

NATIONAL CITIZENS INQUIRY

Toronto, ON

Day 1

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EVIDENCE

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[00:00:00]

Shawn Buckley

You can please bring up Leanne Duke, who should be on Zoom.

Leanne, can you hear us? Can you give us your camera? There you are. And give us a sound test.

Leanne Duke

I can. Can you hear me?

Shawn Buckley

We can hear you. I'm wondering if you can adjust your camera. That's a little better. And we apologize that we've kept you waiting. These things are sometimes hard to time.

I'd like to start by asking if you could state your full name for the record and then spell for the record your first and last name.

Leanne Duke My name is Leanne Duke, L-E-A-N-N-E D-U-K-E.

Shawn Buckley Leanne, do you promise to tell the truth, the whole truth, and nothing but the truth?

Leanne Duke Yes.

Shawn Buckley

Now, my understanding is that you are an office manager; you deal with financial reporting and accounting and payroll and human resources and health and safety.

Yes.

Shawn Buckley

So, you've got quite a mixed bag. And my understanding is that you're here today to tell what happened with your father Wayne Duke when the COVID pandemic arrived, and we started having restrictions on us. So, can you basically start with explaining that you were his primary caregiver and what that means?

Leanne Duke

Yes, so I was my dad's primary caregiver. He had advanced Parkinson's disease and advanced dementia. So, he was living in a retirement home at the beginning of the pandemic.

Shawn Buckley

Okay, and what type of care did you give to your father?

Leanne Duke

When he first went to the home, they were supposed to take his care over, but there was a lot of problems with that. So, I would go in every single morning, Monday to Sunday, and I would provide his medical care. He had a tube that went into his stomach. There was a hole which was called a stoma; and so, the pump would diffuse medication into him consistently throughout the day. The stoma required proper cleaning every morning and night. So, every morning I would go in. I would provide his medical care. I would also clean his room. I would trim his nails, shave him, cut his hair, clean his dentures, stock the Depends in his drawer.

Shawn Buckley

So now, in addition to having the stoma, your father had another condition that made cleaning his room very important. Am I right about that?

Leanne Duke

Yeah, so that was his Parkinson's. He had advanced Parkinson's, so he couldn't have anything in front of him. His room had to be... the floors had to be free of objects. His furniture had to be around the perimeter of the room, because if anything was in front of him, like directly in front of him, his whole body would freeze, and he would fall.

Shawn Buckley

My understanding is, especially with regards to the stoma, you attempted to train the staff at the facility, but they just were not up to the task.

Leanne Duke

Yes.

Shawn Buckley

So, when you say you went in every morning before work, this was essential care that you were providing.

Yes.

Shawn Buckley

And then you're telling us you went every night for two or three hours.

Leanne Duke

Yeah, so every night before the first lockdown, I would go and do his medical care every morning. And then I would drop his dog off, who would stay with him for the day. And then as soon as I was done work, I would go, and I'd sit with him and hang out with him for two or three hours every night before I went home.

Shawn Buckley

Now, the first lockdown, in my understanding, came March 31st, 2020. Can you tell us about that experience and how it changed things?

Leanne Duke

So, I received a call on March 31st. It was probably around lunchtime. From the owner of the home, and she said I was no longer allowed in to provide his care and his dog was no longer allowed to be there either; so, she said, "when you're done work, you need to come get his dog, and you can no longer come in in the mornings to provide his care." So, I was locked out from March 31st until October 21st – was the day I was allowed back in.

Shawn Buckley

And then when you were able to attend back on, well let me just back up.

[00:05:00]

Even though you weren't able to attend after March 31st, you were allowed to take him to medical appointments, am I right?

Leanne Duke

Yes, so all social absences were not permitted. They weren't allowed to go out for social absences. But if they required a medical absence, I was allowed to take him to his medical appointments. He had a lot of medical appointments because in two and a half years, he lost 17 dentures. So, that required a lot of appointments to replace those. And so, every time I would take him out, I would check his stoma and it became extremely infected. And also, when I would be talking with him on the phone, he would be wincing in pain all the time, telling me how bad his stomach hurt. And not once did the home ever contact me as his power of attorney for care – as his substitute decision maker – to notify me of the state of his stoma.

Shawn Buckley

Okay, now you had actually documented what you're speaking about by taking photos of his stoma. Am I correct with that? And David, can you help me? I've got this up on the computer. Can you pull that up? So, Leanne, my understanding is these are all photos that you've taken.

Yes.

Shawn Buckley

I'll scroll down; well, actually I'll scroll up. You had typed in there, "This is how the stoma always looks in my care," and that's the top picture.

Leanne Duke

Yeah, so that's how the stoma is supposed to be.

Shawn Buckley

So, when you describe that, there's literally a tube going into his belly; there is a tube going into his belly here.

Leanne Duke

Yeah.

Shawn Buckley

And that doesn't look inflamed, or it doesn't look dirty at all.

Leanne Duke

No, and that's how it always looked when I was doing his care every morning.

Shawn Buckley

Okay, I'm going to scroll down to some other pictures you've taken. And you've typed into this document, "These are pictures taken of his stoma during the first lockdown. I took these pictures when I took him out to medical appointments."

Leanne Duke

Yes.

Shawn Buckley

So, we will enter this as an exhibit so that the commissioners will be able to refer to this whenever they want. But how would you describe the difference in these pictures, just for the record?

Leanne Duke

So, his stoma was just oozing all this discharge and pus. You can see what – they call it a skin tag, which developed right around the hole, that was very inflamed and large. And I'll also say, once I was allowed back in on October 21st – within one month, I pretty much had his stoma looking back to normal. But it was like this during the entire first wave's lockdown.

Shawn Buckley

And I'm just going to scroll down. There's another photo and you have typed on here, "This was the stoma on March 26, 2022, when the home changed his plan of care from cleaning his stoma morning and night 14 times a week down to three times a week."

Leanne Duke

Yeah. And the home told me that his stoma was not infected with this picture on that day. They told me there was absolutely no infection and his stoma was fine.

Shawn Buckley

So, not only are you seeing his stoma in just an awful condition, but he's reporting to you on the phone when you're having phone conversations, that it's uncomfortable?

Leanne Duke

Yeah, he wouldn't say it was directly related to his stoma; he had kind of lost that capacity. He was just – you'd be talking with him, and he would just start wincing and pain, like "ohhhh." He'd constantly be making those sounds when I was talking to him on the phone, and I'd ask him what was wrong. And he said it was stomach pains.

Shawn Buckley

Okay, now you had said earlier in your testimony that you weren't able to drop his dog off every day. So, can you explain for the commissioners what the routine was and tell us about this dog. And then tell us about the effect of your dad not being able to have the dog every day.

Leanne Duke

It was very detrimental to him. So, going to a home obviously wasn't my first choice but he required care 24/7. And it was a very big adjustment to him. So, being able to drop his dog off and have his dog spend the day with him... In spite of his Parkinson's, he would still go out walking every day. So, he would take his dog on these walks every day. And he had a background in training dogs.

[00:10:00]

So, he would sit there, and he would train his dog in his bedroom. And he just really enjoyed spending time with him. And when his dog was no longer allowed to go to the home to be with him, he kept thinking that he had his dog and he'd lost him. And so, he would actually start wandering.

There was a time one night – it was around midnight – I got a call from the home that my dad had run out and he was looking for his dog at midnight. Because he kept forgetting that his dog wasn't allowed there, and he kept thinking he lost him. There would be other nights I'd be talking with him on the phone, and he'd be all depressed and I'd say, "what's wrong?" And he said "well, you lost him," and I would say "I lost who?" And he said, "well you lost Ozzie," his dog. And I would say, "no, I didn't lose him, he's here with me." But he couldn't comprehend because he wasn't seeing his dog every day. And he became extremely, extremely depressed.

Shawn Buckley

Okay. And so, and my understanding is your dad had basically a walkout unit with his own door to the outside. So, even though he had his own door to the outside, they wouldn't let you drop his dog off for the day?

Leanne Duke

No.

Shawn Buckley

Now, when you were able to come back in October 2020, that was because they made an exemption for essential caregivers?

Leanne Duke

Yeah, so it was in September of 2020, I believe, the government classified essential caregivers and said they could no longer be restricted from providing care. So, the home finally let me back in in October to start providing his care again. So, when I was allowed back in to provide his care, they said, "you can just come in your dad's patio door in the morning." And at this time, public health was saying, if a caregiver was providing any type of care and you were in a certain proximity, you had to wear face goggles; you had to wear gloves; you had to wear a gown and a mask. And there were also all the screening questions you had to do. And I can say: not once during that time that I was coming in his patio door did the home ever screen me, did they ever ask me for my weekly PCR test result. And they were also the ones that were supposed to provide the gown, the gloves, and the eyewear. And not once did I ever wear anything like that while he was at the retirement home. I would just wear a mask and do his medical care every day.

Shawn Buckley

So, this home that wouldn't even allow you to drop his dog off at his door, when you were allowed to return back, didn't comply in any way with the testing, screening, and PPE requirements at the time.

Leanne Duke

Exactly.

Shawn Buckley

Now your dad eventually got moved to long-term care. Can you tell us about that?

Leanne Duke

Yes, so his dementia was getting worse, and the retirement home was quite negligent. So, on September 1st, 2021, he got a bed in a long-term care home. So, before he went to the long-term care home, I had told them I'm not vaccinated. The director of care said, "oh, that's not going to be a problem. You're still going to be allowed in." And so, from September until December, I would go in every single night. Well, actually in the first month that my dad was there, I was going in every morning, every night after work. And then I'd go back in at 10 o'clock to train the nurses on his care. So, they took over his stoma care. So then, come October, I was just coming in every day after work, and I was taking him out walking. He had a high incidence of falls, so they confined him to a wheelchair. So, he wasn't allowed to walk anymore. And I was very worried that he would quickly lose all his muscle mass. So, every single night after work, I would come in and I would walk him in

the parking lot. So, I'd come in and, I'd say, 90 percent of the time when I would get there, he'd be sitting in wet briefs. So, I would have to change him and clean him up, put new pants on him, and then we'd go out walking in the parking lot every day.

Shawn Buckley

And did a point come where you were no longer able to take your father out?

Leanne Duke

Yes, so on December 10th, I got a call in the afternoon.

[00:15:00]

That, due to my vaccination status, I was no longer permitted entry into the home. And it wasn't even in the government directives until December 15th. So, December 15th, the government followed suit and they banned all unvaccinated caregivers from long-term care.

Shawn Buckley

So, were you able to have him for any short-term absences after that time?

Leanne Duke

From December 10th until December 29th or 30th, the home and the directives allowed social absences at that time. But if I took my dad out on a social absence, when he returned, they required him to be antigen-tested upon return, and then he had to have a PCR test on day three and a PCR test on day five.

Shawn Buckley

Because of his dementia, that was problematic, wasn't it?

Leanne Duke

Yes, and his Parkinson's, he was constantly moving around. He had constant sudden movements. And there's a lot of literature on the negative effects of swabbing individuals with dementia. It can be a very scary experience for them. So, Christmas Day, my dad was technically still allowed to have a social absence. But prior to this, the activity director from the home called me and she said, "due to your vaccination status, if you take your dad out for Christmas, he will be required to be isolated for seven days in addition to all the testing."

So, it was a very hard decision to make. I said to myself, "this could be his last Christmas, you never know. So, do I leave him in there so that he doesn't have to go through the testing and be isolated for seven days, or do I take him out?" And I decided to take him out because, like I said, if this was his last Christmas and he spent it alone, it would just kill me inside. So, I took him out and he was very despondent, however. So, on December 10th, when I was no longer permitted entry, within three days, he lost his ability to communicate. He became completely despondent. He just, he gave up. There were so many lockdowns during the three years, and this was it for him. He just completely gave up. And so, when I brought him out for Christmas, he had no interest in opening presents. Mentally, he didn't really seem to be there. He was just despondent. He didn't care about food, which, if you

knew my dad, he loved food. And he didn't, he didn't care about food. He didn't care about his dog. He was just, he wasn't really there mentally.

So, I brought him out for Christmas, and then the next day, I called the home and said, "I'd like to speak with my dad." And the nurse told me, "You can't speak with your dad. He's in isolation." And I said, "well, surely you have to have a cordless phone." And they said, "no, we don't have a cordless phone here." I said, "you cannot lock my father up for seven days in a room, and completely deny him access to even speaking with his family." So, I spoke with the administrator, which is the owner, and also the director of care, and they said that they would get a cordless phone. But during that next week, they never told all of their staff. And so, I would call in, and the staff would tell me they didn't have a cordless phone. And I would say, "you do have a cordless phone." So, that week, I was only able to speak to him about three times, while he was completely isolated in his bedroom. And also, on the Saturday, I was telling him, "You have one more day; you're going to get out of isolation, you have one more day." And on the Sunday, I called him, and the nurse said to me, "I'll bring the phone to him." And I said to her, "what do you mean you'll bring the phone to him? He's supposed to be out of isolation." And the nurse said, "well, didn't you hear? The entire home is in lockdown."

My dad ended up spending a month straight locked in his bedroom all by himself. So, the effects of that mentally: he wasn't there anymore.

Shawn Buckley

Right, he wasn't able to recover from the isolation.

Leanne Duke

No, like I said, he lost his ability to communicate. In mid-February, social absences were permitted again, so I could at least get him out of the home, and take him home.

[00:20:00]

During the entire time when it was permitted. I would take him home every Saturday and have lunch with him and spend the afternoon with him. So, once that was permitted again in February of 2022, I would bring him home. He could no longer feed himself, so I'd make food, I would have to feed him. He couldn't communicate; he just completely gave up. I couldn't walk him anymore. He had completely lost all of his muscle mass. Because the home would tell me that, for them to have somebody walk him, due to health and safety reasons, they needed two people. But they were short-staffed all the time, so they didn't have two people to take the time to walk him. So, during the time I wasn't coming in, he completely lost his ability to walk, to communicate, to feed himself, everything.

Shawn Buckley

So, he's a completely different man.

Leanne Duke Yes.

Shawn Buckley

My understanding is, you were able to take him out for short-term absences, but from December 10, 2021, you were not allowed in. But then you were allowed in after he died.

Leanne Duke

Yes, so he suddenly passed away on September 17, 2022. So, I had not been allowed in the home from December 10 until September 17. And it was very difficult. How do you fulfill your power of attorney duties when you cannot see what's going on inside the home? The day after he passed away, I called the home and said, "I need to come and collect his belongings." And the home said, "yes, you can come in to get his things. So, my mom, my friend, and myself: we went there on September 18. And the home let all of us in. None of us were screened. None of us were tested. There was no documentation whatsoever. They just let the three of us go in, take his things, and go.

Shawn Buckley

So, this home that was so concerned about you showing up even if you were tested and screened, had no concern with the three of you going in and wandering around the facility.

Leanne Duke

Yeah. And on that note as well, I'll also say: during that time from February 22, 2022, until the day that he passed, I was not allowed inside the home. There came a point when I couldn't get my father into my car anymore. My friend would try and help me, but we were both getting hurt. My dad was getting hurt. So, I could no longer get my dad home. There was no accessible community transportation in my town due to the pandemic. So, I couldn't get my dad home with accessible transportation. So I was, however, permitted outdoor visits with him; so, I would go, and I would have an outdoor visit with him. Not once did they test me. I was never screened. My father wasn't screened after our outdoor visit, yet we would be in the same proximity had I been in the home, or had I taken him home on a social absence where he was being required to have all the testing.

Shawn Buckley

So, I'm going to ask you: having experienced all of this, if we were ever to face a situation like this again, how do you think we should have done things differently?

Leanne Duke

There are so many reports that are written by many levels of government. There's the National Seniors Council, the Chief Science Advisor. There's also the Patient Ombudsman who has released all these reports as early as 2020. And in these reports, they stated the importance of continued access to caregivers, to the effects of the lockdown. The government has not listened to any of the scientific evidence that came from these reports that talk about the detrimental effects on our seniors. There's the *Long-Term Care Act*—

Shawn Buckley

I do have to stop you, just because we're about nine minutes over. And like yourself, we've had another witness that's been waiting for a couple of hours. But is it fair to say that you're of the strong opinion that there's just no way that caregivers should be separated from loved ones?

There's not. A time when they're in a long-term care home is when they need their family the most.

[00:25:00]

My dad was already suffering from a disease that was taking away his body, that was taking away his mind. And then the government took away his family and his support, and he had to go through that alone. I would like to say that the government needs to treat our seniors with respect and without discrimination because they deserve to enjoy equal opportunity and be able to live fully in the life of the province, in the life of Canada, the same way as every other Canadian has been afforded.

Shawn Buckley

And, Leanne, I'll just ask the Commissioners if they have any questions for you. And they do not. So, on behalf of the National Citizens Inquiry, I thank you so much for sharing this story. I don't know if you can hear, but the audience is clapping.

It's just so very important to hear from people like you. And thank you so much for sharing this with us.

Leanne Duke Thank you.

[00:26:06]

