**Episode #1:**

(Background music: Welcome page with a blurry city street background. Header text fades in writing “Living with Long COVID in Canada: The St. John’s Rehab Sunnybrook Docu-series.” The subheader text fades in writing “Episode 1 of 5.” Another piece of text fades in writing “The Physical and Cognitive Realities.”)

(Background music continues. The Toronto landscape is followed by a city street partially showing St. John’s Rehab. Beth begins speaking over the video of the city street)

Beth: I pretty consistently have had extreme fatigue, body aches, joint pain, muscle pain, migraines, blood pooling, trouble regulating my body temperature fevers, something called post-exertional malaise, where if I do too much, I get flu-like symptoms 24 hours later. Pretty much full-body symptoms that do impact me every day.

(When Beth says “...extreme fatigue, body aches…,” the video cuts to Beth in an office, sitting at an angle to the camera. A small, blue textbox appears with white lettering in the bottom right corner with the words “Beth P.” Just below the blue textbox, a larger, white textbox appears with blue lettering with the words “Person Living with Long COVID.” The words “Social Media Activist, Spouse, Gamer, Gardener, Pet Mom” are just below that text)

(The video cuts to another woman, Susie in the same office, sitting at an angle to the camera. A small, blue textbox appears with white lettering in the bottom right corner with the words “Susie Goulding” Just below the blue textbox, a larger, white textbox appears with blue lettering with the words “Person Living with Long COVID, Patient-Partner,” The words “Founder of the Long Haulers Support Group Canada, Flower Shop Owner & Mom to Son and Fur Babies” are just below that text.)

Susie: My main issues are brain fog. I have aphasia now. It's difficult to find words.

It was important for me to come in earlier on in the day, because the later the day rolls by, the, the more my brain shuts down.

The gastrointestinal issues, I have issues with my body temperature regulation. So I've had many tests done, that have shown that I have difficulties, like severe difficulties with, cognitive processing speeds.

(The video cuts to a woman on the left side, Mandy and a man on the right side, Jeff, in the same office, sitting at an angle to the camera. On the left side, A small, blue textbox appears with white lettering in the bottom left corner with the words “Mandy O.” Just below the blue textbox, a larger, white textbox appears with blue lettering with the words “Caregiver to a Spouse Living with Long COVID & Mom.” On the right side, A small, blue textbox appears with white lettering in the bottom right corner with the words “Jeff O.” Just below the blue textbox, a larger, white textbox appears with blue lettering with the words “Person Living with Long COVID & Father.”)

Jeff: The major thing that I deal with is just crazy fatigue. Also, brain fog just can't gather my thoughts. I will lose track of what I'm saying in the middle of talking, or just be sitting in a room or things happening. And I will just zone out. Just go completely blank.

(When Jeff says “just go completely blank,” the video cuts to a city skyline and street. The video then cuts to a man, Logan with his back to the camera, sitting in an office working on a double-monitor desktop computer)

Logan: When I took this job,

(The video cuts to Logan and two women. One woman press “up” to use the elevator)

I did not imagine that I could be someone

(The video cuts to Logan’s face close to the camera at an angle. He is sitting in a room with three other women. A small, blue textbox appears with white lettering in the bottom right corner with the words “Logan Reis, MSc.” Just below the blue textbox, a larger, white textbox appears with blue lettering with the words “Research Coordinator, St. John’s Rehab Research Program.” The words “Lived experience with Long COVID, Student Mentor, Cat Dad” are just below that text. The video cuts to a wider shot of Logan and the three women in a sitting area)

who was on both sides of the research.

(The video cuts to Logan sitting in the office from other testimonials, sitting at an angle to the camera)

My first acute COVID infection was in July of 2021. And it hit me very hard. The first month I was basically out I couldn't I was basically bedridden. And at the time, I was writing my thesis, and I couldn't sit at my computer for more than an hour without feeling nauseous and needing to vomit.

(The video cuts to a close-up of trees. The video then cuts to Mandy and Jeff in the office with no textbox)

Jeff: At its worst, I had to ration my energy to go to the shower.

(The video cuts to a close-up of a shower faucet dripping as Jeff says…)

For a long portion of time, I was in bed 20 hours a day.

(The video cuts to a close-up of a woman’s hand driving. Over the video, Susie says…)

Susie: I would have to drive my son to school, and I could barely drive.

(The video cuts to Susie in the office)

Susie: I'd come up to a stoplight and look at it and wonder…

(The videos cuts to a stoplight. The stoplight then turns green)

Susie: …I could see the light is green. But it didn't register in my mind…

(The video cuts back to Susie)

Susie: …“what does green mean?” and I'm sitting there waiting for the information to come.

(The video cuts to the Toronto city skyline. It then cuts to a wide shot of St. John’s Rehab. Two cars appear from the left and right side and both drive across. Another woman, Abby begins speaking)

Abby: Evidence suggests…

(The video cuts to a woman writing on whiteboard)

Abby: …that 20% of the population is living with long COVID…

(The video cuts to a woman typing on a keyboard)

Abby: …So long COVID refers to

(The video cuts to Abby sitting in the same office where previous testimonials took place at an angle to the camera. A small, blue textbox appears with white lettering in the bottom right corner with the words “Abby Vijayakumar, MSc.” Just below the blue textbox, a larger, white textbox appears with blue lettering with the words “Research Coordinator, St. John’s Rehab Research Program.” The words “Researcher, Analyst and Violinist” are just below that text)

Abby: …a range of symptoms that persist for more than 12 weeks after COVID infection, whether it's confirmed or suspected.

(The video cuts to a window with colourful plaque. The heading reads “rebuilding lives” followed by several names. Another woman, Marina begins speaking over this scene)

Marina: So in 2022…

(the video cuts to a name plaque hanging on a wall. The plaque reads “B114.” Below that, the words “Dr. Marina Wasilewski, PhD” in bold. Below that, the word “Scientist” is written)

Marina: …myself and Dr. Robert Simpson…

(The video cuts to Marina sitting in the same office where previous testimonials took place at an angle to the camera. A large, blue textbox appears with white lettering in the bottom right corner with the words “Marina Wasilewski, PhD.” Just below the blue textbox, a large, white textbox appears with blue lettering with the words “Scientist, St. John’s Rehab Research Program.” The words “Assistant Professor (Status), Department of Occupational Science and Occupational Therapy, University of Toronto” are just below that text. The textbox then disappears)

Marina: …led a grant to the Canadian Institutes for Health Research to Learn more about the daily impact of long COVID on people's psychosocial health.

(The video cuts to a wide shot of the entrance for St. John’s Rehab. Marina starts narrating over this shot)

Marina: So this project was three phases. Our first phase was sort of the exploration phase…

(The video cuts to a plaque hung on the outside of St. John’s Rehab with a picture of priests and nuns sitting outside. One person is giving a speech. Below the photo, the plaque reads “Official Opening of St. John’s Convalescent Hospital). Below that, the date “May 22, 1937” is written)

Marina: …It was very, you know, categorical measurement numbers oriented.

(The video cuts back to Marina in the office)

What we really started to hear was that what was missing was education, and awareness. People simply didn't know enough about long COVID. You know, when you ask the average person on the street about cancer or stroke, people can tell you about that. They understand the gravity.

(The video cuts to a board. The title reads “what’s new in rehab research.” The subheading reads “Living with Long COVID: Co-designing a Digital Map of Peer Support across Canada.” The board goes on discuss information regarding Long COVID)

Marina: …And that was sort of where our project took a bit of a different direction.

(The video cuts to a close-up of the subheading “Living with Long COVID: Co-designing a Digital Map of Peer Support across Canada”

We felt what was really needed was more of an education…

(The video cuts to other parts of the board)

Marina: …and awareness hub.

(The video cuts to three women, one of them Abby looking at a computer. One of the women points at the desktop screen. Marina begins narrating over)

The second phase of our research…

(The video cuts to a close-up of one of the three women staring at their desktop screen)

Marina: …was what we called our co-design phase…

(The videos cuts to Marina back in the office)

Marina: …and that was really the meat of the project. And in my opinion, the most unique and fun part about it was really working hand-in-hand with people with long COVID caregivers and health and social care providers to be able to create something that was by the stakeholders and for the stakeholders. And so then we moved into the third phase of the project, which we call the sort of pre-implementation phase, where we held a World Cafe with 28 Long COVID stakeholders, including people with Long COVID, caregivers, health and social care providers, decision-makers in the health and social system. And so we took this back to that stakeholder group and said sort of “here are our ideas. What do you think?” And really, there was a resounding agreement that the docu-series was really important to be able to give a face, a voice and a name to Long COVID in Canada.

(The video cuts to a close-up of Logan and two other women. It then cuts to a woman writing on a whiteboard. Another woman, Michelle starts narrating over the video)

Michelle: Given there still a lack of understanding across a lot of health care professionals…

(The video cuts to Michelle sitting in the same office where previous testimonials took place at an angle to the camera. A large, blue textbox appears with white lettering in the bottom right corner with the words “Michelle Di Lauro.” Just below the blue textbox, a large, white textbox appears with blue lettering with the words “Service Coordinator, University Health Network - Toronto Rehab.” The words “Occupational Therapist, Foodie, Runner, Traveler, & Dog Mom” are just below that text. The textbox then disappears)

Michelle: …especially the primary care field, family physicians, and in the workplace. This has also been a challenge for individuals trying to go back and having employers not fully understand the accommodations they may need or the symptoms they suffer from. So I would say again…

(The video cuts to two women walking in a park with their backs to the camera)

Michelle: …the first step is letting our patients know that we understand…

(The video cuts to two women sitting on a park bench, talking and laughing)

Michelle: …we're listening to what you're going through and…

(The video cuts to Logan, Abby, and another woman sitting at a table talking)

Michelle: …validating their experiences. We hear you, you're not alone…

(The video cuts to Michelle back in the office)

Michelle: …and we have worked with individuals who have made some progress and gotten back to things that are meaningful to them, or even to their day-to-day activities, again, has been really helpful. We do need to continue to advocate for more resources in the acute care setting, primary care, and rehab for these individuals and support for their family members and caregivers as well.

(The video cuts to the same two women sitting on a park bench. It then cuts to Jaylyn sitting in the same office where previous testimonials took place at an angle to the camera. A large, blue textbox appears with white lettering in the bottom right corner with the words “Jaylyn Leighton, PhD.” Just below the blue textbox, a large, white textbox appears with blue lettering with the words “Postdoctoral Trainee, St. John’s Rehab Research Program.” The words “Researcher, Educator, Dog Mom, and Travel Enthusiast” are just below that text. The textbox then disappears)

Jaylyn: I think the biggest thing is is really focusing on the fact that long COVID doesn't just impact one's physical health, but it also impacts their psychological and their social or psychosocial health and well-being.

(The video cuts to the same two women walking with their backs to the camera. The video is shrunken down to fit the credits. A black background with white lettering appears saying “For more information, please visit the ‘Long COVID Education and Awareness Hub.’ Below that, the “[www.LivingWithLongCOVID.ca](http://www.livingwithlongcovid.ca)” hyperlink appears. The text disappears. The video dissolves into the exterior of St. John’s Rehab. The words “Brought to you by” followed by the Sunnybrook St. John’s Rehab logo appear. Below that. The words “with editing and production by” followed by The Influence Agency logo appear. The text disappears. The video dissolves into a close-up of a woman’s hands using a hand sanitizer dispenser. The words “With funding supporting from” followed by the Sunnybrook St. John’s Rehab, Canadian Institutes of Health and Research, Sunnybrook Research Institute, Rehabilitation Science Research Network for COVID, and the Temerty Faculty of Medicine University of Toronto Logo. The text and logos disappear. The text reads “a heartfelt appreciation goes out to the individuals featured in this documentary series, as well as to the community of contributors who have been involved in this project from its inception.” The video dissolves to a Sunnybrook bus with the Sunnybrook logo and the words “this place is special written on the side. “Special” is written much larger. The credits begin to roll with “Participants” as the header and the following names: Beth P., Jeff O., Mandy O., Susie Goulding. The “Health Care Practitioners” heading appears followed by the following names: Alexandra Rendely, MD, FRCPC, Michelle Di Lauro, OT Reg. (Ont.). The “Research Team” heading appears followed by the following names: Abby Vijayakumar, MSc, Jaylyn Leighton, PhD, Logan Reis, MSc, Marina Wasilewski, PhD, Robbery Simpson, PhD, MBChB (MD). The bus begins to drive off. The screen fades to black)

**Episode #2:**

(Background music: Welcome page with a blurry city street background. Header text fades in writing “Living with Long COVID in Canada: The St. John’s Rehab Sunnybrook Docu-series.” The subheader text fades in writing “Episode 2 of 5.” Another piece of text fades in writing “Coping with Anxiety, Fear, Loss, and Isolation”)

(Background music continues. The Toronto landscape is followed by a city street partially showing St. John’s rehab. Jeff begins speaking)

(The video cuts to the exterior of St. John’s Rehab church. It then cuts to the inside of the church with stained glass. Jeff begins speaking over the video of the city street)

Jeff: For a while, yes, I was a shell of myself…

(The video cuts to a woman on the left side, Mandy and a man on the right side, Jeff, in the same office, sitting at an angle to the camera. On the left side, A small, blue textbox appears with white lettering in the bottom left corner with the words “Mandy O.” Just below the blue textbox, a larger, white textbox appears with blue lettering with the words “Caregiver to a Spouse Living with Long COVID & Mom.” On the right side, A small, blue textbox appears with white lettering in the bottom right corner with the words “Jeff O.” Just below the blue textbox, a larger, white textbox appears with blue lettering with the words “Person Living with Long COVID & Father.” The text disappears)

Jeff: …now, it's been three years, we've done a lot of things to try and help me get better, and I've improved a bunch, but you talk to elderly people, and they're like, “I'm trapped in my own body” and that's kind of how I feel like right now.

(The video cuts to a close-up of a tree from the bottom to the top of the trunk. Jeff begins speaking. It then cuts back to a close-up of Jeff)

Jeff: I can't even think about things the same way that I used to. When we did the introduction was like, “who are you?” and it's like, that is still a hard thing for me to deal with because so many people define themselves by what they do, by their job or their career. And I had to let that go, I had to go. “That's not who I am.”

(Background music: The video cuts to the Toronto skyline while the Sun is setting. Susie begins narrating over the video)

Susie: I used to be able to, you know, I was sharp, I could answer things…

(The video cuts to Susie in the same office, sitting at an angle to the camera. A small, blue textbox appears with white lettering in the bottom right corner with the words “Susie Goulding” Just below the blue textbox, a larger, white textbox appears with blue lettering with the words “Person Living with Long COVID, Patient-Partner,” The words “Founder of the Long Haulers Support Group Canada, Flower Shop Owner & Mom to Son and Fur Babies” are just below that text. The text then disappears)

Susie: …I had a wicked sense of humor, I was witty and now, because of the loss of words and the processing speed, it's, it can be very difficult to communicate with people. So I find myself, my personality has changed, where I used to be very engaged in conversation. Now I find where I just kind of shy away from situations and end up being the person who will ask questions, and being the listener, because I don't want to speak.

(The video cuts to a warning sign with a yellow background. An image of a stop sign is large followed by the text “do not visit if you have any of these symptoms” with images of figures coughing, blowing their nose, suffering from a fever, suffering from a sore throat, sitting on the toilet, and vomiting with the corresponding words “cough, runny/stuffy nose, fever, sore throat, diarrhea, vomiting.” A smaller “do not enter” sign is shown below. Susie begins speaking)

Susie: I've been through so much in the last four years…

(The video cuts to a close-up of a woman grabbing a disposable mask from a dispenser)

Susie: …that has changed me as a person…

(The video cuts to a bird’s eye view of a large group of people)

Susie: …It's changed how I see the world. It's a ripple effect.

(The video cuts back to Susie in the office)

Susie: …Also, it's not just me, but it's also changed my son's life, right? I'm no longer the fun parent who can do anything on a whim, you know. It’s unfortunate that he's, you know, he's 15 now, going to be 16. And he understands that mom has, Mom has issues. So it's not just me that it affects. It’s my family, it's my dogs. I feel a sense of loss for my son.

(The video cuts to a close-up of a bride and groom getting married and kissing. It then cuts to Beth in the same office as previous testimonials, sitting at an angle to the camera. A small, blue textbox appears with white lettering in the bottom right corner with the words “Beth P.” Just below the blue textbox, a larger, white textbox appears with blue lettering with the words “Person Living with Long COVID.” The words “Social Media Activist, Spouse, Gamer, Gardener, Pet Mom” are just below that text)

Beth: I got married in February of 2020 and went on my honeymoon and I caught COVID two weeks after I got back from my honeymoon. So my husband, I joke that he married a lemon because he did not marry the woman that he proposed to.

(The video cuts to a man and woman holding hands during a sunset)

Beth: …And I have been very, very lucky with him and his caregiving and I'm very grateful for him.

(The video cuts back to Beth in the office)

Beth: …It has been a challenge in other relationships. Unfortunately, given the fact that COVID is severely politicized. I do have friends who do not believe in Long COVID. I have people who hear snippets of symptoms that I have, and they say, “oh, yeah, I have that, too. It's not that big a deal.”

(The video cuts to a dining room while Beth narrates over)

Beth: …I have just seen a lot of friends kind of dropped by the wayside. And that's been disappointing and hard.

(The video cuts back to Beth in the office)

Beth: Every second of the day, I am cognizant that I'm living in a body with Long COVID. I have to very carefully plan out my daily activities because it's not just physical things that actually can drain my body, it's mental and cognitive things as well. Social interactions. On any given day or given week, I am planning out how many interactions I'm having with other people, how many times I'm leaving the house. “If I do laundry today, what's going to be the impact tomorrow?” I know I'm, I'm well supported compared to some other folks but it still is a challenge to even maintain those relationships given my physical limitations.

(The video cuts to a close-up of a tree. It then cuts to a close-up of Jeff)

Jeff: There are definitely people who are invested. “We've read that this kind of thing helps with chronic fatigue. Do you want to try it? We will fund you because it's not covered.”

(The video cuts to a wider shot showing both Jeff and Mandy)

Jeff: We've also had people that we don't see them as much anymore. It's not like they don't want to still be friends, they still hang out, we still hang out, we still do stuff, we don't do it nearly as much because it makes people uncomfortable. People talk work, or they talk about what's going on in their lives and what's going on in my life has been the same thing for three years. But then there's also people that have reached out to us and go, “Hey, I'd like to come over for coffee. And while I'm here, let's fold laundry…

(The video cuts to a close-up of a woman folding a towel in a laundry hamper in her living room. It then cuts to a close-up of a lawn mower cutting grass)

Jeff: …I want to come I want to spend time with you but I know that you're struggling for time and things to do, so I'm gonna help you do some chores.”

(The video cuts to a wide shot of the entrance to St. John’s Rehab. It then cuts to Michelle sitting in the same office where previous testimonials took place at an angle to the camera. A large, blue textbox appears with white lettering in the bottom right corner with the words “Michelle Di Lauro.” Just below the blue textbox, a large, white textbox appears with blue lettering with the words “Service Coordinator, University Health Network - Toronto Rehab.” The words “Occupational Therapist, Foodie, Runner, Traveler, & Dog Mom” are just below that text. The textbox then disappears)

Michelle: What we see with a lot of our long COVID patients is feelings of anxiety, depression or just low mood, because they really can't get back to doing the things that are meaningful to them. They don't want to continuously talk about their symptoms and be so focused on their illness because they feel that eventually, their family members are going to be tired of hearing this continuously time after time and it just contributes to feeling like a burden. We have patients say they're feeling isolated because they used to maybe be very social people, love to go out with family and friends and now even if they wanted to, they don't have the energy to so they find maybe they're only leaving the house if they have to go to a medical appointment. So a lot of our patients are Saying they feel a bit housebound now.

(The video cuts to a man looking sad outside of a window. It then cuts to Alexandra sitting in the same office where previous testimonials took place at an angle to the camera. A large, blue textbox appears with white lettering in the bottom right corner with the words “Alexandra Renely, MD, FRCPC.” Just below the blue textbox, a large, white textbox appears with blue lettering with the words “Physical Medicine and Rehabilitation, University Health Network - Toronto Rehab.” The words “Clinician in Quality and Innovation, University of Toronto, Department of Medicine, Division of Physical Medicine and Rehabilitation” are just below that text. The textbox then disappears)

Alexandra: the disease itself can impact a patient where one of the symptoms is anxiety or depression or a change in their mental health. And then secondly, when there's a loss in function and a patient's self-identity has changed, whether or not there's a formal diagnosis of mood disorder or anxiety…

(The video cuts to a woman looking sad outside of a living room window. It then cuts back to Alexandra)

Alexandra: …you really do see a change in a patient's mental state and so we want to make sure that we're addressing those needs as part of a holistic comprehensive rehab program.

(The video cuts to Michelle back in the office)

Michelle: We also have noticed patients have big fears of reoccurrence. So, even if they are making some gains and getting back to some of their day-to-day activities, they might be worried or resistant to be going back out in the community engaging in the way they did, because of that fear of reoccurrence. So, it's important our teams and social workers are aware of this to really support full integration back into community or finding those ways that are comfortable for patients to re-engage.

(The video cuts back to Jeff and Mandy in the office)

Jeff: I have to re-define myself because the way that most people do it doesn't work. We all put so much worth based our worth on what we do or what we have or what's going on and it's like, “I can't do that. It doesn't work. If I base my worth off of that, I'm nothing.”

(The video cuts to Mandy speaking while Jeff re-adjusts himself in his seat)

Mandy: And redefining yourself doesn't necessarily have to be a bad thing. It doesn't have to be “I’m the shell of a person. I can't, I can't move forward. I'm sick.” Like, it doesn't have to be kind of in that “woe is me” mentality. It can be rebuilding or redefining, finding new things that you love to do. Yeah, redefine your life, redefine what's important to you. Wefound that overall things now family is a priority. And before it was like making the bills and the budget and working, but that's not - Yeah, we thought we were finding fulfillment in life. And I think we feel a little bit more fulfilled now.

Jeff: or built a much better sense of self. And that doesn't just affect, you know, how I describe myself to others, or how others see me, it describes how I see myself. And if anything else that has given me self-confidence of doesn't matter what I do. Now, it's “who am I?” Well, I'm Jeff, I Mandy's husband, I’m my daughter's father. Identity is built a lot more around, you know, family and my belief and all of that and I feel like I am so much more mentally healthy because of that.

(The video cuts to a forest with trees. It then cuts back to Marina in the office)

Marina: If you ask the average person on the street about long COVID, people really felt that there wasn't a lot out there. People didn't know about this condition. They would say you know, “I have brain fog” and people were like, “what's that? How is that even impacting you? What is Long COVID even?” and because Long COVID is what we call a “hidden disability,” a lot of the symptoms aren't visual. People often look fine but aren't fine and so that kind of adds to the feeling that they're being told that there's nothing wrong with them even though there is.

(The video cuts to the same two women walking with their backs to the camera. The video is shrunken down to fit the credits. A black background with white lettering appears saying “For more information, please visit the ‘Long COVID Education and Awareness Hub.’ Below that, the “[www.LivingWithLongCOVID.ca](http://www.livingwithlongcovid.ca)” hyperlink appears. The text disappears. The video dissolves into the exterior of St. John’s Rehab. The words “Brought to you by” followed by the Sunnybrook St. John’s Rehab logo appear. Below that. The words “with editing and production by” followed by The Influence Agency logo appear. The text disappears. The video dissolves into a close-up of a woman’s hands using a hand sanitizer dispenser. The words “With funding supporting from” followed by the Sunnybrook St. John’s Rehab, Canadian Institutes of Health and Research, Sunnybrook Research Institute, Rehabilitation Science Research Network for COVID, and the Temerty Faculty of Medicine University of Toronto Logo. The text and logos disappear. The text reads “a heartfelt appreciation goes out to the individuals featured in this documentary series, as well as to the community of contributors who have been involved in this project from its inception.” The video dissolves to a Sunnybrook bus with the Sunnybrook logo and the words “this place is special written on the side. “Special” is written much larger. The credits begin to roll with “Participants” as the header and the following names: Beth P., Jeff O., Mandy O., Susie Goulding. The “Health Care Practitioners” heading appears followed by the following names: Alexandra Rendely, MD, FRCPC, Michelle Di Lauro, OT Reg. (Ont.). The “Research Team” heading appears followed by the following names: Abby Vijayakumar, MSc, Jaylyn Leighton, PhD, Logan Reis, MSc, Marina Wasilewski, PhD, Robbery Simpson, PhD, MBChB (MD). The bus begins to drive off. The screen fades to black)

**Episode #3:**

(Background music: Welcome page with a blurry city street background. Header text fades in writing “Living with Long COVID in Canada: The St. John’s Rehab Sunnybrook Docu-series.” The subheader text fades in writing “Episode 3 of 5.” Another piece of text fades in writing “Navigating the (In)visibility of Long COVID.”)

(Background music continues. The Toronto landscape is followed by a wide shot of St. John’s Rehab. The video cuts to a sign outside St. John’s Rehab saying “Stop” in all capital letters followed by the text “clean your hands) with a graphic of hands being washed with soap. The camera drops to reveal another sign saying “please wear the mask provided upon entry. Underneath the text, there is a figure with a disposable face mask with the words “thank you” below the figure. Susie begins speaking over the video of the sign)

Susie: People very close to you, can you no question…

(The video cuts to Susie in an office, sitting at an angle to the camera. A small, blue textbox appears with white lettering in the bottom right corner with the words “Susie Goulding” Just below the blue textbox, a larger, white textbox appears with blue lettering with the words “Person Living with Long COVID, Patient-Partner,” The words “Founder of the Long Haulers Support Group Canada, Flower Shop Owner & Mom to Son and Fur Babies” are just below that text. The text then disappears)

Susie: …and you're left to prove that you're actually sick. They think, “well, you look fine to me and so you can't be having any issues and well, you're getting older, so that just comes with age” and you try to tell them, you know how your life is and, and they don't want to hear it. They just, you know, so they they don't they lack empathy and they lack understanding, because this is an invisible illness.

(The video cuts to a top-down view of a beach. Beth starts narrating over the video)

Beth: I do try to prop myself up and look as normal as possible when I am interacting with folks.

(The video cuts to Beth in the same office as previous testimonials, sitting at an angle to the camera. A small, blue textbox appears with white lettering in the bottom right corner with the words “Beth P.” Just below the blue textbox, a larger, white textbox appears with blue lettering with the words “Person Living with Long COVID.” The words “Social Media Activist, Spouse, Gamer, Gardener, Pet Mom” are just below that text. The text disappears)

Beth: And I think that's another piece of the challenge is there sometimes there's a disconnect between how someone may see me if I meet up with them for lunch or dinner versus the rest I had to do to get to that point to hang out with them and the rest that I had to do a day or two after to recover from that time. I know, on the inside, I feel very different. I don't know if oftentimes, people see how different I am and I'm trying to redefine myself in this new chronically ill body. And it's a, it's a challenge.

(The video cuts to a woman looking said outside of a window while it rains. It then cuts to a woman on the left side, Mandy and a man on the right side, Jeff, in the same office, sitting at an angle to the camera. On the left side, A small, blue textbox appears with white lettering in the bottom left corner with the words “Mandy O.” Just below the blue textbox, a larger, white textbox appears with blue lettering with the words “Caregiver to a Spouse Living with Long COVID & Mom.” On the right side, A small, blue textbox appears with white lettering in the bottom right corner with the words “Jeff O.” Just below the blue textbox, a larger, white textbox appears with blue lettering with the words “Person Living with Long COVID & Father.” The text disappears)

Mandy: And that's the invisibility of it, right, where people see him at a family function and he's got energy and he's doing okay, and they don't see necessarily that he declines throughout the visit. They don't see that he's got to rest before and after. They just see Jeff and think “he's doing not so bad.” But when you look at the whole picture, then it ultimately becomes a different, a different ballgame, right?

(The video cuts to a hospital waiting room with a nurse tending to the patients. Susie narrates over the video)

Susie: I asked to see a neurologist and she did all these tests…

(The video cuts back to Susie in the same office)

Susie: …She did some walking, a gait test and, I literally fell on the floor in her office, walking that straight line. I couldn't keep my balance. I was a disaster. My doctor, my GP I called up after and the results came in and I said “so, what did the neurologist-” thinking she was going to confirm that there was some kind of issue and she the so the my doctor, my GP said “the only thing she wrote in your report was that you're suffering from anxiety [laughs]”

(The video cuts to a woman looking sad outside of a window while it rains. Susie narrates over the video)

Susie: struggles like that just really beat you down.

(The video cuts back to Susie in the same office)

Susie: To be made to think that you're losing your mind because there's nothing wrong with you. “Nothing shows up on the test, you're fine. There's nothing wrong with you, we're just going to chalk it down as you're a woman, and you're suffering from anxiety.”

(The video cuts to two women with their backs to the camera walking in a park. It then cuts to Alexandra sitting in the same office where previous testimonials took place at an angle to the camera. A large, blue textbox appears with white lettering in the bottom right corner with the words “Alexandra Renely, MD, FRCPC.” Just below the blue textbox, a large, white textbox appears with blue lettering with the words “Physical Medicine and Rehabilitation, University Health Network - Toronto Rehab.” The words “Clinician in Quality and Innovation, University of Toronto, Department of Medicine, Division of Physical Medicine and Rehabilitation” are just below that text. The textbox then disappears)

Alexandra: I think as a rehab physician, normalizing this to a patient with Long COVID is very important. Both normalizing it but also teaching the patient strategies on how they can speak about it, both to their health care provider to their workplace, to their friends or family, using different descriptors or different ways that they can express themselves is going to be part of my job in teaching them. But it doesn't just affect the patient, it really does impact their whole support network, their family, their caregivers, because to the outside, it's hard to recognize that a patient can be so debilitated by the symptoms that really don't present themselves externally. We really want to help a patient recognize that, a, they're not alone. This is this is a normal part of what we do in our rehab field, and how can we help them explain that to others that might allow them to feel more supported?

(The video cuts back to Mandy and Jeff in the same office)

Mandy: We were very, like, thankful to have to talk to that we have because we like there are a lot of people that kind of struggle with finding that doctor that believes that long. COVID is a thing.

Jeff: Talking to doctors who understood what was going on was so validating. I'm starting to think I'm cruel and crazy. Like Like, maybe “this isn't as bad as I'm making it out to be I'm just wallowing” And then it's like, oh, no, no, okay. There are people who get it and going like, “No, you're struggling with stuff and it's not just in your head.” So that's huge.

(The video cuts back to Alexandra in the same office)

Alexandra: I’ve had patients come to me and say, “have you seen this study?” Or “have you read this book?” and as much as I stay on top of the information, it would be a full time job to read every single research article. So, I love when patients are proactive in their care and bringing things forward that I can then read that I might not have known. When you think that patients mobilize themselves as early as May 2020 to say, “Hey, I've recovered from the acute infection but something is still wrong” and through the power of social media, we're able to band together and not only create a name but then create a diagnosis and have the World Health Organization come out with a definition and have the ICD 10 codes updated. I think that just speaks to the need to listen to patients at all times.

(The video cuts to Michelle sitting in the same office where previous testimonials took place at an angle to the camera. A large, blue textbox appears with white lettering in the bottom right corner with the words “Michelle Di Lauro.” Just below the blue textbox, a large, white textbox appears with blue lettering with the words “Service Coordinator, University Health Network - Toronto Rehab.” The words “Occupational Therapist, Foodie, Runner, Traveler, & Dog Mom” are just below that text. The textbox then disappears)

Michelle: Patients are out there trying to advocate for themselves, bring awareness that their symptoms are real. It's they're not just because of anxiety. They're actually because of a virus. And the self advocacy that patients have had to do for themselves is quite astounding. I've never had so many phone calls from people in the community suffering or family members, begging for services for their family members suffering with Long COVID.

(The video cuts to a doctor reviewing documents. Beth narrates over the video)

Beth: I've had to explain what long COVID is to a shocking number of medical professionals.

(The video cuts to Beth she was in before)

Beth: I've had to do a lot of my own research, stay up to date on studies, bring that information. So when I'm being pushed into some dangerous therapies that have been disproven in the existing infection, illness induced community, I have had to point out the research that shows that what's being recommended to me is dangerous, and that is a struggle in a medical setting because there is that power dynamic. You're very much at the mercy of the doctor that you're sitting across from. I've literally had doctors sit across from me and say, “what what do you want me to do for you?” And if I didn't have the research, and done some studying, I wouldn't know what to ask for.

(The video cuts to 5 women looking at a desktop screen followed by a closer shot. It then cuts to Jaylyn sitting in the same office where previous testimonials took place at an angle to the camera. A large, blue textbox appears with white lettering in the bottom right corner with the words “Jaylyn Leighton, PhD.” Just below the blue textbox, a large, white textbox appears with blue lettering with the words “Postdoctoral Trainee, St. John’s Rehab Research Program.” The words “Researcher, Educator, Dog Mom, and Travel Enthusiast” are just below that text. The textbox then disappears)

Jaylyn: In Canada, under kind of more medicalized approaches to care, there needs to be that diagnosis first before people can access rehab. And so for people with Long COVID, when there wasn't diagnostic criteria available yet for Long COVID, we learned for people that they had a lot more challenges to to accessing different rehab or care supports. With long COVID not yet being recognized as a disabling condition, it makes it really challenging them to get short and long term disability, it makes it challenging for folks to have insurance and go through the insurance claims process because Long COVID isn't being recognized.

(The video cuts to two women talking on a park bench behind a tree. It then cuts to a close-up of Mandy in the same office as previous testimonials)

Mandy: The frustrating thing is we've applied for ODSP and we've been denied. We've applied for CPP disability and we've been denied because (Mandy uses airquotes) it's not a disability or (Mandy uses airquotes again) he hasn't been sick long enough. How long is not long enough? We applied when he was two years into this While research is happening and funding is happening, it’s not happening fast enough. We're living on a single income that barely covers everything that we need.

(As Mandy continues taking, the video cuts to a food bank with two female volunteers handing food to a man in need)

Mandy: You we're relying on community support, like the food bank to have to explain to people that you don't have ODSP ODSP.

(The video cuts to a close-up shot of bills, calculators, bills, and pens on top of each other in a disorganizaed fashion as Mandy continues to narrate. It then cuts to a disorganized pile of envelopes)

Mandy: And they're like, What do you mean, “he doesn't have ODSP? That just makes sense.” Unfortunately, all the evidence that we have, it makes sense why they denied his appeal.

(The video cuts to a wider shot of Mandy and Jeff in the same office as previous testimonials)

Mandy: His breathing tests have come back normal. Your CAT scans have come back normal. Your bloodwork has come back normal. Everything seems normal, but it's not. And how do you communicate that to people, to doctors, to specialists, to you know the government to benefits to covering certain things? I don't want to say everything has financial but like that gives you some freedoms and that's the freedom that we don't have.

Jeff: It’s tiring, but we also sit on the point of “somebody has to do it.” Somebody has to be the first one to go through it so that others can get help without nearly as much trouble and if it's not gonna be us being the first one and we're gonna go without who's gonna who's gonna be.

(The video cuts back to Susie in the same office as previous testimonials)

Susie: It’s really important be compassionate and to for professionals to give compassionate care.

(The video cuts back to Mihcelle in the same office as previous testimonials)

Michelle: I think for any healthcare practitioner working with individuals that have had Long COVID, it is our job to really listen and validate their symptoms and their experiences.

(The video cuts back to Mandy and Jeff in the same office as previous testimonials)

Mandy: If you've got a friend in your life or if you've got know somebody that is struggling with Long COVID, just because they're not reaching out doesn't mean that they don't need the help they need the help. Reach out, be that person. And that might be the silliest thing, like cutting the grass, (Mandy and Jeff in unison) or doing the laundry. It might be something silly, it might be something small but know that you're impacting them a hundredfold because it's not to you. It’s something little. But to the person that's struggling. It's like phenomenal.

(The video cuts to close-up of a silhouette of a woman during a sunset)

Mandy: it's very hard to advocate for myself as a caregiver because I have to do all these things that then leaves next to no time in the day to help advocate for Jeff, let alone advocate for myself.

(The video cuts to the same two women walking with their backs to the camera. The video is shrunken down to fit the credits. A black background with white lettering appears saying “For more information, please visit the ‘Long COVID Education and Awareness Hub.’ Below that, the “[www.LivingWithLongCOVID.ca](http://www.livingwithlongcovid.ca)” hyperlink appears. The text disappears. The video dissolves into the exterior of St. John’s Rehab. The words “Brought to you by” followed by the Sunnybrook St. John’s Rehab logo appear. Below that. The words “with editing and production by” followed by The Influence Agency logo appear. The text disappears. The video dissolves into a close-up of a woman’s hands using a hand sanitizer dispenser. The words “With funding supporting from” followed by the Sunnybrook St. John’s Rehab, Canadian Institutes of Health and Research, Sunnybrook Research Institute, Rehabilitation Science Research Network for COVID, and the Temerty Faculty of Medicine University of Toronto Logo. The text and logos disappear. The text reads “a heartfelt appreciation goes out to the individuals featured in this documentary series, as well as to the community of contributors who have been involved in this project from its inception.” The video dissolves to a Sunnybrook bus with the Sunnybrook logo and the words “this place is special written on the side. “Special” is written much larger. The credits begin to roll with “Participants” as the header and the following names: Beth P., Jeff O., Mandy O., Susie Goulding. The “Health Care Practitioners” heading appears followed by the following names: Alexandra Rendely, MD, FRCPC, Michelle Di Lauro, OT Reg. (Ont.). The “Research Team” heading appears followed by the following names: Abby Vijayakumar, MSc, Jaylyn Leighton, PhD, Logan Reis, MSc, Marina Wasilewski, PhD, Robbery Simpson, PhD, MBChB (MD). The bus begins to drive off. The screen fades to black)

**Episode #4:**

Background music: A welcome page with a blurry background image of an empty street. Header text appears: "Living with Long COVID in Canada" Subheader text appears: "The St. John’s Rehab Sunnybrook Docu-series" Within seconds, the text appears: "Episode 4 of 5" followed by "The Caregiving Experience."

The text fades and the screen turns black.

Background music.

Scene : A cinematic shot of a man walking with the view of the CN Tower, waterfront, and Toronto city in the background. Cinematic shots of trees and rays of sun transition into a shot of Jeff and Mandy, seated, while Jeff starts talking.

Their names appear in a small, blue text box along with a bigger white text box below that, with white and blue lettering respectively.

Text on screen: "Mandy O. Caregiver to a Spouse Living with Long COVID & Mom" "Jeff O. Person Living with Long COVID & Father"

Jeff : “There were times that Mandy just could not be around me. She's just like, I love you, but I can't be around you. Because right now, what's happening to you is the point of my anger and my frustration. So you being here, brings it bubbling up to the surface. And like, okay, I understand, I know you're not mad at me, but I understand that I represent the problem.”

Jeff chuckles.

Mandy : “When we got to that point where I couldn't be, I said you needed to, you needed to go. You needed to just, like, be in your room a little bit, and give me my time. Then we started being like, this is not healthy. It gave me the opportunity to say, I need to also take care of myself.”

Background music.

Scene : Cuts to a scenic shot with two trees on both corners of the screen and a person sitting on the grass, watching the water and boats in front with headphones on.

“I don't necessarily have a caregiver. I'm a single mom”

Susie Goulding appears on screen, continuing to talk, with her name and title: "Susie Goulding Person Living with Long COVID, Patient-Partner, Founder of the Long Haulers Support Group Canada, Flower Shop Owner & Mom to Son and Fur Babies." in Blue and White text boxes in the right corner, respectively.

Susie Goulding: “I don't have support from my parents. They're both deceased. I just go through my day, and I do whatever I can. And I've accepted that I don't do things as well as I used to. And I don't care. I do what I can, I try to be kind to myself, and I just get whatever done that I can.”

Background music.

Scene : Shot of a person in a field walking under an umbrella and raincoat.

Beth P. appears with her name in bold in a blue text box along with the title: "Person Living with Long COVID, Social Media Activist, Spouse, Gamer, Gardener, Pet Mom." in a white textbox. She continues to talk.

Beth P.: “We very much have a 50/50 approach to our living situation and how we pitch in around the house. Getting sick like this all of a sudden throws that balance out of whack. He unfortunately has to step up and do a lot of things that I can't do anymore. I still can't grocery shop on my own. So I have lost a lot of my independence and had to become really reliant on him. And that has been, I think, harder for me than, than him. I'm sure it's hard on him too. But I do not like feeling like I'm not carrying my own weight in the home. I'm grateful that I have someone who takes care of me, who gives of themself to prop me up so that I can have as many good moments as possible. He helps facilitate that.”

She nods.

Background music. The scene cuts to a building.

Voiceover : “For some patients,”

Alexandra Rendely appears on screen with a small, blue textbox with white lettering in the bottom right corner with the words: "Alexandra Rendely, MD, FRCPC." Just below the blue textbox, a larger, white text box appears with blue lettering with the words: "Physical Medicine and Rehabilitation, University Health Network - Toronto Rehab Clinician in Quality and Innovation, University of Toronto, Department of Medicine Division of Physical Medicine and Rehabilitation." She continues to talk.

“Relying on a loved one, as an unpaid caregiver, might be completely new for them and very challenging to even just accept that help. Someone who might not necessarily have been taking care of that person, or may have been receiving care from that person. And now there's a complete switch. So making sure the caregiver feels supported. So agencies that can either offload, support groups from others in a similar situation, talking to their own family doctor, and just recognizing that they have to prioritize their health and well being as well. So making sure they're getting sleep and eating and exercising. And very much easier said than done when you need to care for a loved one who really relies on you. But seeing if there is a way to create a schedule or look at a week or a month at a glance and find ways that they can take some time to support their own care needs.”

Scene: A girl with her caretaker practicing physical movement. Background music. The caretaker is massaging a ball on her shoulder. A person talks in the background: “There's so little time to get everything done.”

Scene cuts back to Mandy and Jeff in their seats.

Mandy continues: “Because I am 100% responsible for everything. Like all sudden things that Jeff was doing that I was taking for granted almost, like mowing the lawn, all of a sudden, there's more things that you need to do. So then there's no time. We have a very strong relationship. We've been together for a long time.”

Camera gets closer to Mandy and Jeff.

Mandy continues “Thankfully, that has really built our abilities to communicate. For the first year and a bit though, we kind of lived in our own separate lives. Like I didn't feel like I could burden him with any of my mental health issues or how I was feeling anxious or depressed or overwork. Because he was trying his best to heal. He also had all this guilt. So for me to unload any of that I felt guilty to put any more pressure on him. Mental health wise for me, like my work has been fantastic and let me work from home four days a week. And then I go into the office once a once a week. But after three years of doing that, they're getting a little bit tired of that. They want to see me in the office every day. I also have a counselor on call that we've done some work with, um, and she's absolutely fantastic. We would not have been able to get through without the counselors in their lives. It's very hard to advocate for myself as a caregiver because I have to do all these things that that leave next to no time in the day to help advocate for Jeff, let alone advocate for myself. So it's a really like, fine line balance about making sure that you're picking what's most important in life.”

Jeff: “Over the time that we've talked about this, we've said that I am the one who is sick and she is the one who's struggling. We're thankful that we got the roles that we did in this, because if Mandy was in my position, she would have gone insane.”

Mandy interrupts: “You have oodles of patience.”

Jeff: “And I would have burned out long ago. Those weren't the roles that we were hoping to have in life. I'm the one who is sick, but I would say that she's had the harder time with it.”

Mandy continues: “You've even said in the past that you can see that it weighs on me. And the times that I don't speak up and that I don't tell him because I'm trying not to burden him, it burdens him.”

Scene : A couple holding hands with background music.

Voice over : “Because there's such little support.”

Michelle Di Lauro appears on screen while talking. A blue text box with white lettering in the bottom right corner with the words: "Michelle Di Lauro." Just below the blue textbox, a larger, white text box appears with blue lettering with the words: "Service Coordinator, University Health Network - Toronto Rehab, Occupational Therapist, Foodie, Runner, Travel, Dog Mom."

Michelle Di Lauro: “Even for individuals that are suffering from long COVID, these caregivers are often forgotten. And there's just simply not enough resources available. As healthcare practitioners, I am hoping we can really look at this caregiving group and provide them with more psychosocial support if they need it. Peer support among other caregivers, just like with our other patient populations that we have, it's important to know you're not alone and it's okay to feel these feelings. It's a difficult transition for everyone involved, not just the patient, but the caregiver as well. Perhaps their individual, their loved one, was the breadwinner of the family. They did bring in most of the financial compensation for the family, or they took on a lot of the roles for caring for their children or maybe they were caring for an elderly family member. And now, with their support gone, it impacts everyone in the entire family and community.”

Background music.

Scene : Clip of a woman in a gray sweater holding the hand of an elderly person in bed showcasing an emotional moment.

Voiceover: “You have to take care of yourself.”

Mandy and Jeff show up on screen.

Mandy: “You can't not take care of yourself. If you burn out, especially since you said that I'm the glue that holds us together. I'm the support. If you burn out, that's it. If you don't prioritize yourself, you are going to be sick. Take time out of your day. Out of the precious minutes that you have to do something for yourself 10 minutes a day, whether it's like going for a walk or for me I turn on something to watch while I do the dishes. It doesn't seem like it's decompressing time, but it is for me. Your best is good enough for today and that's just the way that it has to be and that's that's good. That's okay.”

Background music.

Scene : A cinematic scene of a high-altitude view with the sun shining over rocks, transitioning to a timelapse of clouds moving across the sky.

Voice over: “I think the hope comes in the fact that there is a lot of research going on."

Michelle continues to talk on screen: "And I don't feel like we're completely starting from scratch. And I think that hopefully gives us a little bit of a leg up when it comes to further treatments and ultimately cures.”

Background music.

Scene : Two people walking in focus, showing their backs in an open area. One person in front of them is unclear and blurry, along with a blurry background of trees, grass, buildings, and an open area. The scene animates, and text pops up in white in the left corner of the screen.

Text on screen: "For more information, please visit the ‘Long COVID Education and Awareness Hub’" "www.LivingWithLongCOVID.ca"

Music continues to play as the people continue walking in the right corner of the screen. The left side of the screen changes text and presents:

“Brought to you by Sunnybrook” with the Sunnybrook St. John’s Rehab Logo.

Editing and production credits to The Influence Agency with their logo appear below that. Funding support credits then fade into the left side and appear.

Text pops up in white in the left corner of the screen stating: “For more information, please visit the ‘Long COVID Education and Awareness Hub’” along with “www.LivingWithLongCOVID.ca” below that.

Background music continues to play as the people continue walking in the right corner of the screen.

Text on screen: "Brought to you by Sunnybrook" with the Sunnybrook St. John’s Rehab Logo.

Editing and production credits to The Influence Agency with their logo appear below that.

Funding support credits then fade into the left side and appear.

Text on screen : A heartfelt appreciation goes to any individuals featured in this documentary series as well as to the community of contributors who have been involved in this project from its inception.

Scene shows a person sanitizing hands and a Sunnybrook bus moving clips on the right side of the screen.

Moving text on the left side of the screen:

Participants:

Beth P.

Jeff O.

Mandy O.

Susie Goulding

Healthcare Practitioners:

Alexandra Rendely, MD, FRCPC

Michelle Di Lauro, OT Reg. (Ont.)

Research Team:

Abby Vijaykumar, MSc

Marina Wasilewski, PhD

Robert Simpson, PhD, MBChB (MD)

Music stops, and the screen fades.

**Episode #5:**

Background music: A welcome page with a blurry background image of an empty street. Header text appears: "Living with Long COVID in Canada" and "The St. John’s Rehab Sunnybrook Docu-series" underneath. Within seconds, the text "Episode 5 of 5" appears followed by "Hope and Recovery in Long COVID…It's Complicated".

The text fades and the screen turns black.

Background music: Timelapse of a shot of the CN Tower with clouds moving in the background from a lower angle

Voice over “Sometimes I find that reading other people's stories, because we”

Mandy O. and Jeff appear on the screen in their seats. Their names appear in a small, blue text box along with a white text box below that, with white and blue lettering respectively: "Mandy O. Caregiver to a Spouse Living with Long COVID & Mom'' and "Jeff O. Person Living with Long COVID & Father"

Mandy continues to talk. “...hope that things are getting better for some people, or that I could help provide that hope to other people.”

Scene cuts to a girl smiling and laughing with her friends, sitting on a round table under an open umbrella. Voice over “What we did hear from people who we were partnering with”

Marina appears with her name, “Marina Wasilewski, PhD” in bold in a blue text box along with the title: "Scientist, St. john’s Rehab Research Program Assistant Professor (Status), Department of Occupational Science and Occupational Therapy, University of Toronto'' in a white textbox.

She talks. Marina: “...and working with them was that they didn't love the word “recovery”. People also weren't keen on the idea of hope. And I think that speaks to and is a testament to”

Scene : a pile of files.

Voice over : “....the lack of focus, there has been on Long COVID”

Background music starts.

Music fades.

Logan Reis appears on screen, talking. A blue textbox with “Logan Reis, MSc” in white text along with a white textbox with “Research Coordinator, St. john’s Rehab Research Progam lived Experience with Long COVID, Student Mentor, Cat Dad” in blue text below that.

Logan : “It's really scary when you're in it, because it truly felt like it wasn't gonna go away. There'll be periods of my brain fog that lasted weeks at a time, and I did not know whether or not that was just going to be the new normal. So that made being hopeful for the future kind of tricky for me. Fortunately, for me, after a few months, the main brain fog had died down, and I was able to see a more clearer vision of what could be what recovery looks like. And that gave me some hope for the future.”

Scene cuts to Beth P, she appears with her name in bold in a blue text box along with the title: "Person Living with Long COVID, Social Media Activist, Spouse, Gamer, Gardener, Pet Mom." in a white textbox.

Beth P: I find the way that I have coped with long COVID is by trying to dive in and learn as much as I can about it, to the extent that we know yet, so staying up to date on whatever research is happening, and that gives me a modicum of control over my situation. But that doesn't mean that there aren't days where I'm still grieving my past life, grieving that person I feel like I left behind. Kind of pivoting and focusing on the things I still can do, gives me a little bit of hope and control over the situation.”

Camera gets a closer shot of Beth. “I think the hope comes from the fact that there is a lot of research going on. There are a lot of folks who have expertise in the, um, post viral illness field who are working on this, we're taking their lessons learned from the last 1015 years of research. And I don't feel like we're completely starting from scratch. And I think that hopefully gives us a little bit of a leg up when it comes to further treatments and ultimately cures.”

Background music : Shot of four people walking away, showing their backs, going down a staircase, smiling and laughing about a conversation they seem to be having.

Voice over “What I would say is that there's a lot of research”

Scene: Susie Goulding appears on screen, continuing to talk, with her name and title: "Susie Goulding Person Living with Long COVID, Patient-Partner, Founder of the Long Haulers Support Group Canada, Flower Shop Owner & Mom to Son and Fur Babies." in blue and white text boxes in the right corner, respectively.

Susie : “....that’s happening, that people don't have any inkling that is going on. There's a huge web that's being organized with over 300…patients and researchers and professionals, there's a lot going on behind the scenes that people are unaware of, we're actually in the best place in Canada, that we really have”

Scene: Doctor consulting with patient.

Voiceover:

“...professionals that are in the realm of Long COVID that care, and that are going to bat for us”

Scene: Another doctor, speaking in a focused view.

Voiceover:

“...that are so supportive. You know, research takes time to happen. Money has been allotted from the government”

Scene: Susie Goulding on screen.

Background music:

Scene: A welcome page with a blurry background image of an empty street. Header text appears: "Living with Long COVID in Canada" with "The St. John’s Rehab Sunnybrook Docu-series" underneath. Within seconds, the text "Episode 5 of 5" appears followed by "Hope and Recovery in Long COVID…It's Complicated". The text fades and the screen turns black.

Background music:

Scene: Timelapse shot of the CN Tower with clouds moving in the background from a lower angle.

Voiceover:

“Sometimes I find that reading other people's stories, because we”

Scene: Mandy O. and Jeff appear on the screen in their seats. Their names appear in a small, blue text box along with a white text box below that, with white and blue lettering respectively: "Mandy O. Caregiver to a Spouse Living with Long COVID & Mom'' and "Jeff O. Person Living with Long COVID & Father". Mandy continues to talk.

Mandy:

“...hope that things are getting better for some people, or that I could help provide that hope to other people.”

Scene cuts to a girl smiling and laughing with her friends, sitting around a round table under an open umbrella.

Voiceover:

“What we did hear from people who we were partnering with”

Scene: Marina appears with her name, “Marina Wasilewski, PhD” in bold in a blue text box along with the title: "Scientist, St. John’s Rehab Research Program Assistant Professor (Status), Department of Occupational Science and Occupational Therapy, University of Toronto" in a white textbox. She talks.

Marina:

“...and working with was that they didn't love the word ‘recovery’. People also weren't keen on the idea of hope. And I think that speaks to and is a testament to”

Scene: A pile of files.

Voiceover:

“...the lack of focus there has been on Long COVID.”

Background music starts.

Scene: Logan Reis appears on screen, talking. A blue textbox with “Logan Reis, MSc” in white text along with a white textbox with “Research Coordinator, St. John’s Rehab Research Program, Lived Experience with Long COVID, Student Mentor, Cat Dad” in blue text below that. Logan speaks.

Logan:

“It's really scary when you're in it, because it truly felt like it wasn't gonna go away. There'll be periods of my brain fog that lasted weeks at a time, and I did not know whether or not that was just going to be the new normal. So that made being hopeful for the future kind of tricky for me. Fortunately for me, after a few months, the main brain fog had died down, and I was able to see a clearer vision of what could be what recovery looks like. And that gave me some hope for the future.”

Scene cuts to Beth P. She appears with her name in bold in a blue text box along with the title: "Person Living with Long COVID, Social Media Activist, Spouse, Gamer, Gardener, Pet Mom." in a white textbox.

Beth P:

“I find the way that I have coped with long COVID is by trying to dive in and learn as much as I can about it, to the extent that we know yet, so staying up to date on whatever research is happening, and that gives me a modicum of control over my situation. But that doesn't mean that there aren't days where I'm still grieving my past life, grieving that person I feel like I left behind. Kind of pivoting and focusing on the things I still can do gives me a little bit of hope and control over the situation.”

Camera gets a closer shot of Beth.

Beth P:

“I think the hope comes in the fact that there is a lot of research going on. There are a lot of folks who have expertise in the, um, post-viral illness field who are working on this, we're taking their lessons learned from the last 10-15 years of research. And I don't feel like we're completely starting from scratch. And I think that hopefully gives us a little bit of a leg up when it comes to further treatments and ultimately cures.”

Background music:

Scene: Shot of four people walking away, showing their backs, going down a staircase, smiling and laughing about a conversation they seem to be having.

Voiceover: “What I would say is that there's a lot of research”

Scene: Susie Goulding appears on screen, continuing to talk, with her name and title: "Susie Goulding Person Living with Long COVID, Patient-Partner, Founder of the Long Haulers Support Group Canada, Flower Shop Owner & Mom to Son and Fur Babies." in blue and white text boxes in the right corner, respectively.

Susie: “...that's happening, that people don't have any inkling that is going on. There's a huge web that's being organized with over 300…patients and researchers and professionals, there's a lot going on behind the scenes that people are unaware of, we're actually in the best place in Canada, that we really have”

Scene: Doctor consulting with patient.

Voiceover: “...professionals that are in the realm of Long COVID that care, and that are going to bat for us”

Scene: Another doctor, speaking in a focused view.

Voiceover: “...that are so supportive. You know, research takes time to happen. Money has been allotted from the government”

Scene: Susie Goulding on screen.

Susie: “...grants have been given. And things are just starting up at Mach speed.”

Scene: Doctor with checklist in hand, explaining to the patient on bed who is blurred in the background.

Voiceover: “Hope is so necessary.”

Scene: Alexandra Rendely appears on screen with a small, blue textbox with white lettering in the bottom right corner with the words: "Alexandra Rendely, MD, FRCPC." Just below the blue textbox, a larger, white textbox appears with blue lettering with the words: "Physical Medicine and Rehabilitation, University Health Network - Toronto Rehab Clinician in Quality and Innovation, University of Toronto, Department of Medicine Division of Physical Medicine and Rehabilitation." She continues to talk.

“I really love that word for this patient population. Because we have seen some really great examples of patient recovery, you can track small changes in your function in your day to day, set very small goals that you can then check off and grow upon and build upon. And while that might take weeks or months or in some cases, years, finding those small pieces of hope to hold on to and talking to others who have made gains will show that there are tools that you can use to cope with your symptoms better. But I think every patient should have some degree of hope, um, as well as being realistic to their current situation, but hopeful that there are individuals out there who can help you, um, make gains over time.”

Scene: Mandy and Jeff appear on screen. Mandy, talking.

Mandy:“It felt like at times that there was no hope”

Camera angle shifts and Mandy looks at Jeff.

Mandy:“...you wanted to work full time, I wanted to be part-time stay at home mom. And that is completely opposite of what's been going on. To have hope you also need to accept where you're at, and maybe change that plan.”

Angle zooms in more. Mandy : “It's really hard to get stuck on what you want to do. But sometimes that is okay to let that go. It's okay to aim a little bit differently to aim a little bit slower. If you look at your journey, in short bits, you might be frustrated. But if you look at it over the whole we have seen change. And we've learned that now we need to have a longevity approach to how we see improvement.”

Scene: Couple walking on a beach by the water with a close sunset cinematic shot.

Voiceover : “In the three years that I've been dealing with this I have seen progress. I've seen progress and myself.”

Scene: Jeff and Mandy on screen. Jeff : “But I've also seen progress in….we keep we try and keep up to date with the research that's being done and with what people are saying and is getting better. Yes, we said before somebody has to jump through their hoops and that's why We're doing it. We're jumping through the hoops now. And we're putting in the work now. So that down the road, however long, you don't have to. Your situation, it's not going to change overnight, it's going to, it's going to suck. And there are going to be very dark days. But you gotta keep your head up, you got to keep looking forwards, and just pull yourself up every single time, because it does get better.

Scene: Blurry building shot and tree branches fade onto the screen. Gains focus. VoiceOver “i think its important”

Marina Wasilewski appears. “ to reflect the harsh realities of what long COVID is and what it means for people's lives. But I also think what we were hoping for in working with our patient partners was to also find what little light there might be at the end of the tunnel.”

Scene : A lady working on her laptop from home.

Voiceover “I think what we heard from some people was that even being part of this project and getting to share their stories”

Scene : A man conversing with two blurred people on screen. voiceover “and their views and their experiences freely and without judgment, in and of itself was something positive for them.”

Mandy and Jeff appear on screen. Mandy : “The reason why I found you guys is because I was hopeless.”

Camera angle refocuses and zooms slightly out.

Mandy : “I didn't know where to turn, I didn't know where to look. Research wasn't there. So I actually found it as a targeted thing [ad] on Facebook. They're interviewing caregivers, how cool. So then we did the interview. And I was like, man, like I felt really heard. I felt like for once somebody was fighting with me, instead of fighting against me. Every time I attended, there was more and more hope there was I was seeing an end to this an end to me having to do all the fighting by myself. So even if like this Docu series, or the research that we use, like, if I can give a little bit of hope to somebody else, that's why I kept pushing. For once, health care wasn't the one thing that was weighing me down. It was the one thing that was fighting for me and advocating for me and standing up for me. And it was the one time I finally felt like we were getting somewhere.”

Scene : Doctors around a table looking at a MacBook and discussing.

Voiceover “I think we know from health care research”

Marina, talking “that hope is really important for you to feel like there's something you are working toward.”

People holding hands close up show up on screen. Voiceover: “you don't believe that it's ever going to get better if you don't hear from anybody else that there was something for them”

Marine, talking “after that long tunnel of darkness. What's the motivation”

Scene : Man walking in a tunnel appears. Voiceover : “to keep walking through the tunnel? I think what we're hoping”

Marina, Talking : “is that there is something in this project and hearing from other people that continues to propel and push those people through the tunnel. Until again, the therapeutics and the treatments, give them that final push out of it.”

Scene : Man and woman walking near rocks and a forest area. Voiceover begins “I would suggest that you join a support group,”

Susie, talking “find like minded people to get the support that you don't have in your life, for better understanding. And just for camaraderie, you know it for being in an environment where people understand. It's an a-ha moment when most people join a support group.”

Four people walking up stairs, showing their backs, entering a building. Voiceover “Historians say that the first proof of civilization”

Jeff and Mandy on screen. Jeff : “is somebody with a healed femur because it takes a group of people to take care of a sick person.”

Mandy nods in agreement.

Background music.

Scene : Timelapse of a blue cloudy sky.

Text : “Living With Long COVID:The Docuseries”

Voiceover : “I pretty consistently have had”

Transitions into Beth P talking “extreme fatigue, body aches, pretty much full body symptoms that do impact me every day.”

Susie on screen. Susie: “It's a ripple effects. Also, it's not just me, but it's also changed my son's life. Right? I'm no longer the fun parent who can do anything on a whim.”

Beth P : “Every second of the day, I am cognizant that I'm living in a body with long COVID.”

Mandy and Jeff on screen. Jeff : “I had to redefine myself because the way that most people do it doesn't work. We all put so much worth based our worth on what we do or what we have or what, what's going on. And it's like, I can't do that.”

Susie: “People very close to you, can you no question and you're left to prove that you're actually sick. They think well, you look fine to me. And so you can't be having any issues and well, you're getting older. So that just comes with age.”

Mandy and Jeff on screen. Jeff : “There are people who get it and going like, No, you're struggling with stuff. And it's not just in your head.” Mandy : “It's very hard to advocate for myself as a caregiver because I have to do all these things that then leaves next to no time in the day to help advocate for Jeff, let alone advocate for myself.”

Jeff: “Over the time that we've talked about this, we've said that I am the one who is sick and she's the one who's struggling.”

Beth P : “I don't feel like we're completely starting from scratch. And I think that hopefully gives us a little bit of a leg up when it comes to further treatments and ultimately cures.”

Zoomed in shot on Jeff. “You gotta keep your head up. You gotta keep looking forward and just pull yourself up every single time because it does get better.

Background music. Scene : People walking.

Scene transitions to the right corner of the screen.

Text pops up in white in the left corner of the screen stating: “For more information, please visit the ‘Long COVID Education and Awareness Hub’” along with “www.LivingWithLongCOVID.ca” below that.

Background music continues to play as the people continue walking in the right corner of the screen.

Text on screen: "Brought to you by Sunnybrook" with the Sunnybrook St. John’s Rehab Logo.

Editing and production credits to The Influence Agency with their logo appear below that.

Funding support credits then fade into the left side and appear.

Text on screen : A heartfelt appreciation goes to any individuals featured in this documentary series as well as to the community of contributors who have been involved in this project from its inception.

Scene shows a person sanitizing hands and a Sunnybrook bus moving clips on the right side of the screen.

Moving text on the left side of the screen:

Participants:

Beth P.

Jeff O.

Mandy O.

Susie Goulding

Healthcare Practitioners:

Alexandra Rendely, MD, FRCPC

Michelle Di Lauro, OT Reg. (Ont.)

Research Team:

Abby Vijaykumar, MSc

Marina Wasilewski, PhD

Robert Simpson, PhD, MBChB (MD)

Music stops, and the screen fades.