

# Long-Term Care COVID-19 Commission Meeting

Bilingual Group Meeting with Commissioner and  
Families/Loved Ones  
on Tuesday, February 9, 2021



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| 6  | MEETING OF THE LONG-TERM CARE                   |
| 7  | COVID-19 COMMISSION                             |
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| 15 | --- Held via Zoom Videoconferencing, with all   |
| 16 | participants attending remotely, on the 9th day |
| 17 | of February, 2021, 4:00 p.m. to 6:00 p.m.       |
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| 23 |   |
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1 BEFORE:

2 Frank N. Marrocco, Lead Commissioner

3 Dr. Jack Kitts, Commissioner

4 Angela Coke, Commissioner

5

6 MEETING WITH THE LONG-TERM CARE COVID-19

7 COMMISSIONERS, FAMILY MEMBERS AND LOVED ONES OF

8 LONG-TERM CARE RESIDENTS.

9

10

11 PARTICIPANTS:

12 Dawn Palin Rokosh, Director, Operations

13 Long-Term Care Commission Secretariat

14 Alain Daoust, Team Lead Long-Term Care

15 Commission Secretariat

16 Adriana Diaz Choconta, Senior Policy Analyst

17 Long-Term Care Commission

18 Angeline Hawthorn, Senior Policy Analyst

19

20 ALSO PRESENT:

21 Tiffany Fearon, Family Councils Ontario

22 Helen Martineau, Stenographer/Transcriptionist

23 NB Interpreter

24 L. Cote Interpreter

25

1 --- Upon commencing at 4:17 p.m.

2 DAWN PALIN ROKOSH: Good afternoon  
3 everyone. I believe we are ready to start. And  
4 I apologize for joining slightly late, I was  
5 having my own set of technical difficulties.

6 Has everyone had an opportunity to  
7 select the interpretation that they would like?

8 At the bottom of your screen there is  
9 a button for interpretation and you can select  
10 the interpretation that you like. And once you  
11 click the button then there's English and French  
12 there and you can select the language that you  
13 would like.

14 If you are comfortable -- there will  
15 be discussion in both English and in French  
16 today and everything will be happening  
17 simultaneously. So if you're completely  
18 comfortable operating in both languages then you  
19 can leave the interpretation off.

20 PARTICIPANT 3: So if someone is  
21 speaking French and my French isn't that great I  
22 should hit the "French" button?

23 DAWN PALIN ROKOSH: You should hit the  
24 "English" button.

25 PARTICIPANT 3: The "English", okay.

1                   DAWN PALIN ROKOSH: If you hit the  
2 "English" button then everything you will hear  
3 throughout the meeting will be in English; and  
4 if you hit the "French" button everything you  
5 will hear throughout the meeting will be in  
6 French.

7                   Alain, could you please repeat that in  
8 French, just very quickly? The instructions for  
9 interpretation.

10                  ALAIN DAOUST: Yes, absolutely. So  
11 for those who wish to receive simultaneous  
12 interpretation services in French you will find  
13 an "Interpretation" button at the bottom of your  
14 Zoom screen. If you wish to hear simultaneous  
15 interpretation in French just select "French".  
16 That's it.

17                  If you're comfortable in both  
18 languages and you wish to hear the participants  
19 directly, either in French or English, without  
20 simultaneous interpretation you don't need to  
21 click on anything at all, you'll get the  
22 original. But if you want French translation  
23 just click "Interpretation" and "French".

24                  DAWN PALIN ROKOSH: Is everyone  
25 feeling okay with the -- any further questions

1 on the interpretation buttons? Okay.  
2 Wonderful.

3 Well, then let's begin our  
4 proceedings. And let me start by saying hello  
5 and good afternoon, and welcome to this  
6 bilingual group meeting with the Long-Term Care  
7 COVID-19 Commission, and family members and  
8 loved ones of long-term care residents from  
9 different areas across Ontario.

10 My name is Dawn Palin Rokosh and I'm a  
11 Director with the Secretariat that supports the  
12 Commission; and I'm joined this afternoon by my  
13 co-facilitator, Alain Daoust, who is a Team Lead  
14 with the Commission; as well as the following  
15 team members, Angeline Hawthorn, who you would  
16 have heard her voice a little bit earlier; and  
17 Adriana Diaz Choconta, who you would have met  
18 when you were entering the session today. Both  
19 Adriana and Angeline are Senior Policy Advisors  
20 for the Commission.

21 ALAIN DAOUST: So this is a bilingual  
22 meeting where both French and English-speaking  
23 participants can express themselves in either  
24 language. Simultaneous interpretation is  
25 provided and participants have the option, at

1 the bottom of the Zoom screen, to participate in  
2 either French or English.

3 Dawn will speak primarily in English,  
4 I will speak primarily in French and  
5 participants can hear us in the language of  
6 their choice.

7 As you perhaps know, the Commission is  
8 led by three Commissioners, who are with us this  
9 afternoon. Dr. Jack Kitts, who is the Chief  
10 Commissioner for today's meeting, and he is with  
11 Chief Commissioner Mr. Frank Marrocco and  
12 Commissioner Mrs. Angela Coke.

13 I would like to acknowledge and thank  
14 Tiffany Fearon, from the Family Councils Ontario  
15 who assisted in sharing and identifying  
16 participants for this meeting today.

17 So today's session is being held over  
18 Zoom. And as we said earlier, if you have any  
19 connection problems throughout the meeting you  
20 can simply join back into the meeting at any  
21 time. And if anyone has technical issues during  
22 the meeting please communicate with Angeline  
23 Hawthorn by email, and you chatted with her just  
24 ahead of the meeting.

25 Moreover, if you are comfortable

1 turning your camera on please feel free to do  
2 so. This session will not be video recorded.  
3 If you would prefer to stay off camera then that  
4 is fine as well.

5 DAWN PALIN ROKOSH: This session is  
6 being taken by our court reporter who is present  
7 on the call. The transcripts will be posted to  
8 our website but your names will not appear in  
9 the transcript. When you are speaking you will  
10 be recorded in the transcript as "Participant  
11 1", for instance.

12 If you wish to refer to another person  
13 during the course of the session please refer to  
14 them by their anonymized participant number,  
15 which is displayed on the screen.

16 So although we have ensured that you  
17 are anonymous, both in our outreach as well as  
18 with your participation here today, the  
19 information you choose to share will be posted  
20 to the website. So please be aware of any  
21 identifiable stories that could reveal your  
22 identity, if that's a concern for you.

23 We'll begin the session with some  
24 introductory remarks in a moment from  
25 Commissioner Dr. Jack Kitts and then we'll

1 proceed to question 1. We'll hear responses  
2 from participants in numerical order asking  
3 Participant 1 to respond first and working our  
4 way through the list of participants. We will  
5 repeat the same process for question 2. And  
6 once we finish hearing from all participants  
7 today we will have some concluding remarks and  
8 then we'll wrap up our session.

9 In order to hear from all of you on  
10 both questions we've asked you each to speak for  
11 up to four minutes, about four minutes in  
12 response to each of the two questions.

13 We've also acknowledged, and we've  
14 discussed in our introductory conversations with  
15 you, that we acknowledge that you've been  
16 through a great deal and four minutes may feel  
17 insufficient to share your experiences and  
18 considerations related to recommendations for  
19 improving things in the future.

20 So we encourage you to focus first on  
21 conveying to the Commissioners the most  
22 important things you want them to know about  
23 your experience.

24 If there's something you weren't able  
25 to cover in your first speaking time you'll have

1 an opportunity to cover it in the second  
2 question.

3 So right now I'd like to invite  
4 Commissioner Dr. Kitts to address the group.  
5 Dr. Kitts.

6 COMMISSIONER JACK KITTS: Thank you,  
7 Dawn and good afternoon everyone.

8  
9 [Small portion in French not translated.]

10  
11 Thank you all for meeting with us  
12 today. As you've heard my name is Jack Kitts  
13 and I'm one of three Commissioners appointed by  
14 the provincial government. My colleagues, which  
15 you've been introduced to, Commissioner Frank  
16 Marrocco and Commissioner Angela Coke, are with  
17 us today.

18 As you are no not doubt aware, this  
19 Commission was set up to investigate the spread  
20 of COVID-19 in long-term care homes and the  
21 impact it has had on families, residents and  
22 staff.

23 But before we begin I want to provide  
24 a bit on context about Commissions in general  
25 and our Commission specifically. Governments

1 will often set up Commissions of Inquiry after a  
2 tragic event has occurred. The purpose of a  
3 Commission is to investigate why the tragedy  
4 occurred and to make recommendations on how to  
5 prevent it from happening again.

6 Most Commissions begin their  
7 investigation after the tragedy is over. In our  
8 case we are conducting our investigation as the  
9 crisis continues to unfold.

10 Our final report and recommendations  
11 will be submitted to government at the end of  
12 April this year. However, we have already  
13 submitted two interim letters of recommendations  
14 to government because we believe they will help  
15 manage this second wave as it continues to  
16 unfold.

17 Our Commission is independent of  
18 government. Our role is to report our findings  
19 and recommendations. The decision, however, to  
20 accept and implement the recommendations is that  
21 of government.

22 As I stated earlier, an important part  
23 of our investigation is to learn how residents,  
24 staff and family members have been impacted by  
25 the spread of COVID-19 in long-term care homes.

1 So today we are asking you, as family members,  
2 to help us understand the impact COVID-19 has  
3 had on you personally and tell us what you would  
4 recommend to prevent this tragedy in the future.

5 We understand that many of you may be  
6 a little nervous about participating in this  
7 meeting but we want you to know that we truly  
8 appreciate your courage in taking time to help  
9 us with this very important task.

10 Our hope is that the work of our  
11 Commission will help ensure that such a tragedy  
12 is never repeated. And we believe that by  
13 sharing your stories you will help the public  
14 and government understand why it is so important  
15 that this never, ever happens again.

16 Now, before we begin I'd like to ask  
17 you to join me in observing a moment of silence  
18 in memory of those residents and staff of  
19 long-term care homes who have lost their lives  
20 to COVID-19.

21

22 [Moment of silence observed.]

23

24 COMMISSIONER JACK KITTS: Thank you.

25 I will turn it back to your facilitators, Dawn

1 and Alain, to continue the meeting.

2 DAWN PALIN ROKOSH: Thank you very  
3 much, Commissioner Kitts.

4 So we'll start now with the first  
5 question. And the first question is:

6 Please tell us about your experience  
7 caring for a loved one in a long-term care home  
8 during the pandemic. How has the pandemic  
9 impacted you and your loved one or family  
10 member? Is there anything in particular that  
11 concerns you?

12 And I would like to call on  
13 Participant 1 please to start us off.

14 PARTICIPANT 1: Okay. First, my  
15 husband is sitting here with me, Carl, and we'd  
16 like to thank you for hosting this meeting and  
17 allowing us to voice our concerns.

18 It is mostly about emotion. It's been  
19 very taxing having mom in a home during the  
20 COVID time and at the same time we had to move;  
21 and again, the move was caused from COVID. The  
22 sale of our home during COVID and the closing of  
23 our bed and breakfast. So everything was  
24 happening at once.

25 And we felt that it was not in her

1 best interest to move homes, for her to -- to  
2 bring her down here with us. She didn't adjust  
3 well in going from one section of the home to  
4 the lockdown section so a whole home move would  
5 have been worse. Plus Bancroft has almost zero  
6 incidents -- has zero incidents actually and  
7 bringing her down here, even though there were  
8 just fewer, it just didn't make sense.

9 But we committed to regular visits to  
10 the home but they were so restrictive. Only  
11 certain hours, only certain days and only for 45  
12 minutes. Well, one hour but by the time you got  
13 gowned and signed in and then said your goodbyes  
14 it was only 45 minutes. And we had to drive  
15 three hours each way for this 45-minute visit.  
16 And you couldn't go day after day. Like, it was  
17 like, okay, this is your time this week.

18 And so we had hoped that we could go  
19 up for several days and have several visits but  
20 you couldn't because they didn't visit -- you  
21 couldn't go in on Thursdays and you couldn't go  
22 in on Saturdays. So, I mean, it was just so  
23 frustrating.

24 And often in asking for these times  
25 they would say, No, we don't have -- we don't

1 have any time. Well, I'm a fairly strong  
2 individual so I would stand my ground and say, I  
3 am coming on Thursday and you'd better find a  
4 time for us.

5 So at this time we were just doing --  
6 we were doing the visits and we were not aware  
7 of being able to be essential caregivers.

8 But I have to say that it was  
9 exhausting going through the process each and  
10 every time. We did try to combine it with other  
11 tasks that we had in the area so that it made  
12 the three-hour drive sort of one day we would do  
13 our tasks and the other day we would visit mom.  
14 But it was exhausting trying to get a meeting.

15 And when -- I would always say, like,  
16 you've got to open it up. You've got to allow  
17 us in. And they would say, Well, we're lack of  
18 staff. They would say, Call your MP. Which I  
19 did but nothing happened.

20 But then we were made aware of being  
21 able to become an essential caregiver, but this  
22 brought on more limitations. Only one person at  
23 a time, and this was even worse.

24 So I am a good communicator. My late  
25 husband was deaf and I learned to communicate

1 through sign -- not signing but, you know,  
2 through -- he could lip read me and I would -- I  
3 learned how to give distinct words for certain  
4 things and how to repeat. So getting through to  
5 mom was very good for me. But Carl has a very  
6 deep, low voice and mom can't understand him.  
7 So together I could keep a conversation going  
8 and I would repeat things, and she would start  
9 to get the gist of what he was talking about.

10 We had hearing aids but she keeps  
11 losing them and the home didn't care for them so  
12 we basically had to give up on that.

13 But with all the gowning -- so you put  
14 on a gown, you put on a mask, you put on a  
15 shield. We'd come in with these Haz-mat suits  
16 and she'd -- who are you? There was nothing to  
17 recognize.

18 And this week when I went in I  
19 immediately took her hands, and the head of  
20 nursing was there and she just about had a fit  
21 and said I had to go through all this getting  
22 degowned and getting into something else because  
23 I was touching her. Well, I call her my mom.  
24 She's my mom of course I'm going to touch her.  
25 I'm not going to sit on the other side of the

1 room.

2 But -- so now we have to have one day  
3 is for me to visit and I look after her hair and  
4 nails and pretty her up and tell her she's  
5 beautiful. The next day Carl goes in and  
6 there's no communication. She doesn't recognize  
7 him because he's so gowned. And she doesn't --  
8 she can't understand him and I'm not there to  
9 interpret.

10 I don't understand why two people  
11 can't be there. So I asked, Can one day I go in  
12 to the home and do all the things and the next  
13 day we have a visit in one of those other rooms  
14 for Carl and I so that it's more family? No,  
15 you can't do that.

16 You can only have two essential  
17 caregivers. And because we don't live there we  
18 wanted to assign -- we wanted to assign a local  
19 person who knew her well, actually lived with  
20 us, and have her go in and visit and then Carl  
21 and I come in. No, you have to give up.

22 Well, I'm the one she can communicate  
23 with but Carl's her son and she loves him. And  
24 one day when I went in it's -- it was all about  
25 Carl, all about Carl, all about Carl. The next

1 day he goes in and she doesn't even recognize  
2 him.

3           The isolation has been terrible. And  
4 we've watched mom go from a participant to just  
5 about a vegetable. She just sits and stares.  
6 We used to be able to get her engaged in talking  
7 about when she worked at Heinz. And she'd  
8 always go on with lots and lots of stories but  
9 we can't do it now.

10           We can't get a local caregiver. I'm  
11 the one who looks after things but Carl's all  
12 that she has. And having to go in with all this  
13 garb and be so isolated, and there are so many  
14 rules. It's all regimented.

15           We take -- we take precautions. We  
16 have our COVID test. And now they're going to  
17 come in with this 15-minute test? I don't  
18 understand how -- and why we can't just wear a  
19 mask so they can see our lips? Most seniors are  
20 hearing impaired. I mean, why can't we just  
21 wear a face shield? The hospitals gave them to  
22 us. The hospital accepted it. But there are so  
23 many rules and regulations.

24           And I just say that we have to open  
25 this up. We're constantly tested. We are safe.

1 We would never, ever put our loved ones in  
2 danger. It's -- we just can't handle the  
3 isolation, it's the isolation. That's all I  
4 have to say.

5 DAWN PALIN ROKOSH: Thank you so much,  
6 Participant 1, for sharing that experience.

7 I'll now move to Participant 2 to  
8 respond to question 1. Participant 2.

9 PARTICIPANT 2: All right. So in  
10 answering your questions I'm not answering just  
11 for myself but as well as for others, as I'm a  
12 co-chair for a Family Council. And I'm going to  
13 represent my family's experience as well as  
14 theirs.

15 With the abrupt closure to access in  
16 long-term care in March there was mass  
17 confusion, anger and panic, and then there was  
18 the guilt, the overwhelming sense that we had  
19 abandoned those who needed us most.

20 During the first wave my facility was  
21 COVID free but getting updates and information  
22 was really difficult. Opportunities for  
23 Facetime and window visits were distressing as  
24 many of the residents didn't understand what was  
25 happening, and for many these communication

1 options were a source of upset and tears on both  
2 sides, even though we conducted support rallies,  
3 ribbon tieing, pizza lunches, gift cards and  
4 more to support the staff.

5 In June when the government allowed  
6 essential caregivers access our home remained  
7 shut. They kept saying Public Health told them  
8 it was necessary, but there was no COVID or  
9 outbreak in the facility at the time. We  
10 reached out to the Inspector of Public Health  
11 for our facility, who was really displeased  
12 because it wasn't true. They hadn't said they  
13 weren't allowed to be open. Interestingly,  
14 within 24 hours we had access with guidelines.

15 Once access was provided we noted,  
16 with concern, the lack of mask wearing from the  
17 staff, and very few other protocols.

18 For many the change that had taken  
19 place with their loved ones was a very bitter  
20 pill to swallow. Declining physical and  
21 cognitive functions were vastly apparent, the  
22 feelings of relief were tainted with guilt and  
23 despair.

24 During the summer and fall months we  
25 had constant questions about COVID-19

1 preparedness in the second wave and what the  
2 back-up plans were. We were reassured during  
3 Family Council meetings that everything was  
4 under control and that should COVID ever occur  
5 we were prepared. That didn't happen.

6           When the December announcement came  
7 that COVID was in our facility the staff and  
8 agency staff didn't want to work; back-up agency  
9 staff were not COVID tested; and, therefore,  
10 units were critically short staffed for days.  
11 Most staff were completely untrained on droplet  
12 precaution protocols. Some were resistant to  
13 shields and donning and doffing protocols.  
14 There was panic, disorganization and distress  
15 from staff and residents and families.

16           Communication to families of  
17 COVID-positive residents was critically slow and  
18 families were frantic for updates on their loved  
19 ones. Communication to the entire facility was  
20 also slow and our Council pushed for better and  
21 faster communications; town halls were  
22 conducted. And after a huge outcry based on  
23 format and attitude changes had to be made.

24           The residents were confined to their  
25 room and there was neglect in regards to

1 feeding, toiletry and medication distribution.  
2 Diaper changes were slow to happen, sometimes  
3 over 12 hours between changes and very poorly  
4 done.

5 Staffing members did not take into  
6 account -- staffing numbers did not take into  
7 account the additional time required for donning  
8 and doffing PPE, which results in much slower  
9 response times. Residents are getting far less  
10 care, some are not provided with a bed or sponge  
11 bath for over a month.

12 When these issues were brought forward  
13 they seemed to be addressed, but why should  
14 Family Council have to address basic care needs?  
15 Where were the audits? No one seemed to know  
16 what was being done or not done in the home.

17 Everything was thrown out the window  
18 when COVID actually happened. They weren't  
19 prepared. All of our management was deployed to  
20 home unit areas to provide additional support,  
21 which left their own areas understaffed and  
22 underutilized.

23 Let it be said that many of our  
24 regular staff tried their best. They worked  
25 long hours without adequate support from their

1 head offices. Physiotherapy all but stopped,  
2 meaning residents who were mobile were no longer  
3 so. Recreational programs were suspended and  
4 there was little for residents to participant  
5 in, and cognitive decline has been significant.  
6 All of these shortcomings were arguably to save  
7 the lives of the residents. But it leaves one  
8 asking, if this new existence is not living then  
9 what is it? It's torture.

10 The residents are virtual prisoners in  
11 their rooms, and once they are dressed and  
12 toileted are left alone. We've been told that  
13 staffing is currently at 125 percent, but the  
14 agency staff are not trained, they have no  
15 commitment to the facility or the residents and  
16 the residents are suffering. Many are rough  
17 with the residents because they don't know how  
18 to manage them. As long as there is bodies in  
19 the building the care doesn't matter so much.

20 Staff who do try are exhausted,  
21 they're injured and they're in despair.  
22 Essential caregivers were considered a problem  
23 if they complained; they were treated as if they  
24 were the cause of the COVID outbreak, but it was  
25 actually the staff.

1           Our presence was problematic as we  
2 were the eyes and ears of what was happening in  
3 the facility, and there lies the problem. When  
4 you see a day ratio of 1 to 28 because of short  
5 staffing it's only a point because we saw it.  
6 Kind of like that old question, if a tree falls  
7 in the forest and there is no one there does it  
8 make a sound? There were sounds. Cries of  
9 distress.

10           In closing -- this part gets me. I  
11 reached out to our Chairman. In my letter I  
12 asked for a different perspective of long-term  
13 care moving forward, I did not even discuss a  
14 pandemic response. And I was thanked. I was  
15 told that all care standards are set by the  
16 government and long-term care companies can't do  
17 more. I was advised that management would get  
18 back to me, and they did. Our CEO actually said  
19 they were really pleased that they didn't  
20 require third-party intervention, even though  
21 thirteen people die, and that they didn't need  
22 the military or Red Cross.

23           And I said -- I'm thinking, if a CEO  
24 is comparing death toll and catastrophic  
25 failures as a standard to be measured against

1 I'm terrified there's no hope.

2 That's all I have to say.

3 DAWN PALIN ROKOSH: Thank you very  
4 much, Participant 2, for that. Thank you.

5 Participant 3, I would like to call on  
6 you now to answer question 1 please.

7 Can you make sure you're off mute?

8 Wonderful, thank you.

9 PARTICIPANT 3: Thank you. I do that  
10 all the time.

11 Thank you, Commissioners, for allowing  
12 me to speak on behalf of my wife and I.

13 And I want to speak to how our  
14 family's been impacted. And -- but I just don't  
15 want to focus on the idea of the pandemic, I  
16 want to really remind everyone that this started  
17 decades ago, years ago. And your work and your  
18 recommendations will carry weight.

19 Today I'm here as an essential family  
20 caregiver, and you'll notice I use the word  
21 "family" and there's a reason why and I'll  
22 explain it. Essential family caregivers and/or  
23 chosen family caregivers support long-term care  
24 by providing direct healthcare, emotional care,  
25 essential oversight for their loved ones.

1           Many in the medical profession will  
2 say openly, and quietly, that caregivers are  
3 indeed experts. And one example is the Ottawa  
4 Hospital, which now recognizes families and  
5 others who are trusted by a patient, i.e. a  
6 chosen family caregiver, as essential care  
7 partners. It just makes sense.

8           It took the military just to remind  
9 everyone to speak for residents. But not one  
10 single family caregiver, not one with lived  
11 experience was shocked. We went, Oh yeah,  
12 what's new? In other words, COVID-19 had  
13 nothing to do with the abuse that went on for  
14 decades, and it was abuse.

15           At the start I didn't understand why  
16 federal and provincial governments, and some in  
17 the LTC, or long-term care industry, refused to  
18 acknowledge the essential role of family and  
19 chosen family caregivers. Now I understand why.  
20 Simple. It's because they provide the  
21 much-needed oversight that has been lacking in  
22 long-term care. Period. They are far from just  
23 being a visitor.

24           Caregivers in fact ensure medications  
25 are properly dispensed, ensure that proper

1 hygiene and disinfection protocols are adhered  
2 to. They provide much-needed emotional,  
3 physical and spiritual support and beyond. I  
4 ask the Commissioners and everyone, does that  
5 sound like just a visitor?

6           The most conservative estimate today  
7 by the National Institute on Aging is that  
8 there's well over 8.1 million caregivers in  
9 Canada, more startling, 7.8 million caregivers  
10 have been doing it for more than a year. They  
11 contribute well over 25 billion a year.  
12 Caregivers are the largest unpaid, unrecognized  
13 un -- I guess less thankful force in Canada,  
14 period, work force. And yet rather than the  
15 industry welcoming them, and government, they  
16 are viewed as troublesome. The troublesome  
17 family. That's because -- again it goes back  
18 that they're the overseers. They report on what  
19 they see even when they're often afraid to do  
20 so.

21           I recall coming into the -- in the  
22 evenings after work, taking off my suit jacket  
23 to help change my mother-in-law while she was in  
24 bed. I would have thought that this would have  
25 made her feel or me feel uncomfortable, and at

1 first it did. But very soon after, later I  
2 realized she needed help. Don't we all?

3 What we do, each morning I go in to  
4 support my mom-in-law to help her with her  
5 nutritional needs. My bonus mom, I call her.  
6 She needs our help. We all do at some point in  
7 our lives, don't we?

8 It's a privilege to change her. It  
9 changed my life to care for her, I should say.  
10 It changed my life and it taught me more about  
11 myself than I would have ever known in all the  
12 work I've ever done.

13 My wife and I -- my wife then goes in  
14 for lunch and suppers staying there until she  
15 goes to bed. So she has some quality time with  
16 her mother and vice versa.

17 We spend collectively over 50 hours a  
18 week in direct care of my mother-in-law, and an  
19 additional 20 or so advocating, dealing with the  
20 Ministry, dealing with the administration,  
21 trying to work with them. Far from a visitor.

22 Impacts. So, yes, my wife and I have  
23 been impacted tremendously. I never thought it  
24 would be -- I would be an advocate for long-term  
25 care. I became one after witnessing first-hand

1 what my mother-in-law experienced when entering  
2 an LTC home. I was naive but my wife wasn't as  
3 she had cared for her father for many years.

4 I will say that in our particular case  
5 we have seen some improvements, but I speak for  
6 ourselves only.

7 Impact again. It costs us financially  
8 hundreds of thousands of dollars over the years  
9 easily. Careers lost, opportunities lost, my  
10 wife basically stopped her profession. And more  
11 importantly, I think we now suffer from a form  
12 of PTSD, believe it or not. I don't sleep at  
13 night. I wake up grinding my teeth to the point  
14 of my jaw locking and my shoulders aching. My  
15 wife as well grinding her teeth to the point  
16 that now she needs significant dental treatment.

17 So if you wonder if I see myself as a  
18 victim? No. If you're asking me if I'm angry?  
19 No. And that's because there was one thing one  
20 person taught me a long time ago, you can't be  
21 angry and smart at the same time.

22 So I want to get things done. I want  
23 to contribute to LTC and I want to see it as a  
24 welcome place to go and not a place to fear.

25 So retaliation? Yes. My wife and I

1 experienced intimidation and harassment in the  
2 past. All we can be accused of though is trying  
3 to do the best for my mother-in-law.

4 If it were not for my wife, for the  
5 most part, and the medical communities, some of  
6 which co-operated tremendously, my mom-in-law  
7 would have been dead, or in such horrific  
8 condition that the suffering would have been  
9 unbearable.

10 To answer part 2 of your question, my  
11 biggest concern is that Canadians want to go  
12 back to some sort of normal. But if normal  
13 means we go back to preCOVID normal then  
14 nothing's going to change. Caregivers will keep  
15 being harassed. And as a fellow caregiver I  
16 know, and others, now they are currently  
17 experiencing harassment, intimidation because  
18 they recently spoke to the media. That means  
19 residents will keep being mistreated and that is  
20 what keeps me up at night and wakes me up at  
21 3:00 every morning. I thought we lived in  
22 Canada not what we were witnessing south of the  
23 border.

24 DAWN PALIN ROKOSH: Participant 3,  
25 thank you so much for sharing that experience.

1 I'd now like to call on participant 4  
2 to respond to the first question. Participant  
3 4.

4 PARTICIPANT 4: Hello, first of all  
5 I'm going to talk about my experience with my  
6 family and my father.

7 My family is in a residence. In  
8 October and November and December there was an  
9 outbreak of COVID and there were 95 residents  
10 that were affected. And of the 95, 15 died and  
11 about 70 employees were also affected; but  
12 everything went well for the employees.

13 My father is 91 years old. He's  
14 blind. He cannot eat by himself. He has  
15 problems with his hands. He has arthritis. And  
16 if you want to add something further, icing on  
17 the cake, during the first week my father had to  
18 have an eye removed, because in the residence  
19 the frequency of him receiving medication  
20 required in order to be able to maintain his  
21 eyesight was not met.

22 In order for my father not to have any  
23 pain he had to have drops every hour. And  
24 sometimes he had to wait 15 minutes between each  
25 application of these drops. The family all of a

1 sudden had to be made aware that it was  
2 impossible for the staff -- in order for the  
3 staff to be able to provide these drops. So we  
4 decided to go ahead with the surgery because  
5 this was very painful. He was in extreme pain  
6 for a year.

7           So my father was supposed to have his  
8 eye removed on April 5th and he was not able to  
9 have the surgery. We were stuck in the COVID  
10 no-man's-land. The hospitals didn't know what  
11 to do. The residence didn't know what to do in  
12 April either so everything was delayed. So my  
13 father went from April, May, June, July alone  
14 and he had -- he was subjected to this pain in  
15 his eye. Then in August he was able to have the  
16 surgery.

17           I am on the Family Council and I  
18 haven't been very pro-active, or active in this  
19 council because the people on the council with  
20 me are people who are aged 80 years or older,  
21 usually it's the spouses of the people who are  
22 residents.

23           And at that time people weren't doing  
24 Zoom or Skype or anything. It's my view that  
25 currently the spouses are more able to have

1 electronic meetings but many of those people saw  
2 their spouses die.

3 And there is a trend within these  
4 councils, when there's a family member who has  
5 died then you abandon the council. You want to  
6 be able to move on, to think about other things.

7 My only contribution with respect to  
8 my role in the Family Council is that I learned  
9 that priests were not able to enter residences;  
10 and this began in March. And even during the  
11 COVID crisis priests were not allowed to go into  
12 the residences.

13 So I wrote to Minister Fullerton and I  
14 asked her to explain that; and to allow the  
15 priest to be on the same wave length as  
16 pharmacy, specialists, et cetera. But we were  
17 told that priests could not enter into these  
18 residences. So basically we were going around  
19 in circles.

20 During the pandemic my father had  
21 COVID. He's extremely healthy, apart from the  
22 fact that he's blind and that he cannot walk and  
23 he is in a wheelchair almost all day.

24 But during the pandemic I didn't like  
25 the communication with the residents. One nurse

1 that was not part of the regular staff, she was  
2 hired specifically for this purpose to  
3 communicate with families. And she would read,  
4 from her home, something that would say, Your  
5 father's medical condition hasn't changed since  
6 the beginning. That was one person who was not  
7 part of the residence's staff. She was hired.  
8 She was sitting in her home. She didn't know my  
9 father. All she could see was a picture on the  
10 screen. This person was giving me bad  
11 information. Because when I saw that my father  
12 was unable then I started to call his room,  
13 because he had access to the phone fifteen  
14 minutes a day.

15           What I was led -- what I was able to  
16 understand is that at 4:15 every day he had his  
17 diaper changed. So he spent eight weeks, eight  
18 weeks in his bed; bedridden for eight weeks.  
19 And when I wanted to call him he was bedridden.  
20 He was not able to answer the phone. So there  
21 was a person who would give him the phone and  
22 then I would be able to talk to him at 4:15 when  
23 this was happening. And that's how I was able  
24 to keep the channels of communication open.

25           Myself and the other members of the

1 family we called every day at 4:15, and at one  
2 point when it was time to change his diaper we  
3 were able to talk to him. And what he was  
4 saying to us is that, The conditions here are  
5 unliveable. Well, COVID ended on December 8th  
6 but we weren't able to have the status as a  
7 caregiver until January, because the person who  
8 was responsible for training caregivers had  
9 COVID and she had a bad case of it.

10 So we allowed her to get well again  
11 and currently we are seeing my father. He has a  
12 good morale, he's lucid. This is someone who  
13 doesn't have any signs of dementia. So I think  
14 personally that he's doing quite well, but the  
15 situation was very difficult for a long period  
16 of time. And the visit protocols are too  
17 strict. Something really was not done properly.

18 But really what I wanted to say is  
19 that communication, when my father was sick they  
20 did it. They said that they weren't -- they  
21 didn't have to communicate with us. Okay, fine,  
22 but this person was a stranger. They didn't  
23 know my father. This person was reading off the  
24 screen a message and that person couldn't tell  
25 us anything. They couldn't tell us anything.

1 She didn't make us feel that she understood or  
2 she knew my father.

3 So Participant 3 said something, and  
4 this is what I say to people who are in the  
5 Family Councils, go visit your loved ones and  
6 never go the same time of the day, because in a  
7 residence you are the eyes and ears for the  
8 other families. That's all.

9 DAWN PALIN ROKOSH: Thank you very  
10 much, Participant number 4. We very much  
11 appreciate that you were able to share your  
12 experience with us. Thank you.

13 So now I'd like to call on Participant  
14 5, please, to share your experiences in response  
15 to question 1.

16 PARTICIPANT 5: Okay, thank you.

17 First of all, I'd like to just say  
18 that a lot of the emotions and observations that  
19 Participant 2 had spoken about is something that  
20 was certainly felt in my sphere of contact, and  
21 equally so as participant 4 just said something  
22 as well that was quite relatable.

23 But my story is actually -- I guess  
24 when I hear the others I feel as though my story  
25 is quite a fortunate one in that my mother lives

1 in long-term care that is owned and operated by  
2 a large, for-profit organization, and I'll call  
3 it "head office".

4 I've been -- have six years experience  
5 with this particular home. My father was there  
6 and my mother is now. My father passed away a  
7 few years ago. And I am the chairperson of the  
8 Family Council and I have been for the past two  
9 years.

10 From March to July of 2020 the  
11 Executive Director of this home was forthcoming  
12 and pro-active and communicative. She received  
13 guidance from support services at head office  
14 regularly; and before the province instituted  
15 any LTC directives the home was screening on  
16 entry, turning away anyone who had traveled out  
17 of the country or was showing symptoms.

18 And the employer had also encouraged  
19 people to stay home, and had provided sick pay  
20 so that anyone who had travelled abroad could be  
21 at home until they were clearly not showing any  
22 symptoms and then come to work.

23 They also ensured employment at one  
24 site very early on, and additional hours were  
25 provided to staff so that they could make up any

1 lost hours that they may have experienced  
2 because they had to commit to one home. The  
3 morale at the home is good and the majority of  
4 the staff chose to work at our home.

5 Head office provided -- sorry, also  
6 the staff were encouraged to change from their  
7 street clothes into work clothes when they  
8 arrived and then back out of their work clothes  
9 into their street clothes when they left. And  
10 there was ample PPE and the home was encouraged  
11 to allow to -- to tell support services of head  
12 office of any requirements that they needed,  
13 whether it was resources or PPE.

14 So as a result of the guidance and the  
15 prompt and pro-active action of this particular  
16 Executive Director heeding all of the support  
17 that was offered to them, and providing that  
18 guidance to the leadership team, I think was one  
19 of the reasons why this home was actually quite  
20 fortunate in that they only had two asymptomatic  
21 resident cases and three staff cases from the  
22 period of March to July 2020.

23 And I have all of this knowledge  
24 because I was in touch with the Executive  
25 Director, and we realized that families needed

1 to have information. So I started hosting  
2 on-line Family Council meetings in April and  
3 these would be every week. And as the  
4 chairperson of Family Council I reached out to  
5 the email addresses I had, as I'm not privy to  
6 getting email addresses from the actual home. I  
7 have to sort of -- it has to be a reach-out and  
8 through newsletters that are sent out by the  
9 home.

10 But nonetheless, I hosted weekly  
11 meetings. And at each of these meetings the --  
12 a member of the leadership team, or two,  
13 attended and provided regular updates with  
14 regards to what they were doing in the home as  
15 preventative measures, how the staff morale was,  
16 what the staffing situation was and provided a  
17 lot of very valuable information. And as time  
18 went on more and more families joined on as this  
19 was the only source of real communication they  
20 were getting from the home.

21 And I took notes of all of these  
22 meetings and distributed them to families as  
23 well, so those who could not attend the Zoom  
24 meeting at least had some form of information so  
25 that they could be sure or they would know what

1 was going on. They were posted to our website  
2 as well.

3 As time went on our Family Council  
4 grew. And I actually found out that there were  
5 some family members whose loved ones had just  
6 moved into the home before it had been locked  
7 down so they did not have an opportunity to get  
8 to know the care teams, nor did the care teams  
9 have an opportunity to get to know their loved  
10 ones. And so this was -- this was a huge gap  
11 that was felt.

12 And so despite all of the good things  
13 that the home was able to do they did not have  
14 enough support staff to keep on that  
15 communication front and provide that guidance to  
16 families, especially the new families who did  
17 not know their way around the home. They didn't  
18 know what was happening so they truly were left  
19 in a void. And you know, it was through the  
20 Family Council meetings that we were able to  
21 provide them guidance.

22 So what I would do is I would have a  
23 Part 1 with the leadership team and then a Part  
24 2 with families only where we could talk about  
25 concerns and we could share experiences. And

1 once we were able to get in as essential  
2 caregivers we also could be made aware of, you  
3 know, if there were certain cleanliness issues  
4 or if staff weren't following IPAC protocols,  
5 and so forth.

6           However, December -- September to  
7 December COVID cases increased. Our Executive  
8 Director was promoted and there was -- there  
9 were interim directors. Outbreaks were lengthy  
10 and the families' questions and concerns were  
11 not being addressed directly as they once were.

12           But continuing to proceed and having  
13 this information and contact with the home, a  
14 new Executive Director being brought on board  
15 has now improved a lot of that.

16           But -- so lengthy outbreaks and no  
17 in-person visits after -- like when they were in  
18 outbreaks, had a negative impact on my mom, who  
19 has dementia. She has started a lot of weight  
20 loss and it was something I wasn't able to see  
21 until I could be an essential caregiver.

22 Although gratefully, the nurses and the care  
23 team did inform me that she was losing weight,  
24 she wasn't eating properly and her condition,  
25 her cognitive condition had declined. And

1 family members, during council meeting, had also  
2 noted that their loves ones' conditions had  
3 significantly declined.

4 And actually this was also seen when  
5 we would go for virtual visits or for window  
6 visits, when they were permitted. Because there  
7 were outbreaks for such a long time nobody could  
8 actually see any of their loved ones unless they  
9 were essential visitors.

10 But -- so, you know, the concern here  
11 is that despite the fact that they did so many  
12 things right at the front end there still was  
13 not enough staff to keep the -- to engage with  
14 the residents and to keep them active and to  
15 help keep their minds active. So you know,  
16 residents -- I don't think that they would have  
17 declined in such a way if there had been that  
18 type of support provided to them.

19 New residents fell through the cracks.  
20 And this was, you know, partly because this  
21 particular home has very few office and support  
22 staff. They are mostly -- they are DOCs or  
23 ADOCs and one social worker and, you know, and  
24 an administrative officer. Anyway, there is not  
25 very many of them. So they really didn't have

1 the people in place to be able to communicate  
2 effectively with families, and I'm happy that I  
3 was able to act as that conduit for them.

4 But that definitely needs to be  
5 improved and families do need to become more  
6 active, I think, in their loved one's care. I  
7 mean, we grew from only eight people to now I  
8 have over forty people on the email list. And  
9 we're all actively engaging with the new  
10 Executive Director and getting responses from  
11 them so it's been very good that way.

12 Anyway, even though it's somewhat of a  
13 better story it's -- I think still something to  
14 learn from that the leadership really can make a  
15 difference.

16 DAWN PALIN ROKOSH: Absolutely it is,  
17 Participant 5. And I thank you very much for  
18 sharing that. And with Participant 5 we've come  
19 to -- we've now heard from all of our  
20 participants today in respect of question 1.

21 And I'd like to, at this juncture,  
22 thank all the participants for their very  
23 thoughtful statements that you've shared about  
24 your experiences and the experiences of your  
25 loved ones; which will absolutely be helpful for

1 ensuring the Commission's understanding, and  
2 also the public's understanding of what has  
3 happened in long-term care homes throughout the  
4 pandemic.

5 So now I would like to hand things  
6 over to my colleague, Alain Daoust, who is going  
7 to lead us through question 2.

8 Alain.

9 ALAIN DAOUST: Thank you very much,  
10 Dawn. Thank you.

11 So question number 2 is as following:  
12 Reflecting on your experience, is there anything  
13 that could have been done that would have made  
14 the situation better? What is the most  
15 important thing that the Commissioners need to  
16 know as they consider recommendations?

17 So I would like to invite Participant  
18 number 1 to take the mic please. So Participant  
19 number 1, over to you.

20 PARTICIPANT 1: Well, isolation has  
21 been the main issue. And even at the dinner  
22 table they are all sitting at their own table.  
23 And there was a certain form of community before  
24 but I just feel that the precautions, especially  
25 when there's no outbreak, and especially between

1 the residents, that they need to lighten up.  
2 There's no reason, when there's no outbreak, for  
3 residents to be sitting at their own table with  
4 nobody there. They need to bring a sense of  
5 community back with activities and with  
6 essential caregivers. With it being restricted  
7 to only one person again that sense of family is  
8 lost.

9           And we saw a huge decline in cognitive  
10 with mom, a huge decline. Just can't get  
11 through to her. And the way to get through to  
12 her is touching. And you just get through with,  
13 you know, massaging her hands, et cetera, maybe  
14 giving her a bit of a back rub after brushing  
15 her hair and, boom, your time is up. You have  
16 to go.

17           The gowning. I just feel like when we  
18 are going through the regular COVID testing, if  
19 we're going through -- I'm not sure what this is  
20 called, the 15-minute test. When we're being  
21 so, so careful, when we're not travelling, when  
22 we're not out and about socially in our own  
23 area, that we need to be allowed to come in as a  
24 couple and to be able -- to at least be able to  
25 get our masks down. I see wearing a shield, but

1 our masks off so that they can hear us so that  
2 there is a form of communication. Because  
3 otherwise there's just this Haz-mat person  
4 coming in and doing something.

5 So I don't know exactly what to  
6 recommend except it has to open up, with  
7 precautions. I'm not saying just open the  
8 doors, but they have to open it up to family and  
9 to essential caregivers. It's got to be opened  
10 up because mom's not eating, all she wants to do  
11 is sleep. They've got her on supplements all  
12 the time now. It's no fun to eat because she's  
13 sitting at a table all by herself.

14 And she sits in the hallway with her  
15 head down like this. And she says, I love my  
16 bed. Yes, because it's an escape from the  
17 horror she's living in. That's all I have to  
18 say. Open it up.

19 ALAIN DAOUST: Thank you very much  
20 Participant 1 for sharing your comments with the  
21 Commission.

22 I would now like to call on  
23 Participant number 2. You have the floor.

24 PARTICIPANT 2: Thank you. I'm not  
25 going to cry this time. I'm not going to cry

1 this time.

2           So first, what could have been done  
3 better? Staffing. When staff are limited to  
4 one location permanent staff should have been  
5 offered full-time positions with benefits. Many  
6 left for better paying jobs, and who can blame  
7 them? There was no urgency in locking in our  
8 very best resources, rather staff were  
9 considered expendable because the care standards  
10 are not a priority.

11           Detailed study on what an outbreak  
12 would mean and what kind of staffing levels  
13 would be required, not just to meet basic care  
14 but to support residents during the lockdown.  
15 Current staffing ratios are already unacceptable  
16 outside of the pandemic; it should be similar to  
17 our daycare system. During the pandemic our  
18 situation was awful. So little basic care was  
19 actually done.

20           Auditing. There should have been  
21 ongoing auditing of basic care in the homes. So  
22 many lapses and poor standards resulted in the  
23 neglect of our residents. It's unacceptable.

24           Training and education. Staff were  
25 completely unprepared for COVID. They didn't

1 know any PPE protocols and thought the residents  
2 were their source of danger, but the infection  
3 was coming in from the staff. They didn't  
4 understand if they had sick people at home that  
5 they were putting themselves, their colleagues  
6 and residents at risk. And that's how COVID  
7 came into our facilities, because they had  
8 contact with loved ones at home who were COVID  
9 positive and still came to work. There was no  
10 understanding that their outside behaviour and  
11 risk to self and the residents. This should  
12 have been an ongoing discussion when COVID  
13 started. It never was.

14 Staff who didn't follow the PPE  
15 protocols were rarely reprimanded because people  
16 are so grateful that they show up it's easier to  
17 say nothing and let them breach protocol.

18 At the outset of the pandemic ongoing  
19 training and practicing to prepare for an  
20 outbreak should have happened. Training  
21 requirements already so minimal for PSWs and  
22 it has to be really increased.

23 The agency staff don't know how to  
24 train -- are not trained for seniors; they don't  
25 understand cognitive impairment; they don't know

1 how to toilet people; they don't know how to  
2 provide dental hygiene such as brushing their  
3 teeth; and often they don't care. They call in  
4 sick and are not committed to the home,  
5 resulting in massive shortages in staffing.

6 COVID testing. Standardized rules for  
7 testing. As an essential caregiver I can't go  
8 in without a COVID result that's within seven  
9 days but the staff can. When there's a gap in a  
10 results and their shift the staff went in and  
11 went to work, and only after they were in the  
12 home and working did the results come in and  
13 they were positive; which meant they had exposed  
14 the residents and multiple staff members.

15 Dietary needs. There is little done  
16 to improve the quality of the diets for those  
17 who did become ill. Families were vocal and  
18 demanding more soups and Jello, and other more  
19 proper options for people who are ill, that had  
20 positive outcomes. However, our long-term care  
21 currently gets half the funding that prisons do  
22 in terms of food preparations. There has to be  
23 better resources for fresh, wholesome food for  
24 our seniors.

25 Planning. Preparing and operating in

1 a pandemic requires strategic planning. There  
2 were no plan B options. When things fell apart  
3 the scrambling was crazy to watch. The  
4 residents were dirty and hungry, garbages were  
5 overflowing and on-site staff were completely  
6 distraught.

7 IPAC protocols. They are poor  
8 protocols outside of COVID anyway. And staff  
9 don't understand infection control and this is  
10 how the spread took over in so many homes.

11 IPAC inspections should be separate  
12 and not limited to outbreak but conducted  
13 regularly to ensure the best practices are the  
14 standard not the exception.

15 Home inspections. Homes that are not  
16 in compliance with inspections rarely face any  
17 significant repercussions. Poor inspection  
18 results are posted and that's that. Follow-up  
19 to enforce compliance doesn't happen. Again,  
20 our system should be like a daycare where when  
21 they have infractions they are penalize and  
22 penalized swiftly and harshly.

23 Importance of services recognized for  
24 mental and physical well-being. Programming for  
25 physiotherapy and recreational departments are

1 critical to overall wellness of residents.  
2 There is little commitment to ensure the quality  
3 of life during a pandemic. Residents are left  
4 to sit in their rooms lonely and distressed and  
5 lost cognitive and physical capability. There  
6 is no accountability for no standard of care.

7           The changes during a pandemic can only  
8 be sued -- the changes in law that long-term  
9 care can only be sued for gross negligence meant  
10 that there was less initiative from long-term  
11 corporations to do what was needed during the  
12 second wave. They don't have to any more  
13 because proving gross negligence is almost  
14 impossible. This should be reversed  
15 immediately. It's only the threat of litigation  
16 that seems to get any notice from the long-term  
17 care corporations.

18           Profits over residents. During a  
19 pandemic all shareholder profit shares should be  
20 suspended immediately to ensure the funds are  
21 allocated to resident care and resident care and  
22 staffing only.

23           Re-funding and reorganization of  
24 long-term care allocations. Staff ratios, fresh  
25 food ratios and spending. Care standards have

1 to be reset to provide the same attention as do  
2 daycare and prisons. As it is there are very  
3 few supports for those with cognitive  
4 impairment, and less for those who are only  
5 physically impaired but not cognitively impaired  
6 in long-term care. There are no standards to  
7 acceptable programming, supports, or day-to-day  
8 care or staff ratios. When infractions are  
9 noted nothing is done. There has to be a way to  
10 address noncompliance.

11 Thank you.

12 ALAIN DAOUST: Thank you very much for  
13 your comments, Participant number 2.

14 We will now go to Participant  
15 number 3. Participant number 3, you have the  
16 floor for the second question please.

17 PARTICIPANT 3: Thank you again. As I  
18 mentioned earlier, families and Powers of  
19 Attorney need to be recognized in legislation as  
20 essential. They need to be recognized for who  
21 they are and the value they bring to healthcare.  
22 This never should have been a debate in the  
23 first place.

24 I ask you, the Commissioners, is there  
25 anyone here on the Commission that does not

1 believe that families are essential in the care  
2 of their loved ones?

3 I also ask you to consider this point,  
4 it's a tough one, ageism. It exist. And  
5 it's -- and that needs to become an open and  
6 authentic conversation in Canada, let alone just  
7 Ontario.

8 A friend of mine, and I'm going to try  
9 and keep this light, who some of you may have  
10 heard of him, his name is Mike McCurry. He was  
11 the former press secretary to President Bill  
12 Clinton. Him and I became friends, former --  
13 through mutual interests, and we speak often  
14 about many subjects. Just recently one day I  
15 said to Mike that ageism is a big problem and no  
16 one really wants to talk about it.

17 I said, it's like when you turn the  
18 magic 60 or 65 and you're supposed to retire, go  
19 play some golf and get ready to pass on or die.  
20 Mike paused and said, very quietly he said,  
21 Well, I like the golfing part but not so much  
22 the other. And I laughed but he said it better  
23 than what I could have ever said.

24 The reality of ageism is why this  
25 tragedy occurred, in my view. If not imagine if

1 this was happening in daycares across the  
2 country. It would be -- there would be a  
3 revolt.

4 Before I go further, here are four  
5 points I want you to consider and keep in mind  
6 if you can.

7 Point 1: Without the support of  
8 essential family caregivers many loved ones  
9 would have not survived.

10 Point 2: Caregivers are the largest,  
11 unpaid work force in Canada saving us, the  
12 taxpayers, billions.

13 Essential caregivers care for the  
14 physical, emotional and spiritual needs of their  
15 loves ones unconditionally. There is no vested  
16 interest. It could be the right arm to support  
17 PSWs, nurses, and doctors. It just makes  
18 sense. Nobody is taking a position. It just  
19 makes sense to support.

20 The demographic -- the demography is  
21 changing. There will be an explosion and the  
22 need is compelling to fix long-term care once  
23 and for all.

24 Here are some recommendations, that  
25 while some will be outside of your mandate I

1 bring them forward as the issue on aging has no  
2 boundaries. After all, these are unprecedented  
3 times.

4 Recommendation one: Bring long-term  
5 care under the umbrella of the Canada Health  
6 Act. The rationale is that while it's true that  
7 the delivery of healthcare is a provincial  
8 jurisdiction, it is also equally true that  
9 equitable access be provided to all Canadians  
10 notwithstanding their age, as described in the  
11 Canada Health Act.

12 Point 2, sub point: Short of bringing  
13 long-term care under the legislative authorities  
14 of the Canada Health Act, set a separate,  
15 national, stand-alone Act be created perhaps  
16 called the "Long-Term Care Act" the "Elder Care  
17 Act" or "Protecting Our Seniors Act", just  
18 recommendations.

19 Point 2: The governments explicitly  
20 define and acknowledge that the role of families  
21 is essential to the care of their loved ones  
22 and, therefore, be defined as essential family  
23 caregivers and chosen family caregivers in  
24 legislation.

25 Who are chosen family caregivers?

1 They are trusted friends outside of the typical  
2 family unit and are trusted by the resident.

3 Three: Encourage investment in  
4 smaller, group-type home settings under the  
5 Canada Infrastructure Program and the National  
6 Housing Program, in collaboration with  
7 provincial and territorial partnerships. Those  
8 programs already exist. After all, they are --  
9 a residence home is classed as a "home".

10 Four: Create a national essential  
11 family caregivers or essential caregivers  
12 working table; bring them to the table as full  
13 partners, again unpaid caregivers contribute, at  
14 a minimum, 25 billion.

15 Five: Increase training and salaries  
16 for PSWs in recognition of their critical  
17 role. Note that PSWs need to be truly  
18 recognize as professionals and have a career  
19 path forward.

20 Six: Strengthen enforcement,  
21 implement rigorous inspection protocols and give  
22 long-term care inspection officers greater  
23 authority to sanction licensees for repeated  
24 noncompliance.

25 Seven: Prosecute those who violate

1 existing laws related to abuse, neglect, mental,  
2 verbal or emotional harassment and/or  
3 retaliation. You don't need new laws, they  
4 currently exist under the current Criminal Code.

5 I want to end with these points:  
6 Today a marvelous book written by Moira Welsh  
7 was released entitled "Happily Ever after". I  
8 suggest you get it. It is a book of solutions,  
9 of hope and practicality, and evidence-based  
10 success stories.

11 Also, reach out to the true advocates  
12 and organizations making significant impacts  
13 with little gain for themselves, if any; i.e.  
14 Family Council Ontario, a group of four people  
15 who have done more in communications than anyone  
16 I know.

17 Two: Those within the bureaucracy,  
18 they are brilliant people making solid  
19 recommendations and often not heard from, or  
20 even their solutions are not implemented because  
21 they're not maybe politically palatable.

22 Three: Medical professionals,  
23 doctors, nurses, PSWs, people like Samir  
24 Sinha, Nathan Stall and too many others to  
25 mention, they need to be supported. I don't

1 think they're making a dime on this. It's  
2 costing them.

3 And stay away -- I'm going to really  
4 point this out, and stay away from what I call  
5 the "professional advocates", respectfully.  
6 Many of them never, in my view, have been in  
7 long-term care but now have magically somehow  
8 appeared.

9 This generation is our collective  
10 parents or friends and who made Canada what it  
11 is today; and they paid for it. We owe it to  
12 them to put the care back into healthcare.  
13 Right now we have a lucrative sick care industry  
14 not healthcare. That's what keeps us going.  
15 That's what keeps me up at night and millions of  
16 other caregivers.

17 Thank you.

18 ALAIN DAOUST: Thank you very much for  
19 sharing those comments and for your  
20 recommendations.

21 I would now like to move to  
22 Participant number 4 please.

23 PARTICIPANT 4: Okay. I would like to  
24 start by stating that what needs to happen in  
25 long-term healthcare is not to come back to the

1 situation that existed before March 2020.

2 Because, I mean, there's several  
3 things in the system which, in my opinion, gave  
4 the impression that everything was well and that  
5 everything was perfect in the healthcare system  
6 for long-term care before the start of the  
7 pandemic.

8 The first thing that I would like to  
9 highlight is that the department, or the  
10 Ministry, during a two to four year plan would  
11 like each residence to assess quality  
12 indicators, quality indicators, performance and  
13 I forget the rest of it in English.

14 So the Ministry in 2012 selected ten  
15 indicators of quality. Under the present-day  
16 government the Ministry has only selected four  
17 quality indicators. So we went from ten  
18 indicators to four.

19 I prepared a document for you, Mr. and  
20 Mrs. Commissioners, and I expect you to read it  
21 because if I have to go through it all I  
22 won't -- I'll be short of time.

23 One of the indicators, indicator  
24 number 2 says, from the annual resident survey,  
25 what number would you use -- sorry, indicator 3,

1 so based on the annual resident survey, what are  
2 you prepared to give a positive answer to? I  
3 can state my opinion without fearing reprisals.  
4 That's indicator number 3 for the annual survey.

5 Indicator 4 talks about, and listen  
6 well, how clear was the noting of palliative  
7 care needs? All I can tell you about indicators  
8 is that they weren't chosen by families.

9 Indicators of quality in the system  
10 should, in part, be chosen by family. I'll give  
11 you a percentage for indicator number 3 at the  
12 residence where my father lives. Here is the  
13 question: Can your parent express his or her  
14 opinion without fearing reprisals? The  
15 residents of my father's residence responded,  
16 76 percent, Yes, I can express my opinion.  
17 Families responded 58 percent, Yes, I can  
18 express my opinion. I don't agree that we use  
19 surveys by using residents' opinions and not  
20 also families' opinions.

21 The indicators of quality should --  
22 there should be questions on indicators of  
23 quality and families should be allowed to  
24 express their opinion.

25 I would also like to say that I'd like

1 to see a question like this one in the  
2 indicators of quality, the question could be the  
3 following: What is the percentage of  
4 absenteeism of your staff on Fridays, Saturday,  
5 and Sunday nights? And what is that percentage  
6 of absenteeism that is not filled? Not  
7 backfilled? Not replaced?

8 We are in a PSW crisis. It's not just  
9 a crisis of workers, it is a crisis of  
10 absenteeism sometimes and shortage of. But as a  
11 Family Council member when I travel through  
12 all -- when I go to all the groups, Ottawa and  
13 others, I realize that we can't get -- and when  
14 we talk to people and say we need to change  
15 things they think we're inventing data. I would  
16 like to have some data, hard data.

17 I also think that we need to change  
18 the surveys that are used in residences.  
19 Surveys are prepared by two large firms and I  
20 don't approve of the questions.

21 I think there should be a question  
22 such as this one, When you arrived in the  
23 residence did you wear a diaper? When did they  
24 put a diaper on you?

25 My father did not wear a diaper when

1 he came in; three weeks later he started wearing  
2 a diaper. They put him in a diaper and that had  
3 such an impact on his psyche. It was horrible.

4 I think that surveys should look into  
5 that. When you arrived in the residence did you  
6 wear a diaper? Do you wear one now? When did  
7 you start wearing a diaper? Why are you wearing  
8 a diaper? Do you wish to wear a diaper? Why do  
9 you wear a diaper? Well, it's probably because  
10 there aren't enough workers on the floor.

11 We have some of the best scores in  
12 health apparently in the world, our nurses  
13 RNs, assistant nurses. You know, they provide  
14 four hours of care, but they want to reduce the  
15 care time but we don't have any data. What's  
16 the impact with the shortage of workers? In my  
17 residence we're 3.2 hours and residents have to  
18 wear diapers.

19 And when we tell the workers, Change  
20 my father's diaper, they don't want to do it  
21 because apparently the blue section in the  
22 residents is not blue enough. So they won't go  
23 and change the diaper until the diaper is  
24 saturated and they know that when something  
25 happens with the blue line.

1                   So all that to say I'd like the  
2 surveys to be changed because the caregivers  
3 know what questions should be asked; because the  
4 family caregivers know all of the weak points  
5 from the system, all of the weak points in the  
6 care of our loved ones. Because the personal  
7 support workers are tired, there's too much of a  
8 shortage, et cetera.

9                   Another thing, personal workers.  
10 There's a professionalization, that comes from a  
11 word that someone in Quebec used in front of you  
12 on September 22nd, it's at page 19, line 19 of  
13 the report of that session.

14                   The PSSPs or PSWs are not invited  
15 when drafting the annual plan. PSWs are never  
16 there. When I go through my father's plan it's  
17 a group of people that they -- they're not  
18 valued. PSWs should be on that planning  
19 committee where we talk about how care is going  
20 to line up for the year to come.

21                   I'm a nutritionist. Well -- I'm  
22 sorry, the nutritionist at the residence sees my  
23 father once a year. She's not the one who feeds  
24 my father and my father is blind. It's the PSW,  
25 the personal support worker that feeds my father

1 so she's the one who can say how he is, not  
2 others.

3 Participant 3 told you to stay away  
4 from people with lots of diplomas, I have the  
5 same advice.

6 I'd like us to review Collective  
7 Agreements. I know that's impossible.  
8 Collective Agreements of personal support  
9 workers, they don't promote work-life balance in  
10 my residence. The older PSWs take the best  
11 weeks of holidays, for instance. They take  
12 their leave all of July, and what happens with  
13 the young PSW that's been working for a year and  
14 a half with two young children and can't take  
15 her holidays with her children in the summer?  
16 Well, she leaves that line of work. So  
17 Collective Agreements of PSWs, there is no  
18 attempt to provide for work-life balance and  
19 that's one of the reasons why PSWs leave their  
20 job so quickly. It's impossible to find any  
21 kind of balance between their family life and  
22 their work life.

23 I gave you, in my document, an  
24 overview of absences in terms of days. There  
25 are more absences on Fridays and Saturdays so

1 that means that there's a problem with work-life  
2 balance, once again.

3 I would like us to have access to --  
4 think about Family Council. Samantha Peck lines  
5 1, 2, 3 it was saying that the Family Councils  
6 are an organization that is provided for in the  
7 legislation but most members don't know what to  
8 do. Where do their responsibilities start?  
9 Where do they end?

10 Let me explain why. There are a lot  
11 of caregivers in a home. In my home there are  
12 104 residents, but the 104 residents, well,  
13 there is -- the Ministry didn't allow caregivers  
14 going into the homes thinking that in a  
15 residence of 104 residents there were 50  
16 families that could provide caregiving services?  
17 It's a Ministry that doesn't understand the  
18 reality. Caregivers the -- well there are four  
19 of us. There are four families that are acting  
20 as caregivers, the other residents are alone.  
21 So we need data on the number of caregivers. We  
22 need metrics. The Ministry doesn't have this  
23 information.

24 Another thing I want to say, in my  
25 home there is a new person who arrived on

1 September 28th. She got COVID in October and  
2 she died at the end of October.

3 Let me tell you this, I've just said  
4 that I don't have any figures on a whole series  
5 of things that are happening in the home. I  
6 spoke to you about the number of caregivers.  
7 This should be known, it should have been known  
8 before the pandemic. And given that there are  
9 so few caregivers the risk of accepting is very  
10 low.

11 What I want to say, I have read a lot  
12 because I've had time to do it. I want to say  
13 that we know more things on the medical side of  
14 things of how to treat people than what we know  
15 that actually happens on the ground with respect  
16 to people eating, walking, people who are doing  
17 this or that.

18 In a document that I read it says that  
19 there are five principal factors that can lead  
20 to death in a home. First of all, the  
21 insufficiency of liquids. Secondly, weight  
22 loss, and I'm thinking of participant number 1.  
23 The third factor, respiratory problems. Fourth  
24 one, fever. And the fifth one, to be a new  
25 admission.

1           When I read the study, and when you  
2 see my document you'll understand what I'm  
3 referring to, but the fifth cause of death in  
4 the residence in a home is to be -- the  
5 incapacity to adapt to life in a home when  
6 you're a new person being admitted. And yet we  
7 continue to admit people into homes during the  
8 pandemic. There is a woman who died during the  
9 pandemic without having seen her family.

10           New residents will always ask their  
11 families to act as interpreters with PSWs and  
12 others. They're shy. They want us to act on  
13 their behalf. It takes about a month for  
14 residents to understand the system. And during  
15 the pandemic there was basically, you know what?  
16 Find your own way. But there were a number of  
17 people who died, including this new resident,  
18 and that was a scandal in the local media. And  
19 currently there is a case before the courts.

20           Why do we admit new residents during a  
21 pandemic? These people have no support. And  
22 it's written in a brief report of examining  
23 factors associated with death within 31 days  
24 after assessment in long-term care homes.

25           So the fifth factor is to be a new

1 resident. Why are we admitting new residents?  
2 If I can, I simply want to provide time for  
3 other people -- actually I'll stop there. I had  
4 a lot to say.

5 ALAIN DAOUST: Thank you very much.  
6 Thank you for your comments and the suggestions  
7 that you've put forward to the Commission. It's  
8 very much appreciated.

9 And now I'd like to move to  
10 Participant number 5.

11 PARTICIPANT 5: Okay. What could have  
12 been done differently to make the situation  
13 better? Having more staff. Having more  
14 full-time staff, not only PSWs but also  
15 activation staff, nursing staff and support  
16 staff within the home.

17 Having the province increase salaries  
18 is probably very nice, but having that permanent  
19 increase for full-time staff, they would have  
20 benefits as well, is something that if we had  
21 that perhaps we would have been in a better  
22 situation.

23 Working in a long-term care home also  
24 requires specialized training, communicating  
25 with residents who have dementia, being aware of

1 the pressure sores, proper placement in  
2 wheelchairs, toileting, dental hygiene, and  
3 hygiene particularly, and just how to be able to  
4 relate to them.

5 It's a specialized skill and it's  
6 something that needs to be promoted in terms of  
7 something that is a positive thing that people  
8 can be proud of having that type of a job.

9 Perhaps we need to make the job a  
10 little more -- just promote it in such a way so  
11 that people actually can see the benefits of  
12 being a PSW, or an activation staff person, or  
13 having some form of role in long-term care.

14 But in fact leadership in the home, as  
15 I mentioned previously, is probably most  
16 important. So going forward whoever is  
17 responsible for hiring an executive leader or  
18 other leadership team members, whether it is in  
19 a for-profit, not-for-profit, municipal home,  
20 they must be hired effectively.

21 Leadership in long-term care requires  
22 an interactive leader who will provide guidance  
23 and support to their staff, helping them provide  
24 meaningful information to families and to their  
25 fellow staff. They should be willing to be

1 transparent and collaborative, they care about  
2 the home and its residents. They set standards  
3 and they hold their team accountable for  
4 adhering to those standards.

5 Pro-active, innovative, empathetic,  
6 strategic and forward-thinking, I think those  
7 are some of the qualities that are required if  
8 you're going to be working effectively in a  
9 long-term care home.

10 The collaboration between Family  
11 Council and leadership at the home is important  
12 and Family Councils play an important role. And  
13 perhaps that means the general population needs  
14 to be more aware of what Family Councils are and  
15 the role that they play.

16 However, it is not up to the Family  
17 Councils alone to be holding the homes  
18 accountable for adhering to a specific standard.  
19 It is a collaborative relationship but  
20 ultimately it is the home's responsibility to  
21 ensure that those standards are being met.

22 And where are the standards coming  
23 from? Well there should be higher standards  
24 that need to be set by governments at all levels  
25 perhaps. For that -- that I'm not sure federal,

1 provincial, municipal, everybody may have a role  
2 in it. But communication and training to the  
3 standard should be adhered to, and regular IPAC  
4 audits. Ministry of Health inspections need to  
5 take place. And the repercussions of those who  
6 are not compliant need to be much more serious  
7 and perhaps more public so they are adhered to.

8           And finally, just a recommendation in  
9 terms of where do we go from here? How do we  
10 know what to do? Let's not be in our own  
11 cocoon, right? Let's not just be looking at  
12 ourselves. Let's look at best practices in  
13 elder care in other provinces, in other  
14 countries. What has worked well? What have  
15 people been able to do? And how much did it  
16 actually cost to implement some of these things?

17           Those are my comments. So thank you  
18 very much for the opportunity.

19           ALAIN DAOUST: Thank you very much.

20           Thank you very much, everyone. This  
21 concludes the segment for this evening.  
22 Everyone has had a chance to answer both  
23 questions, and I would like to thank everyone,  
24 all of you, the participants, for taking the  
25 time to share your experiences and having the

1 courage to do so and share your experiences with  
2 the Commission.

3 And I would like now, if I may, to  
4 hand it back to Commissioner Kitts for the  
5 closing remarks for this evening.

6 COMMISSIONER JACK KITTS: Thank you,  
7 Alain. And thank you all again for your courage  
8 in recounting your experiences with us today.

9 You know, seeing this tragedy through  
10 your eyes and listening to your heart-felt  
11 messages has been very helpful in making the  
12 impact of this pandemic very real for me, and I  
13 know I speak for the other members of the  
14 Commission.

15 We will do our very best to submit a  
16 report that reflects your experiences, and your  
17 recommendations that you've given us today, to  
18 government so that they and the public at large  
19 can understand why this tragedy must never  
20 happen again.

21 Your presence today has been a big  
22 help in helping us shape the report that we will  
23 submit on behalf of you, your families and the  
24 public at large.

25 So I think one of you said we should

1 create an environment where we look forward to  
2 aging in a long-term care home as opposed to  
3 fearing that day. So we've heard you, we've  
4 listened and we will do our best.

5 Thank you very much and have a good  
6 evening. Bye bye.

7 COMMISSIONER ANGELA COKE: Thank you.

8 -- Meeting ended at 5:51 p.m.

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1 REPORTER'S CERTIFICATE

2  
3 I, HELEN MARTINEAU, CSR, Certified  
4 Shorthand Reporter, certify;

5 That the foregoing meeting was taken  
6 before me at the time and date therein set  
7 forth;

8 All discussions had by the  
9 participants were recorded stenographically by  
10 me and were thereafter transcribed;

11 That the foregoing is a true and  
12 accurate transcript of my shorthand notes so  
13 taken. Dated this 9th day of February, 2021.

14  
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16 \_\_\_\_\_

17 PER: HELEN MARTINEAU  
18 CERTIFIED SHORTHAND REPORTER.  
19  
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25

C L A R I F I C A T I O N S

Page 56, line 7: "Happily Ever Older" not  
"Happily Ever after"

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