offset by the savings in health care delivery.

In summary: Ontario residents must have consistent universal access to high-quality palliative care that they can obtain where and when they need it, regardless of postal code, diagnosis, income level or location.

Ontario needs to implement nationally-agreed-to standards and core competencies for health care professionals in primary- and specialist-level palliative care—

The Chair (Ms. Goldie Ghamari): One minute left.

Dr. Leonie Herx:—including dedicated funding for palliative care residency training programs and an increased number of positions to meet the population need.

The provincial government must recognize minimum standards for credentialing in specialist palliative care with appropriate specialist billing codes.

Quality standards need to be evaluated for improvements in care through the use of patient-reported outcomes that are consistently measured across all provinces, so that patients and families receive superior and consistent experiences, while every health care provider is empowered to ensure seamless, quality palliative care throughout a patient's journey. Thank you.

The Chair (Ms. Goldie Ghamari): Thank you very much.

At this time, we are going to turn to our first round of questioning. We'll begin with the government side for five and a half minutes. MPP Kusendova, you may begin.

Ms. Natalia Kusendova: Thank you to all of our presenters today.

My first question is to Hospice Niagara. You said that hospice care saves health care dollars, and I couldn't agree more with you. This is an important aspect, but it's not the most important, I would say.

You also said that the appropriate level of palliative care beds should be seven to 10 per 100,000 citizens. Citizens will continue to die in hallways in hospitals unless we start investing in palliative care. So for a city of my size, which is 800,000 people, we should have 56 to 80 hospice residential beds. We currently have none. I'm very proud that our government is supporting the building and

construction of 10 residential beds in my city of Mississauga, but the fact that we are in 2020 and we have zero, I think, speaks to the decades of neglect by previous administrations.

I believe, and I think you believe, based on your discourse today, that Ontarians deserve a better strategy that's not as patchwork for end-of-life care. An integrated approach is needed to improve quality of life.

In your view, what are some of the elements that would be necessary in a palliative care strategy in order to achieve that?

Ms. Carol Nagy: Thank you very much for that question.

We need an integrated strategy. It's not just about bricks-and-mortar, and it's not just about hospice beds. Yes, we should aim for that—and actually, it should be updated—criteria of beds. That was what the Auditor General recommended in 2014. But as we increase community palliative care and provide more education, as has already been said, to family physicians, and provide the appropriate billing codes—family physicians have to have an incentive in order to provide palliative care, which doesn't happen 9 to 5. We need after-hours care. We need consultations that are available from the specialty teams. We need to build in-home care supports and make them accessible. Right now, it is such a confusing system for families that are at end of life. They don't know who to call. They often have to go through two or three different providers in order to get palliative care at home.

We also need to strengthen what people understand as palliative care—that it's not at the last few hours of life or the last day; it is from the time of diagnosis, in order to help manage symptoms.

So it's a whole integrated approach that needs to be looked at. It's not ever going to be one strategy or strengthening one area. It really is saying that all of it is a priority—and how do we grow it, and how do we take what already exists and make it better in the system?

Ms. Natalia Kusendova: My next question is for Cardinal Collins.

Your Eminence, it's always great to see you.

To be clear, Ontario is investing over \$36 million in capital funding to build more than 200 residential hospice beds across the province over the next three years. This will increase the availability of these beds to 622 approved hospice beds at 103 sites across the province.

Your Eminence, you spoke of the fact that only about 30% of Canadians have access to palliative care. And I share some of your concerns with regard to conscience protection for physicians and nurses like me when it comes to medical assistance in dying. Bill 3 is an important start, but we recognize that there is much more work to do.

How would you suggest we guide future investments in this area?

Cardinal Thomas Collins: Well, I think it's very important to have future investment in this area. The actual way in which it should be spent is something that I'm not really capable of giving you wise advice on. But I do think that, certainly, particularly groups that are involved close

to the ground, the neighbourhood people in the different towns and things like that, private groups, not-for-profit groups—these people all need a lot of help.

The Chair (Ms. Goldie Ghamari): One minute left.

Cardinal Thomas Collins: It was mentioned that there's only one place—I think it was Prince Edward Island—where they give you 100% funding for this type of help. I think anything that would go in that direction would be good.

I think the conscience protection is very important. We don't really have that in legislative form. We have some regulations, but regulations are not always that permanent or that effective. So I'm really concerned that nurses, doctors, medical students, as they're going through their medical training, are very often put under considerable pressure, and I find that is very, very difficult. It does come up, certainly, in connection to palliative care, as well. We need legislative assistance to protect conscience in our province.

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Ms. Natalia Kusendova: Thank you, Your Eminence.

The Chair (Ms. Goldie Ghamari): Seven seconds.

Ms. Natalia Kusendova: Thank you.

The Chair (Ms. Goldie Ghamari): I'll now turn to the official opposition for five and a half minutes. You may begin.

M^{me} France Gélinas: Thank you to Hospice Niagara, Archbishop Collins and the Canadian Society of Palliative Care Physicians for coming at this late hour. It's very much appreciated.

My first question will be to you, Ms. Nagy, as to how much of your operating budget is coming from the government and how much of it you have to fundraise.

Ms. Carol Nagy: Thank you for that question.

Right now, it's an ever-increasing number. We have to fundraise 50% of our budget, which is \$1.8 million every single year. The concerning part about that is that now the salaries that are in that fundraised portion are frightening. You can't put 60% of a salary in fundraised dollars, because how do you run a business? How do you make sure that that is a sustainable income source, as you're providing a way of life to a professional or to a person in Ontario? So that's what's becoming ever more concerning from our perspective—the amount of salary dollars that is in that fundraising amount.

M^{me} France Gélinas: So are you able to guarantee a full-time job when you cannot guarantee that you will have the money to pay them?

Ms. Carol Nagy: Here's what happens: We have to guarantee the jobs, because the need for our services continues to grow by 45% every single year. I don't know about other people, but having to say no and explain to over 300 and up to 400 families every year why they can't come to hospice, or to look my workers in the eyes and say, "I'm sorry. There's a wait-list. We have to start a wait-list in our counselling services"—it's just horrific. We have to raise it.

What happens is, we put off expenses for our buildings. We go with windows that have a break in them from an

accident for an extra period of time. We don't replace the beds. We continue to fix them until they're dangerous for staff. Right now, I'm borrowing a bed because we have to wait to raise the money in order to put a new bed in.

We use volunteers, of course, but we're asking our volunteers to do more and more care in order to help us out, so that we can continue to meet the growing need in our community. It's fantastic that we have that volunteer pool, but that's not the way to provide health care.

M^{me} France Gélinas: I fully agree with you. It seems like the amounts are so small. Don't get me wrong; I wouldn't want to pay \$1.8 million myself—it wouldn't happen—but \$1.8 million, when they have a budget of \$64 billion, and yet you're not able to make headway to get at least your full staff cost paid for?

Have you asked for more money? What was the answer?

Ms. Carol Nagy: We've advocated through HPCO, and then also with our local LHIN. It becomes a circular discussion where we can't increase the amount that we can be covered for our salaries unless we increase the amount of services, or it's net new. So we never can get out of that discussion where we can't get ahead without providing a net new service, but as soon as you provide a net new service you're again putting more salary dollars in the funding line. So it just continued to be this circular conversation, because governments and government entities were not prepared to increase funding to the base costs of providing hospice palliative care.

M^{me} France Gélinas: This is very sad.

You told us that 350 to 400 people were turned away from your services. Where did they end up? Do you follow through? Do you have an idea?

Ms. Carol Nagy: Most people would end up in hospital as a result of that—

The Chair (Ms. Goldie Ghamari): One minute left.

Ms. Carol Nagy: —and that's the heartbreaking part.

M^{me} France Gélinas: So they end up where they don't want to go, where it costs the taxpayers three times as much as if we had funded the hospice palliative care. None of this makes too much sense.

Ms. Carol Nagy: It doesn't make sense.

For example, according to provincial Ontario Health data, Niagara had the second-highest acute palliative care costs in this province—in 1997, that was \$118 billion in hospital acute palliative care. That is a system going the wrong way.

M^{me} France Gélinas: I fully agree.

The Chair (Ms. Goldie Ghamari): We will turn to the independent member for three and a half minutes. You may begin.

Mr. Mike Schreiner: I thank all three presenters for coming to committee, and especially this late in the day.

Cardinal Collins, it's always wonderful to have you at Queen's Park—especially somebody of your prominence and with such deep roots from Guelph.

I haven't had an opportunity just to give a quick shout-out to Pat Stuart and her team at Hospice Wellington for the wonderful work they do, as well.

Cardinal Collins, the story about your sister's experience with pancreatic cancer really resonated with me. My dad passed away from pancreatic cancer much too young. I was very fortunate that I was able to take two months off from work and spend them with him. End of life can be a very challenging but also a very beautiful and lovely experience.

I want to give you an opportunity to reflect on how important palliative care is—and especially those family connections, as part of the palliative care end-of-life process.

Cardinal Thomas Collins: Well, I think it is an important thing, and not everybody has the opportunity to have it. In fact, in the situation of my sister Patsy—Cathy and she lived together in an apartment. She was cared for, almost to the end, not in a hospice of any type, but in her own home, in my sisters' place. We took advantage of visiting nurses who would come in. Patsy would sometimes have to go out for various things, but people took care of her in her own home. When it got to the point of it just becoming more and more difficult—she was near the end—she went, basically, to the general hospital. In fact, she never did experience special hospice-type palliative care.

But I must say, I found the care they gave in the hospital was very, very compassionate, with the gentle way in which they would approach her—she was suffering quite a bit, because that can be very painful—and the way they would give her the different painkillers and things to help her as she was dying.

My other sister and I spent—well, as soon as I realized she was in the hospital, the two of us were with her from then on, pretty well, and it was very touching near the end.

The Chair (Ms. Goldie Ghamari): One minute left.

Mr. Mike Schreiner: I agree.

Carol, you talked about support for family caregivers, and that not every family member can provide the kind of support that Cardinal Collins and I provided our loved ones. Can you talk about how we could support family caregivers?

Ms. Carol Nagy: Thank you for the question.

We need to provide upstream support for family caregivers. I think part of it is public awareness of what services are available and how palliative care can help earlier in the illness trajectory, as well as preparing them to be caregivers. Being diagnosed and finding out that your loved one is dying is a life-turning event, and often, people don't even understand what's being told to them. So we need to be along there with our supports, with education on how to manage the health care and navigate the health care system on different illnesses, how to access primary care, what questions to ask your primary care provider, when does it look like things are not going to go well—

The Chair (Ms. Goldie Ghamari): Thank you very much. Sorry; I have to cut you off there.

We'll now turn to the government. MPP Kusendova, five and a half minutes. You may begin.

Ms. Natalia Kusendova: My question is for the Canadian Association of Palliative Care Physicians.

Dr. Herx, you spoke a lot about the education and training of health care providers, and you spoke about standards that should be based on patient outcomes and that there should be a framework that is based on minimum competencies for health care providers. Can you describe what such a framework would look like?

Dr. Leonie Herx: Actually, we already have a framework that the Ontario Palliative Care Network has developed that applies to different disciplines: nursing, social work, spiritual care, volunteers, physicians.

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Importantly, there are two levels of competencies that need to be built into training programs, and then also for people in practice who didn't have the ability to train when that was available. Every clinician, every person who works in health care, including volunteers, should have training on basic approaches to palliative care: how to have an advance care planning conversation, how to talk about what your goals and wishes are, what's important to you, basic symptom management, how to understand your illness. All those things are really important to improving a person's ability to make the best decisions for themselves.

There's also another level of specialty competencies for people who are experts in palliative care, for more complex situations. Those people, as I mentioned earlier, build the capacity and maintain the capacity for other people to do that good work for their own patients. That's why we need those two levels.

The national palliative care framework that Health Canada is putting out, a standard set across all disciplines, will be coming out soon—but they've really studied the Ontario Palliative Care Network's framework, as well.

I think the point of this is that we know what to do, but now this framework in Ontario needs the resources to implement it. We need to make sure that those people who are becoming nurses and doctors and social workers have those competencies held accountable, so that when they graduate from their programs, they have those core skills. That's the part that we're not seeing right now in Ontario.

Ms. Natalia Kusendova: I'd like to pass it on to my colleague MPP Wai.

Mrs. Daisy Wai: I want to, first of all, thank the presenters for staying here and sharing so many great experiences with passion. It's really touching.

I think we all agree that the key goal for palliative care should be to ensure that people are treated with dignity and respect—and have access to meaningful support for the individuals and their families, as part of the end of their journey. I would like to know, how does this bill help us to achieve this goal—so that we can make this bill achieve what you're coming in here for and asking us to modify?

Ms. Carol Nagy: First of all, it has to include all aspects of hospice palliative care. It shouldn't focus or put a priority on any one area.

As well, it has to create a pathway, which is often what we call a pathway to care—but a pathway to equitable funding. We've done wonderful things in the field—Ontario Palliative Care Network, HPCO, every single organization. But the time has come that we need funding

support to continue to provide these services and move them into the future.

Mrs. Daisy Wai: I hear you.

Any other comments from the other presenters?

Cardinal Thomas Collins: I agree exactly with what she was saying. The funding is very, very important.

The bill is very good, but a lot could be put in.

The Chair (Ms. Goldie Ghamari): One minute left.

Cardinal Thomas Collins: It's rather brief.

I think issues relating to funding would be very important—and also some ways in which it might provide how different groups, for example non-profits and groups like that, would be able to be helped by it. But that's the key point.

Dr. Leonie Herx: I'll just add that I agree with everything that Carol and Cardinal Collins have said—

The Chair (Ms. Goldie Ghamari): You have 30 seconds.

Dr. Leonie Herx: Okay.

Really, we know what needs to be done. We've studied this for a long time. Great work has been done by The Way Forward and by all our national and provincial organizations. We need the money and the accountability to make sure that it's happening and that we're moving in the right direction. So it's the infrastructure, but also the accountability that standards are upheld.

The Chair (Ms. Goldie Ghamari): At this time, we'll turn to the official opposition. You have five and a half minutes. You may begin.

M^{me} France Gélinas: I will ask the same questions to all three presenters, and I'll take them in the order that you presented.

There's so much goodwill. There's so much knowledge. There's so much that has already been done. There's unanimous support among the MPPs to move forward with palliative care. We all want better access. We all want it to be funded. Yet it seems like—the archbishop said it best—there is no political will to make this a priority.

My question to each of you is, do you really think that this framework will be the way to make it a political priority to fund palliative care so everybody has access? If not, how else would you like to light a big fire so we move forward?

I'll start with you, Carol.

Ms. Carol Nagy: That's a great question.

We've never tried this before, so I think this is a step in the right direction. I think with the additions that are needed in this act—and I would look to our Canadian and provincial organizations to suggest those changes. What's needed, I think—for so long, dying and death have been an afterthought. It has been something that we don't talk about. I think that time has changed. I think that people in our communities will mobilize behind hospices. I've been speaking to many of my municipal and regional governments lately, and they are mobilized. They are prepared to start to get behind hospices and say, "We need better funding, because this has to exist not only because of our

aging demographic but because more people are living longer with life-limiting illnesses." So the time is now.

M^{me} France Gélinas: Cardinal Collins?

Cardinal Thomas Collins: I would agree with that very much. The bill is a good start—and it must be said that it's a framework; we need that. That's a start. I think we could add in a lot of things that people who are experts in the field say should be there, especially the funding—some reference to that—and accountability.

There's an old saying—I think it was a Prime Minister in England in the 19th century who said, "It's the horse, not the harness, that drags the coach along." The best structure is not going to do anything unless you have someone who will actually do it. I'm afraid that this is what happens: We get a beautiful structure, and unless we have people actually willing to keep at it, as the people engaged in the work are doing, it just stalls.

I think what we need to do is to keep up that pressure and encouragement to the political leadership and any others in government to make sure that it doesn't just sit there—a beautiful bill that doesn't have any oomph to it. We've got to get moving on that. Our role is to keep encouraging people do that.

M^{me} France Gélinas: Dr. Herx?

Dr. Leonie Herx: I definitely agree with everything that Carol and Cardinal Collins have said.

I think that we need workforce planning and we need resources for boots on the ground, and we need those competencies embedded and we need the people with training and skills now. We have a lot of need to keep people in-community. That's where people want to be. Unfortunately, we don't have a skilled workforce out there in palliative care.

I can speak for my own LHIN. We don't pay people well to work in the community. The turnover is very high. We end up with people who don't have palliative care skills and don't know how to respond. People end up in hospital—they can't stay at home if that's where they want to be, or they can't get into hospice if that's where they want to be—because we don't have the resources.

We need a properly planned workforce that has the skills. There needs to be funding to get people who are currently working trained to have minimum standards for palliative care. Of course, I'm interested in doctors. We need more doctors to be able to do the work and build the capacity. We do not have enough residency training positions for palliative care in Ontario.

The Chair (Ms. Goldie Ghamari): One minute left.

Dr. Leonie Herx: The Ministry of Health needs to fund those so that we can work on program development in each of our regions in Ontario.

M^{me} France Gélinas: Just a quick yes-or-no, if you're able: Would you say that some of the investment could be made now? We don't have to wait for a framework. For some of this stuff, we already know it needs money and should be funded while we develop the framework. Do I get a yes from all three?

Interjections.

M^{me} France Gélinas: I get a yes from all three. Thank you very much.

The Chair (Ms. Goldie Ghamari): At this time, we'll turn to the independent Green Party member for the final round of three and a half minutes. You may begin.

Mr. Mike Schreiner: Hopefully, we are creating lots of horses to pull this beautiful carriage forward. I agree: Let's hope we can get it moving before we even have a framework in place.

Dr. Herx, you brought up accountability. Can you elaborate a bit more on what type of accountability mechanisms you think we need around standards?

Dr. Leonie Herx: The provincial associations that are responsible for maintaining standards for nursing, social work, physicians—they have built into their ongoing professional development requirements a minimum of educational resources that have to be completed each year, so that people have certain levels of competency in palliative care. In order to renew your privileges, say, for example, at a hospital, or to renew your professional membership, you have to show that you've done so much training in palliative care and meet that standard. That's one important thing.

The other, I think, is in looking at quality indicators for programs, so that they can show—we have a good dashboard with the Ontario Palliative Care Network, but we need to have more accountability for where funding is going; and that people are held to that, that they're reducing the number of emergency room visits and they're keeping people out of hospital and getting more people into hospice. Funding should be held accountable to meeting those measures so there is incentive to improve the quality of care that's provided, especially for community palliative care.

Mr. Mike Schreiner: You also talked about equitable access to palliative care, especially for the most vulnerable in our society and folks who sometimes are on the margins of our society.

Can you talk about some ways that we can break down some of those barriers, to ensure that there is equitable access for everyone in our society?

Dr. Leonie Herx: I'm sure Carol has some wise words of wisdom here, as well. It would be good to hear her perspective.

The Chair (Ms. Goldie Ghamari): One minute left.

Dr. Leonie Herx: I think we have to go to those communities. We need to be talking to Indigenous Ontarians and people who are vulnerably housed, and working with them on what they see as the solutions. It's not reasonable for us to say, "This is how it's going to work."

That's one of the things I'm trying to do with the prison system right now. Obviously, we have lots of federal penitentiaries in Kingston—so we're working with, what are the local resources, what are their needs? It has to be very needs-based, but for that unique person.

Ms. Carol Nagy: Yes, I completely agree. For example, we are working to have an Indigenous-informed palliative care approach in our community in Niagara, and they are informing it and they are driving the change—and it's not one that's different; it's embedded in the practice for everybody to do going forward. That's what we need to do—not separate approaches. This is the one approach that meets the cultural differences and the safety requirements for everybody who needs palliative care.

The Chair (Ms. Goldie Ghamari): This concludes this final round of questioning.

I'd like to thank the presenters for joining us here today. It was very informative. Our apologies for the delay; it sometimes happens with the procedure. You may step down.

I want to thank committee members for their co-operation in ensuring a smooth hearing today.

Just a quick reminder that written submissions are due tomorrow at 7 p.m.

At this point, we'll adjourn for the day and resume tomorrow morning at 9 a.m.

The committee adjourned at 1814.

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