



TRANSCRIPT

PSW Webinar One: Experiences of Providing Care During COVID

Guest Speaker: Dr. David K. Wright

Host: Kath Murray, Life and Death Matters **Co-Host:** Michelle O'Rourke

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Kath Murray:

We've got such an exciting day; welcome to the first of the free webinar series for PSW is HCAs and CCA is brought to you by Life and Death Matters, [Hospice Palliative Care Ontario](#), and the [Canadian Hospice Palliative Care Association](#). It is very exciting to be with you, nearly 500 people have signed up for this series! You include PSW, PSW students, allied health workers, nurses, managers, and educators. We will have some interesting discussion today. I realized that many of you are referred to as healthcare systems or continuing care assistance, but in this series, we will refer to you as PSW and personal support workers, and I hope that you feel acknowledged with that title too. There are a number of people who wanted to attend, but are unable to, so we will be recording this session and we'll post the recording on the Life and Death Matters website in the coming days. You'll receive an email with that link, and you're welcome to share that. Wherever you come from, I welcome you.

I hope you will leave this session, feeling the support of our team across the country. I hope you will be inspired by David's presentation, that you will have ideas that you can integrate in your practice and new ways to connect with colleagues from across the country. My name is *Kath Murray*. I am a hospice palliative care nurse, educator, author, thanatologist and founder of Life and Death Matters, a Canadian palliative care education company.

Some of you may know me because I wrote a book titled [Integrating a Palliative Approach: Essentials For Personal Support Workers](#). This text and companion workbook, podcasts and videos are used in many PSW programs across Canada, as well as for education and long-term care, hospice, and palliative care facilities, and in community care. As personal support workers you are often referred to as the eyes, the ears and the hands of the healthcare team, people that you care for often describe you as the heart of the team.

In the [Ontario report on staffing and long-term care](#) published in June-July of 2020, the long-term care associations, the operators, residents, families, and labor partners often referred to you as the backbone of the long-term care system, and they even acknowledged that you did much of the heavy lifting this past year. During the pandemic in the media, you have been referred to as heroes. Heroes, hearts, hands, eyes, ears, backbone. Wow, sounds incredible, and incredible you are.

Today in collaboration with the Canadian Hospice Palliative Care Association, and Hospice Palliative Care Ontario, we are excited to announce that one of you will be chosen to receive a free course registration to a course in the new online program based for PSW called PACE for PSWs. This online education is specifically created to support you as a PSW to learn the skills that you need to integrate a palliative approach and provide excellent palliative care. We will share more about PACE for PSWs after the presentation.

Now I will introduce you to my co-host, Michelle O'Rourke and our speaker David Wright, Michelle O'Rourke is a hospice palliative care nurse and an author. I am so grateful to have her helping with this series. Michelle is a co-host today and will help me monitor the chat. Next month, she will be presenting the session titled, "Addressing our Grief Associated with COVID," which will link in so beautifully with some of the challenges and the grief that David will be discussing today.

I am thrilled to introduce you to Dr. David Kenneth Wright. David is a nurse, educator, and researcher at the University of Ottawa. He is a nurse at the St. Raphael's Palliative Care Home and Day Center in Montreal, is a member of the Canadian Palliative Care Nursing Association and is a dear friend. If we were not in the midst of COVID restrictions, I would wish that we could gather in the forest around David's home for a campfire and roast marshmallows and share stories. We had thought this might be possible online, but instead of having 30 people sign up for this, we've had over 400, closer to 500 sign-up, how exciting is that!

David is going to talk today about experiences of providing care during COVID. He will share some stories from the media and some from his own research. He will invite us to think about the impact of COVID on how we relate with one another in giving and receiving palliative care. During his presentation, he will invite you to share your own ideas and stories in the chat box. David will talk for about 30 minutes and then David, Michelle, and I will share and respond to some of your stories, comments, ideas, and questions that you have submitted. Please enjoy reading the comments contributed in the chat, we look forward to hearing your thoughts. If you want to share your thoughts with the entire group, then send them to all attendees and panelists. If you want to share your thoughts just with David, Michelle, and myself, then please just send it to panelists. David, I'll turn the time now to you, thank you for being here.

Dr. David K. Wright:

Thank you so much. Hello everyone, I'm thrilled to be here with you all. I was super excited to see the amazing registration which I think speaks to the enthusiasm in this community for education and for excellent care. So, thank you so much for having me. As Kath mentioned, I'm going to spend the next half an hour or so sharing some stories. I really believe that stories are one of the most powerful ways that we can share knowledge about what matters most in healthcare. As healthcare providers, we become characters in the stories that patients and families tell and retell long after they leave our care. I just want to give you one example to show you what I mean.

Just a few weeks ago, I was on a zoom call with a colleague of mine from the UK. Her name is Marie Cooper. And before our meeting started, she came online and she was super excited and emotional because she had just received an email earlier that day from a man who had been one of her patients 30 years ago. Now, I don't know what prompted him to reach out and track her down, maybe it was all the attention that healthcare workers have received over the last year, but in his email, he just wanted her to know that on that particular day, 30 years ago, she had cared for him. He had felt scared, and she had made him feel safe, and this made a world of difference to him. So think about that. Think about all of the people that you have cared for or will care for, who are out there in the world, holding the memories of their time with you so close to their heart, that they will be thinking about you for decades, even if they probably won't write you an email to tell you.

So perhaps some of you have your own stories of receiving healthcare, or your own examples of that one memorable person who made a huge difference either in a good way or maybe a bad way, I certainly do. The point that I want to make here is that when we share and collect stories from people receiving and providing care, it becomes possible to see what's most important to people. What is at stake and what really matters. So let's begin with a story. This is the story of Brian and Joanne, and it comes from several different pieces that appeared, over a number of months in the Canadian news media. This is a picture of Brian and Joanne that you see here. Joanne had severe Parkinson's disease and lived across the street from Brian in a long-term care facility. When the pandemic struck, Brian was not able to visit with her. So, although they were only meters away, they were worlds apart. On March 16th of 2020, early in the pandemic, Brian had wanted to give his wife Joanne some flowers, but when he went to the store to buy a card, he felt uninspired by all of the options in front of him. So instead, he decided to handwrite a letter to accompany the flowers that he would deliver to her. And this is what he wrote in that letter:

Dearest Joanne, I will need to keep this letter short. I hope the PSW has given you the flowers to enjoy. Needless to say, that I miss you and love you as much as ever. If you only remember one thing, remember that I have loved you very much for over 48 years. Now, this virus outbreak, COVID-19, is terrible and has been the most disruptive thing in my entire life. I have no idea as to when we will be able to return to a normal life. Please try to stay positive and be strong. I am trying my best to do likewise. Your husband, Brian.

Brian then proceeded to write more than 300 letters to Joanne over the course of the pandemic. The letters were about different things, sometimes just about whatever was happening that day. Other times, he shared memories and retold stories of their life together. For example, on Christmas, he wrote a letter recounting the story of their son's birth. That was letter number 92 pictured here. It begins:

Tonight's letter starts very late on Christmas Eve, 1986. You went upstairs at approximately 1230 while I stayed downstairs with your father. When I came up about 20 minutes later, you were again putting on your new Christmas maternity sweater. When I asked why, you said, I think we will be going to the hospital soon.

Now, because Brian was barred from seeing Joanne due to COVID-19 visit restrictions in long-term care, Brian would hand-deliver these letters to the PSW and the nurses of the facility, who would then read them aloud to Joanne. Sometimes Joanne would ask to hold the letters as she settled into bed for the night and staff would report back to Brian that she had slept through the night, holding a letter against her chest. Brian would also encourage staff to read letters on their own. He did not consider them private. He wanted staff to come to know Joanne and the life that she had through his letters.

What I want us to focus on here is the long-term care staff and particularly the PSWs who play a vital role in facilitating this connection between Brian and Joanne. In placing these letters into a PSW's hands, Brian puts all of his trust as well. This has shown so clearly in the first letter, which began with "I hope the PSW has given you the flowers."

Dr. David K. Wright:

My colleague, [Christine McPherson](#), who is a nursing professor at the University of Ottawa, has done research with a PSW about their work, providing palliative care to older clients and families in the home. On this slide, you see a screenshot of her paper, which is available open access online, you can Google it and read it. [In this paper](#), she reminds us that **80% of direct care to Canadians 65 years and older in the community is provided by PSW**. Through chart reviews and interviews with PSWs directly, she and her team demonstrate the many ways that PSWs are hugely influential in helping people at the end of life to experience comfort, dignity, and quality of life. For example, PSWs will notice how family members are coping and may offer suggestions and support. One example that she writes about is a PSW that noticed that a patient's wife was having to give her husband a lot of morphine doses, so the PSW suggested to the wife that she use a book to keep a log of these doses. This seems minor, but probably had a huge impact because we know that the responsibilities of caring for family members in the home, including the huge responsibility for medication administration can be incredibly daunting and overwhelming for families.

Personal support workers in this study also spoke about adjusting their routines to suit the client's rhythm. For example, one PSW said

"Nothing is set in stone. If the client is having a bad day and doesn't want to shower, but just wants you to listen. If that is what makes them feel better than that is what I do."

This willingness and ability to adjust to whatever the patient needs is hugely important for person-centered care. And especially at the end of life when preferences and routines can change very unpredictably.

So here on the slide, you see a quote from one of the PSWs in this study.

"I have one woman who is in a wheelchair; She is palliative. I wash and curl her hair. I do anything that has to do with personal care, doing her fingernails, making her feel good, reminding her how to feel alive; that she is not forgotten. "

Let's just take a moment and appreciate the weight of what is being communicated here. Helping someone with personal hygiene is not just a task that must be completed. It's a meaningful intervention that reminds someone that they are alive, that they have not been forgotten. As [Cicely Saunders](#) who founded the palliative care movement many years ago famously said,

"You matter because you are you, and you matter to the last moment of your life. We will do all we can to help you not only to die peacefully, but to live until you die."

Here we see how important PSWs are to making good on that promise. But how does COVID challenge all of this? Joanne had her husband, Brian to write her letters, and in their case, the way that PSWs helped was that they received and read those letters to Joanne and to themselves. Now, Brian was eventually able to visit his wife himself. And he pointed out in one of his media interviews that when he did, he noticed there were people on Joanne's floor who didn't even get a visitor they're lonely and they need a bit of recognition. So with that, I'd like to invite you to share your ideas, what are your ideas for helping someone else like Joanne, but who doesn't have someone to write them 300 letters over the course of the pandemic? What are your ideas for helping someone like that feel seen and feel valued assuming that they are separated from their loved ones because of COVID-19. At this point, we'll just ask you, just whatever you're thinking or feeling in this moment in response to this question, throw it into the chat and Kath and Michelle will come back to what some of what you offer, at the end of the talk.

Kath Murray:

And David comments are coming in, so thank you. And again, just send your messages to either everyone or all panelists, however you would like, and we'll be able to pull these together later. Thank you, David.

Dr. David K. Wright:

It's great. And I'm just going to continue, but please feel free to continue using the chat, and continue listening to me. The next two stories are from people providing care during COVID. This first story comes from interviews that we are conducting with palliative care nurses during the pandemic. Here you see the names of my colleagues on the bottom left including Christine MacPherson, who led to the PSW study that I mentioned earlier.

The first story that I will bring you comes from Laura. Laura is a nurse who prior to the pandemic had been coordinating a palliative care volunteer program, but she was redeployed to the local hospice when the pandemic began. At the very end of her interview with us, Laura spoke to us for about an hour and she talked about her perspectives on COVID and on how that's impacting palliative care nursing, but at the

very end of our interviews, we always ask our participants, is there anything else that we haven't talked about that you would like to share with us? And it was only at that time that she told us this story. She says,

"I had an experience last week that just has been kind of sitting with me. And to be honest, I'm starting to feel a little bit burnt out. I dread going to work. Some days I'll come home and cry more than I did before. Especially if a patient has died. Last week, there was a young mom in her forties who was dying and she was no longer really conscious. Her partner was at her bedside and we had the window cracked open because her two children were also visiting, a son and daughter in their twenties, on the other side of the window. This woman ended up dying while her kids were outside. And just seeing the daughter just crying and wailing and calling for her mom through the window was just so heartbreaking."

"I think we all understand why these limits are put in place, but we were all just so angry. And I was even thinking for myself, if I were that daughter, I would be barging through here to be with my mom. I would not care about the regulation."

And she finishes by saying, *"And then at the same time, I'm the person who's imposing those restrictions on people."* So I just feel really torn a lot of the time."

Dr. David K. Wright:

Laura's sentiments of feeling torn are also experienced by PSWs. For example, [Anna Perry](#), who you see pictured here is a PSW who has been working in long-term care during the pandemic. She was profiled in a story on CTV news. And in that story, she describes feeling both physically and mentally exhausted as her hours have gotten longer and staffing has gotten worse. She says the hardest thing is just not having the ability to have that time with the residents and be able to talk to them and just see how they're doing. So here, Anna is highlighting a gap between the type of care that she knows should be possible and the type of care she is able to provide because of how stretched she and her colleagues are. Other nurses we interviewed in our own research have said similar things. They talk about continuously having to make decisions about whether to care for themselves. For example, something as simple as taking a lunch break and when they do take a break, feeling guilt over what is being missed. For example, one nurse told us about having to choose between finding time to eat and rest her back during a particular shift or finding time to hold an iPad up to a dying resident so that they could talk with their family. Because on that day, it simply wasn't possible to do both. Returning to Anna here, she talks about holding patients' hands as they've died and how much these experiences affect her personally. She says that "these experiences will

be with me for a very long time.” And she goes on to say, “I feel like during these tough times, everyone and herself included, just needs someone to talk to.”

Another PSW, Elizabeth Perez, worked at a long-term care facility that saw all of its 100 plus residents test positive for COVID-19 in one month. In total, more than 70 residents died from the virus. In an interview with CTV news Perez said that, “It felt like a war zone. It was hell. It was complete total hell.” Like Anna, Elizabeth Perez spoke about holding the hands of people who died right in front of her and this having a tremendous impact. So, as we sit with the enormity of that, let me say that I was very happy to see that as part of this webinar series, the next session is going to be about grief. This is so important because while Laura talks about feeling burnout and Anna talks about feeling exhausted, what is also going on here, is grief. And that needs to be named. As healthcare providers we hold the grief of the patients and families that we care for. And we also feel tremendous grief ourselves as the people that we care for are dying. And particularly when the people that we care for are dying in sometimes horrible circumstances. And like anyone experiencing loss, we also need support in our grief.

And so once again, I'll now flip it back over to you, and I will ask you, what are your ideas for how you could best be supported as you grieve heartbreaking situations like the ones that, Laura or Anna have experienced? I want to point out, I think as Kathy mentioned at the beginning, there's a lot of PSWs and PSW students on this call, but there are also leaders including formal health care leaders, including nursing leaders on this call. This is a good opportunity for us to maybe share with each other how we could be better supporting each other in our grief. And if you are a nurse on this call, you could choose to tell us how you feel like you could be supported. You can also share with us ideas for how you might support the PSWs that you work with.

Kath Murray:

Thank you, David. And again, the chats working, people have been able to respond to your first question on and are starting now with the second question. Thank you. Wonderful. And I just need to say this is just so moving to hear you present these stories and to hear you address this. Thank you.

Dr. David K. Wright:

Thank you. I'll move on, but again, please feel free to continue sharing your ideas with us in the chat. The next nurse that I will introduce is Talia, also a nurse that that we spoke to in our interview study of palliative care nurses caring for patients during COVID. Talia, like Laura, has been working in residential hospice as a frontline RN during the pandemic. Early on in our interview with her, we asked her the question that you see here on the slide: “*How has the pandemic affected hands-on care, the way you relate to patients and families?*” And this is what she told us.

“It's awful. That's probably the most that I bring home with me every day, which is very odd because you'd think I would be more fearful of bringing home what could be a life-threatening virus, but what I'm carrying with me more.”

And at that point, she paused, she became emotional, and her voice started to crack. She says,

“What I'm carrying with me more is the inability to have the therapeutic interaction, you know, the personability of it. To hold their hand and have them see your face, sort of wearing that journey with them, meaning on her face, as opposed to this big mask and goggles.”

And then she went on like Laura to just tell us a story about somebody that she had cared for just the other day. She says,

“I had this gentleman just the other night who has advanced dementia. When I first introduce myself, I usually go into the room and I take down my mask six feet away so they can see my face and they know who I look like. And I have a button on that has my picture, but for any sort of personal care, I have to be all gowned up. I went in about an hour later to give him some care and I had to have all of my stuff on, and he was sort of half asleep and he woke up and he saw me there. And he was just terrified. Because I guess” she says, “I would look terrifying to him.”

And that for me hit home, because it shouldn't be that way because I introduced myself to him an hour earlier, it was jovial, it was welcomed, it was a sense of peace. He felt comfort. But at that moment, it really resonated with me how awful it is for these people. Their environment has changed so much. Their loved ones are not around as much as usual. And now you're essentially coming in and you're like this 'monster' (So this is her word). She says, *“Who is now expecting to what, give you a bed bath or a shower? How terrifying would that be?”* So Talia's concern that she is perceived as a 'monster' by her patients is something that we actually heard from other nurses as well, and using different words.

For example, another word that recurred was 'alien'. One of our participants who used the word 'alien', Zoe, she spoke about how the entire tone of her hospice had changed since COVID, that she feels that the anxiety of her patients is much higher, in part because of what it feels like to only ever encounter other people who are dressed in full PPE. Now, interestingly, Zoe has found one thing that sometimes helps her patients to recognize her when she is their nurse. Zoe actually has a very unique fashion style. During our interview, she was wearing these very large, almost fluorescent eyeglasses. And she tells us that while these glasses do not fit under her safety goggles, she has another pair that are bright red. She has become known amongst her patients as the nurse with the red glasses, to the point where when she enters a room in PPE, her patients immediately recognize her, “Oh, it's you?” they say. And so here again, I will invite you to think about, what other kind of creative ideas might be possible to connect with people despite having to wear full PPE whenever we interact with them.

Kath Murray:

Thanks, David. Again, comments are coming in and coming through.

Dr. David K. Wright:

When Zoe was talking with us about the transformations that have happened in her hospice, with patients experiencing their final days only to ever interact with other people in PPE, she made an analogy to the AIDS crisis, which was a time when people with the virus, so in that case, the HIV virus were viewed by society purely as a risk to other people and how dehumanizing and stigmatizing that was. And, you know, I think Zoe's analogy is so incredibly insightful and it brings me to another set of stories. Last summer I was part of a team that conducted focus group interviews - that just means group interviews, with representatives of an LGBTQ, lesbian, gay, bisexual, transgender, queer, and community organization that support older adults in the community. And we spoke to these people about their experiences of giving and receiving care, including during COVID-19. We asked them, what is important for someone from the outside, so meaning outside of the LGBTQ community, to know? They talked with us about how many people in this community are survivors of trauma and they wanted us to understand what that meant. One of our participants made a connection between his experience of living through the AIDS crisis and how those experiences are now being activated in COVID-19. These are his words:

"I can remember hauling people off bedpans because they were left there by nurses who would not enter the door. This pandemic, currently COVID-19, it's bringing back a lot of really tough memories."

And at that point, his voice cracked with emotion and other participants around our virtual focus group, other people that we could see on camera over zoom had started to nod. He continues,

"I can remember picking up a guy's lunch from outside the room because people wouldn't open the door and take it to him. We had to also take on the medical community and teach them about gays, about gay families. I think I was probably involved in 60 to 100 deaths."

I wanted to highlight this story for two reasons. One, because it's a great example of how our life experiences continue to affect us as we age, for years into the future. When caring for an older adult, it is impossible to know where they are at or what they've been through, unless we ask. And when we don't know their past, we may be missing very important information about how they are experiencing the present.

But another reason that I wanted to focus on this story is that it explicitly centers the perspectives of LGBTQ people, whose stories are often missing from our teaching and our practice in healthcare. This invisibility has huge consequences for the comfort, dignity, and quality of life of older LGBTQ people in care. For example, we know from research that LGBTQ people often return to the metaphorical closet when they enter long-term care, because this is not always perceived to be a safe environment where they can be truly themselves. In our focus groups, our participants talked about this phenomenon of returning to the closet in older age and how this is likely made even worse because of COVID. One of our participants said,

"I wouldn't be surprised to see within our community that people have started isolating again, almost subconsciously using the pandemic as an excuse to isolate again. We have worked so hard getting people in our community out. We have all encountered people coming to a dance for the first time in 30 years or coming up to the Pride parade and they're 80 something years old. And they're there for the first time. I can see this COVID lockdown, just having such a negative impact on people, just sending them right back into that closet, even subconsciously."

On this same theme, here is a story about a same-sex couple experiencing end of life care. The story is from before COVID, but I'm going to suggest a link to our COVID times in a minute. This story comes from a published article in the [December 2020 issue of *The Gerontologist*](#). The names of the authors are on the slide. This is the story of Esther and Kathy. They were a couple for 33 years. Esther explains that Kathy had a rare form of leukemia, and as she got sicker, they would be in and out of hospital. When they would go into hospital, Esther would always fill out the required forms and would always tick the married box. This became a problem for the couple as Kathy got closer to end of life. And I'm now going to read from the paper itself - this is the authors who are telling Esther story.

"Kathy and Esther started noticing subtle changes with the way a nurse was interacting with them. The nurse came less frequently to their room. And when he did, he spent noticeably less time in the room. The couple noticed that the nurse asked fewer questions than before. And the questions focused on medical needs rather than emotional ones. When the nurse did ask a question, very little eye contact was made with Esther and Kathy. As Kathy got sicker, she noticed the nurse's demeanor becoming more overt and negative when Esther disclosed their relationship status and therefore their sexual orientation. Kathy got anxious about how far this behavior would go and how it might influence the treatment and care she and Esther would receive. At the next appointment, Kathy told Esther, "Don't say anything about being married anymore." And so, Esther started checking the box for emergency contact instead of spouse. So that staff would think they were friends and not partners of 33 years. And what this meant was that when Kathy eventually did die, Esther was known as her best friend and not as her grieving spouse."

So here, I want us to come back to Brian and Joanne, and I want us to remember how important it was that Brian be able to trust the healthcare staff, trust the PSWs and the nurses in keeping Joanne connected to him. If Kathy and Esther had found themselves separated because of this pandemic, the way that Brian and Joanne were, would they have been able to trust their care providers in the same way?

We're coming to the end of the invitations for you to share your ideas. But I'm now actually asking you the exact same question that I asked you earlier. So earlier I asked you to think about somebody like Joanne in long term care. What are your ideas for helping somebody like that to feel seen and valued if they were separated from their loved ones because of COVID-19? And here I'm presenting the exact same

question. But let's think about somebody like Kathy, what are your ideas for helping someone like Kathy to feel seen and valued if she were separated from her loved ones because of COVID-19? And so at this point, please do answer this question. Please also, at this point, feel free to put into the chat, more general reflections, comments, questions, because we're coming to the end and it would be good for Kath and Michelle to have those. I'm not sure how busy the chat is, but there are a lot of you on the call so I'm sure that if not everybody's contributions, if we, if don't make it into the discussion that we have, you have, you know, there are more webinars forthcoming. So please do still put things in the chat, even if we don't have time to get to what you say. But as you continue to interact with the chat, I'm going to now conclude with what I hope are three main takeaway messages that if I've done my job properly, I've emphasized in this talk.

“The first point that I really want to make is that palliative care is ultimately about helping people to experience comfort, dignity, and quality of life before death, but also after death.”

For example, attending to the grief that family members have in the immediate aftermath of the death, caring for a body after death, in a way that promotes dignity and personhood, and also attending to the grief of families into bereavement. None of this work happens without PSWs. COVID-19 creates new levels of social isolation that cause suffering of patients, families, and staff. And we've seen examples of this, today, and we've also seen examples of how PSW can make a huge difference in supporting people in this social isolation. But I don't want to end this talk without emphasizing that, although it's important to focus on the contribution that PSWs make through their work, we also need to recognize their vulnerability, and ensure that they are provided the support that they need to be able to do this work. And I want to offer one final reflection about vulnerability and social support needs of PSWs. And I think this reflection applies to COVID, but it also applies beyond COVID. The main theme of this talk has been on recognizing the humanity of people that we care for and attending to their grief and attending to our own grief. When conditions are such that we cannot offer the type of care that we know that they deserve. All of that is very important, but we also need to be very aware of the ways in which the humanity of PSWs themselves can be at risk in our current healthcare climate. For example, in the research paper by Christine McPherson that I mentioned at the start of this talk, she documents that some PSWs experienced racism from clients and families, and she highlights that in comparison to the wider workforce, a higher proportion of PSWs are racialized and have immigrant status.

Now too often, the culture of our healthcare training normalizes these types of experiences. So experiences of being on the receiving end of a, for example, racist comments from clients and families as kind of a “hazard of the job.” For example, workers who are subjected to harassment, such as racial harassment, are expected to kind of put that to the side, not take it personally, and deliver nonjudgmental care anyway. I want to be super clear and real with everybody on this call that I wholeheartedly reject this logic. Violence is violence and personal support workers deserve to do their work in dignity and safety. The COVID-19 crisis has highlighted the vulnerabilities of the personal support worker workforce and how our system too often fails to adequately protect them. For example, it is absolutely unethical that while PSWs are lauded as the heroes and essential workers of this pandemic, they can feel forced to show up

sick to work during COVID-19 because without paid sick days, they cannot afford to stay home. So, there's a huge need for advocacy and leadership to attend to the working conditions that personal support workers inhabit, without doing so, none of what I've presented today in terms of the ethics of individual relationships between personal support workers and patients and families has any meaning.

To close I'll come back one last time to Brian and Joanne. Joanne actually died in January. And so, Brian is now grieving, and he takes comfort in the letters that he wrote. Here is an excerpt from an exchange that Brian had with a PSW before Joanne died. And so this is the PSW speaking, she told Brian,

"I'll tell you one thing, Brian, when Joanne passes, I will cry because these letters have made me get to know her, not as a resident, but as a person."

And I think ultimately that's the whole point, and the fact that this was able to happen even during COVID and even during what is inarguably the worst healthcare crisis we have ever seen in our lifetimes, is hugely inspiring. And it leads me to wonder, you know, COVID-19 has changed so much in our world, and we need to respond to that obviously, but what, what can COVID 19 not change or what should it not change? So that's the final reflection that I leave you all with. And I thank you very much.

Kath Murray:

David, thank you. And then, in the tradition of the First Nation folks in the community where I live, [Huy ch g'u](#), thank you. And I pay tribute to you for what you have done. Michelle, and David, your thoughts have been incredible. Michelle and I think have been writing notes as we've gone and taken notes from the chat room. There's lots of comments to thank you, David, right on the mark, et cetera. Michelle, do you want to do work your magic of just pulling together a couple of thoughts? I don't think we're going to be able to respond individually, but do you want to just pull together a few thoughts?

Michelle O'Rourke:

Absolutely, first of all, I want to thank all of you for sharing your ideas. And hopefully most people were able to see what each other wrote, but you know, some of those things that we talked about, how we keep people valued, being able to help with calls and video chats. One of the ones that I loved was I always tried to make sure my resident's phone is charged so that when their family calls there, their phone is ready for them. Finding time to sing, to hold hands. All of those things are so profound in helping that person feel valued and, you know, they don't take extra time. That intimacy that we share with the residents, which it's very difficult because we're wearing PPE and we have barriers, can still be expressed. And some of you had some really good ideas about how you can kind of help your residents and clients to recognize you.

I think one of the ones that was new for me was, you know, before you don your PPE, when you're standing at the doorway of the room to actually lift your mask where it's safe, just for a moment and show

your face and say, good morning, Mr. Jones, or, you know, being able to wear your picture, being able to maybe start with a funny joke so they kind of get to know who you are, as a person. So there's lots of different ideas for how we can stay connected and how we can also, you know, be able to make sure that people realize we want to connect human to human and not as, as an alien would. Other ideas for connecting with people, you know, helping people to feel seen, providing passionate care, wanting them to feel that I'm treating them with no judgment. And I think those last two, two stories were very profound and in how the impact is for us who are so close to them. And yet, just one thing that we can say or do can make a difference or even just a gesture. You know, I love my Angelou's saying about, you know, sometimes people forget what you said and what you did, but they're never going to forget how you made them feel. And the PSWs are so amazing for that at the hospice that I worked with, they were the ones who really had the privilege to have more of the intimate moments with the residents and their families. And so what you do is so important.

Kath Murray:

Thank you, Michelle, beautiful. And I was struck also by the number of people who mentioned keeping their phone charged, like so little and so crucial, so big. So thank you and David, I think we'll all go away, probably there'll be a number of us who will come back and want to listen again to your presentation and and listen to your stories. Thank you. And thank you for the research that you and Christine MacPherson are doing, that is also bringing the voice of personal support workers to the literature and to the table.

So, the next on the agenda, I would like everyone, who's still here, if they can to just put their name, if they want, their email, but their full name in the chat so that we can choose the name of the winner of the PACE for PSWs, we can choose the winner of that course from those people who are here.

And well, but I also want to just give you a little bit more information. I promised you that when the teaser at the beginning, so PACE for PSWs is a joint education project with Canadian Hospice Palliative Care Association, Hospice Palliative Care Ontario and Life and Death Matters. PACE for PSW is palliative care education specifically for personal support workers. And as we said before, also known as healthcare assistants, continuing care assistants and other similar care providers. The courses are specifically written for you to support you to learn the skills for providing hospice and palliative care and integrating a palliative approach, which talks about the integration of palliative care principles from time of diagnosis, through life, through declining, through death and following. So regardless of location or diagnosis.

The unique features of each of the courses, each course is interactive and includes videos, podcasts and learning activities. Each course is short and it takes approximately three hours to complete. You can learn when it's convenient for you, so if you're a normal night person, you can learn at night, you can learn in the day, whenever it works for you. You can select the courses that meet your current needs, or you can complete all 10 courses and receive a national certificate in palliative care from the Canadian Hospice Palliative Care Association, Hospice Palliative Care Ontario, and Life and Death Matters. Very, very exciting.

We thank CHPCA, HPCO, Health Canada, and the [Sovereign Order of Saint John of Jerusalem](#) for supporting this project. We acknowledged them and we acknowledged Richard and the techies that have helped make this happen too. Now, the recipient for the course will be contacted by email and will be presented during our next webinar on June 1st, when Michelle speaks about grief and our grief and COVID, and I've lost the name right in front of me here. So please Michelle chime in.

Before you finish, before you exit, please fill out the feedback on there's a quick survey. So just fill that out right away.

The recording of this session will be posted on the Life and Death Matters site. You'll receive a link to the recording in the next day or so.

If you want to connect with colleagues from across the country, I invite you to join the Facebook group LDM community, the Life and Death Matters community page. We welcome you and welcome discussion there. Love to see some of this, some of the reflections from this webinar entered in there and start discussion.

You'll also receive an email about the webinar on June 1st, and please share the emails with your friends and colleagues. Stay tuned for more information about page for personal support workers. And if you want to connect with us, please go to lifeanddeathmatters.ca and click on contact us.

Thank you for being here. I wanted to start today by saying I am a fan of PSWs and I have been a fan of PSWs for over 30 years. I have always felt that you are the, the hands, the heart, the eyes, the ears of the healthcare team. I hadn't thought about backbone, but that absolutely is true. And I often sympathize with you that you are also too often the nose of the healthcare team too. So with that, Michelle has a lovely tradition she does, which is putting her hand over her heart, which supposedly releases oxytocin, which is the hormone of attachment and love and caring. So, to you, we acknowledge the work that you do. We acknowledge the work that David has done and Richard and providing the technology here, and we send our care and our thoughts and our concerns to you. May you care for yourselves as well as you care for your people. And we hope to see you next month in the session on grief and your grief and working in the midst of this pandemic. Thank you. And you are welcome to make any continuing comments in the chat while we finished up.

Michelle O'Rourke:

As we sign off the zoom, there's also a dropdown quick survey from HPCO that shows up. So don't sign off zoom right away, watch for that survey.

Kath Murray:

Great. Thanks folks.



Michelle O'Rourke:

And we'll see you in June, have a great month, happy palliative care week!