



This project was carried out by the Jewish General Hospital Humanization of Care (HOC) Committee, in collaboration with the Directorate of Quality, Transformation, Evaluation, Performance and Ethics (DQTEPE) of the CIUSSS West-Central Montreal. The HOC Committee is made up of volunteers from the community and JGH/CIUSSS West-Central Montreal employees. The Committee's mission is to improve the hospital experience for patients and families, by integrating, enhancing and promoting patient-centric care.

### **Storytellers \***

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**\*Pseudonyms**

## INTRODUCTION

The COVID-19 pandemic has created unprecedented challenges to patients, their families, hospitals, and hospital staff throughout the world. Because the care of patients with COVID-19 has taken an enormous toll on the hospital staff, researchers (Shechter et al, 2020) propose that hospitals develop programs to mitigate their staff's anxiety and facilitate their coping. Thus, we at the Humanization of Care (HOC) Committee, in collaboration with DQTEPE, collected stories from patients and family members of those who had been admitted to the Jewish General Hospital (JGH). We asked them to talk about their positive COVID-19 experiences while hospitalized and the role the medical staff played in their care.

Patients' stories matter! Not only were the stories captivating and remarkable; sharing stories served as a reminder for all that the virus is serious. The stories provided the storytellers with a platform to share their COVID-19 journey and to have their experiences heard and validated. The stories brought awareness of what went on during patients' care while they were at the JGH, how the hospital staff played a positive role in their care, and how the staff's decisions reflected the patients' preferences, needs, and values. It was where the storytellers showed their gratitude to the hospital staff and teams for their dedication and competency, and their appreciation of how the staff used compassion to humanize their care. The stories also included suggestions for other patients with COVID-19.

Hopefully, these testimonials will let the JGH Community vicariously understand what patients with COVID-19 lived through. Our wish is that the sharing of these first-hand testimonials will promote a more positive understanding for others of what to expect when they are hospitalized, diminish their misconceptions about being hospitalized, and offer them a deeper sense of the kind of care that is provided at the JGH. We hope that these stories will build learning, promote dialogue between the hospital staff and patients, and facilitate changes on the COVID-19 units, thus improving patients' social, emotional, spiritual, and physical care. We anticipate that giving voice to positive experiences while on a COVID-19 ward will provide the hospital staff with a better understanding of their patients' lived experiences, trauma, and triumphs. These new layers of information can improve the practice and treatment of patients with COVID-19 and add to the patients' experiences while at the hospital. And finally, we hope that these stories will provide a legacy of what patients with COVID-19 endure and how the medical and support teams helped in humanizing their care.

## **First in Quebec**

### **Cantor Dave**

Cantor Dave is an older adult. He caught COVID-19 in the middle of March 2020. He was one of the first cases in Quebec. Cantor Dave lives in Montreal with his wife and 5 children. His children contracted COVID-19, but they were not hospitalized. His wife had pneumonia.

Three days after attending a gathering in someone's basement on a Saturday evening, Cantor Dave came down with COVID-19 type symptoms, including being feverish and feeling weak. Apparently, one of the attendees, who had just returned from Florida, was asymptomatic. By Thursday, he went to the Jewish General Hospital because he was dehydrated and unable to get up.

Cantor Dave was really quickly triaged to a garage, which the hospital was using as a semi-Emergency Room. They did tests to assess the situation, took his blood, and gave him IV for his dehydration. Then they discharged him because his oxygen was good, gave him a prescription for antibiotics, and advised him to monitor himself for 48 hours. Cantor Dave was to contact them right away if anything changed.

A doctor called him at his house the next morning to check in and to see how he was feeling. Although the doctor informed him that he tested positive for COVID-19, he advised him to wait a couple of days as Cantor Dave was already on an antibiotic. The doctor also told him that someone from the government would contact him to find out where he had been and with whom he was in contact. The doctor called a couple more times that day to check on his temperature and whether he was having any difficulty breathing. They also discussed whether he should take Hydroxychloroquine. However, the government put a hold on it.

A few days later, on Saturday night, Cantor Dave had to be taken right away to the hospital by ambulance, as his breathing started to become labored. He knew that the antibiotics were not working. His immune system was low and he was very weak. The doctors decided as soon as they checked his blood and his oxygen level that he needed to be hospitalized. They moved him to Pavilion K10. As per Cantor Dave, the staff on K10 were on top of everything. They prescribed Hydroxychloroquine for the next 5 days, continued the antibiotic regime, gave him oxygen through his nose, and hydrated him. They administered the antibiotic intravenously.

As his lungs were full of water, they prescribed a drug that made him urinate every hour so that the water would drain out of his lungs. He also took a medication to control the bad diarrhea and to make sure that he did not have C-difficile. A nurse called the floor doctor because he was feeling anxious. Cantor Dave was able to cope better after the doctor prescribed a relaxant. They took his EKG three times during the week to check on his heart and to make sure he did not have blood clots. They prescribed a blood thinner which he took daily to avoid the possibility of a blood clot, a common side-effect of COVID. They checked his blood sugar level which was going up.

But Cantor Dave wasn't getting better. He couldn't move and he felt weak. He thought that after a week that things would get better, but he was getting worse. It finally came to a point where they thought he had to go to the ICU. After 10 days in the hospital, his oxygen level fell to 89. He couldn't breathe on his own. The tube in the nostril was not enough. After the ICU evaluated him, they decided to do oxygen therapy throughout the night. The next morning, he was able to breathe on his own without problems. It was amazing. He had beaten COVID-19.

After 2 weeks in the hospital and 3 weeks since his first visit to the hospital, Cantor Dave slowly started getting better and started getting his strength back. He described how good he felt when he got up for the first time. By week three, he realized that he was getting better when he wanted chips and coke. It was reassuring. When he was able to take his oxygen mask off, breathe on his own, and his bloods came back with much, much improvement, the doctor offered him the choice to go home or stay for 2 more weeks. He obviously chose to go home.

Since Cantor Dave's discharge, he no longer takes the blood thinner he was prescribed when he left the hospital. His blood/sugar level is back to normal. He has had phone sessions and in-person visits with his pulmonologist. He had pneumonia a couple of times and his lungs would sometimes hurt him. It took a while for his lungs to heal and for him to get back into shape. Because he finds that his lungs were affected, he used a puffer for a while and continued to follow the breathing exercises they gave him. Although he still gets tired, he finds that he feels stronger and things are getting better, especially since he got the vaccine.

Although it was not a fun ordeal, Cantor Dave had survived. He found the doctors he saw in Emergency, on K10, and the ICU amazing. He watched the doctors go from room to room all morning long. He appreciated that the doctors would speak to him on the phone and answer all his questions. If he had another question, the nurse would get the doctor to come back and speak to him when they finished their rounds. Everyone did their job from the nurses to the cleaners to the aids. He watched how they worked as a team and how they organized themselves. He observed them following "army type protocol" when they would pick up their PPE and put them on and how they would wash their hands for 2 minutes. He observed the nurses huddling together with the doctors.

When Cantor Dave was not thirsty or hungry but needed to be hydrated, the personnel would encourage him to eat and "to drink, drink, drink" or to just "take one bite". The social worker assigned to him helped him deal with his anxiety. Even the cleaning staff were amazing and unbelievable. The cleaning guy on the 10<sup>th</sup> floor, who came in twice a day, repeatedly told him that he was going to go home. He would say, "Don't worry. You are going home. There is a guy next door who just went home".

All put together, Cantor Dave attributed the treatment, the dedication of the staff, and their constant care for making his stay at the JGH a positive experience. There was good communication between the family and the staff. They took the calls from his family no matter when they called. When his family wanted him to have extra clothes, the security guard

brought it up. As he surmised, “everyone was doing their jobs TREMENDOUSLY well. Nobody ran away. Nobody was afraid”. They had patience and understanding while caring for him. He used the Hebrew word *Savlanoot* to express the importance of using a lot of patience. According to Cantor Dave, “they were on top of everything. They were on the ball”. One time, a doctor questioned him about redness on his scalp which they concluded was not due to COVID.

The one outstanding person during his stay at the JGH was a nurse on the 10<sup>th</sup> floor. He found her care amazing. She made sure that he got whatever he needed. She always knew right away when he wanted ice. One time when he couldn’t go to the bathroom, she changed him. She gave him oxygen therapy, which meant she blasted him with oxygen through the BIG mask they put on him. It was an incredible experience. She worked with him all night long. She alternated from high to low and then high amounts of oxygen. She made sure that he was breathing through the mask for hours on end. He remembers that when the oxygen went back to normal that she just gave him the thumbs up from where she was sitting behind the glass. He will never forget her gesture. When he started getting better and wanted to have outside food, she made sure he got it.

Cantor Dave finished the interview with the following comments and advice: First, “**take your vaccine**”. Next, he finds that it is important to “**make sure that the doctors and nurses have stress free time**”, especially since the virus has been with us for almost 2 years. Thirdly, he feels that it is essential for doctors and health care workers “**to listen to the patients**”. He appreciates the JGH medical staff’s questions to him and their desire to learn how he felt.

## **You Can Never Be Too Careful**

### **Chandra**

Chandra is 59 years old. She lives with her partner and her son. She works in health science industry. She was at the Jewish General Hospital for 14 days, ten of which were in the ICU. Her partner tested positive for COVID-19 a few days after she was admitted to the hospital.

“It absolutely boggled my mind when on December 22nd (2020) I started getting [COVID] symptoms”. Chandra had been very careful, super careful about everything. She worked remotely and hardly left her house except to get the occasional groceries or to go for a walk on her own. On the 23<sup>rd</sup> of December, Chandra decided to get tested. She got the call that it was positive on the 26th. She was literally in shock and questioned how on earth she caught COVID-19.

At first, Chandra felt very tired, had a fever, and aches and pains. She thought that she had a mild case and could just sleep it off. But, as the days progressed through Christmas and after Christmas, she became increasingly tired. She couldn't get out of bed. It took a lot of mental effort just to go to the washroom, and coming back was exhausting. She lost track of time. At a certain point she had not eaten for five days. She became very dehydrated as she would put the glass of water next to the pillow and fell back to sleep, hardly touching it. She did not realize that her blood-oxygen level was really low. If she had had a pulse oximeter at home, she would have sought medical help sooner.

Chandra was not being herself. She argued with her partner that she would be fine and all she had to do was sleep it off. Usually, she has a very high awareness of diseases, conditions, and especially when to seek help. But this time she attributed her reactions to being oxygen deprived. When on the 30<sup>th</sup>, her partner told her, “You look awful, I am going to call the ambulance”, she argued that she would be fine and told him to leave her alone. On the 31<sup>st</sup>, her partner and her son made the executive decision that it was time to call an ambulance, and off she went, alone to the hospital.

Thankfully when the ambulance took her to the Jewish General Hospital, the Emergency Department (ED) was not too busy. Chandra went through the triage very quickly where she was seen by multiple doctors. They did a lung scan and all kinds of blood tests. They gave her oxygen right away because her oxygen level was in the 80s. She was delirious from a lack of oxygen. Although there are many ways to deliver oxygen to a patient, they tried whatever was available in the ED. Chandra does not remember how long she was in the ED, except that they brought her upstairs to a room with a view of the Oratory. They had tried different ways to give her oxygen. Whatever they used was insufficient and not making any difference to her oxygen level at all. Chandra did not stay in this unit the whole night even though she was mildly better. They decided to move her to the ICU because they were very concerned as she was weak and very sick. She could barely talk and she could not catch her breath.

Chandra did not do very well the first few days in the ICU. At one point the blood oxygen level dropped to the mid 70's. There was a big likelihood that she wasn't going to leave the hospital by walking out. One of the physicians told her that it was a good thing that she came when she did; if she had waited a day or two, they were not sure what state she would be in and what they might have been able to do for her. She was very open to having a discussion about the treatment they would administer. High flow oxygen was okay. They also talked about her family and who had the rights to make the final decisions for her. She repeated her wishes to the doctors and nurses and they noted it in her chart and showed it to her, which made her feel good.

Chandra found the ICU surreal. "There were endless people coming in and out. I did not have time to be afraid. I was just going along with whatever was being done to me". Chandra felt that she was truly in the hands of these professionals and there was not much she could do but just try to breathe. She felt like she was not in control of the situation even though in her personal life, she feels that she generally has control of what she does and what happens to her. In normal times, Chandra is a very introspective person. However, during the ICU stay, she was simply focusing on every breath she took because it took so much effort and nothing else. It felt like she was being wheeled from one place to another and that she was just reacting and responding to their questions. She felt like she was moving along almost as if she was on a production line, moving from one station to the next even though she was stationary in her room.

The noise from the oxygen, the beeping, the endless blood tests made it hard for Chandra to sleep. As she laid awake, she observed the morning shift doing a huddle and a bit of exercise to motivate themselves for the shift ahead. She got a kick out of watching them do their lunges. She knew that even though the medical staff were tired at the end of their shift, they were always very cheerful, very caring, and really wanted her to get well. They would continue to encourage her to keep doing the breathing exercises and would give her a cheer when she kept the ball in the spirometer up for a long interval of time. It was almost like this was a community.

Chandra's recovery was basically really, really, really long. It was hard. Because Chandra could not see any members of her family, and because she couldn't catch her breath, she communicated with them through texting. The whole time she was in the hospital, her human contact was really only the staff and she found them amazing. Chandra felt bad that she had to rely on them for everything. Even going to the bathroom was an ordeal because she had to press the button to get them to come. One of the nurses actually brought in her own shampoo to wash Chandra's hair. The nurse also brought her own cream because Chandra's skin was so dry.

Before being discharged, they moved her from the ICU to another unit. Because she spent most of her time in the ICU lying in bed other than going to the commode, she thought that she would continue to stay in bed. However, while there, she was encouraged to walk around the room very, very slowly, holding onto the walls. Chandra felt like she was 150 years old. She was thankful that there was a bench to sit on when she took a shower. She realized that because it



took so much effort to do the small things, the recovery ahead of her would be long and that much DAMAGE was done to her lungs.

When she was ready to be discharged, two doctors came to see her. She asked as many questions as she could, but there were things that she did not know would happen. She remembered that when they brought her out of the hospital in a wheelchair, she thought that she wasn't going to make it to the taxi as she was literally gasping. It was like that for many days.

Once she was home, the morning routine of simply brushing her teeth and trying to take a shower, took such an enormous effort. She would take a plastic chair into the shower because she did not have the strength to stand and take a normal shower. Then she would quickly dry her hair, climbed back into bed, and slept for the next few hours to recover. It was like that for several weeks, which scared her because she was concerned that this was going to be her life moving forward and she wondered if she would ever get back to where she was before. She was very concerned about her recovery. It took her until the end of March 2021 to be able to walk up a flight of stairs without gasping, without stopping, and to climb at the normal pace. She was relieved and thrilled when she saw the improvement. It was unbelievable. She can now deal with the small irritants that lingered.

She commented that "everybody was REALLY, REALLY, REALLY amazing". She "felt BLESSED to have been sent to the Jewish". She knows that if she had been sent to another hospital, it would have been a very different experience. Although, this was the first time she stayed overnight at a hospital and doesn't have a lot of experiences being in a hospital, this was a very different experience as she was at the Jewish during very unusual times.

Chandra really felt appreciative of everyone, from the cleaning staff to the nurses, to the doctors. Chandra really felt SPECIAL and appreciated the nurses who took care of her. A lot of the nurses who took care of Chandra in the ICU did not normally work in the ICU. They were transferred from different departments to work in the ICU. She found them amazing and unbelievable. They came in and chatted with her.

Chandra commented that the people coming in many times a day to disinfect the room were always cheerful. If she wasn't sleeping, they would have a little 'chit chat'. She found the human contact really nice especially since her family could not come to see her. For Chandra, "the staff became almost like family, [her] support system". She appreciated the conversation, the encouragement, the rapport and having caring people who did more than just take your blood, tell you to take your medicine, and then leave.

What touched Chandra was that none of the people at the hospital had a chance to be vaccinated at that point, and yet they decided to risk their lives to take care of her and the other patients. At the time, there was still so much unknown. When she shared that she couldn't thank them enough, she had tears in her eyes. She wished that she could go back and thank everybody. She emphasized that the medical staff were "really, really, really good. They

totally surpassed [her] expectations". Although the nurses were tired and had long shifts, they never gave the feeling that they wanted to rush out of the hospital at the end of their shift. They always took their time when she needed them. Although Chandra was in the hospital when there was a curfew and sometimes the staff would be stopped by the police on the way home from their shift; when they were at work, they were so caring and nice. "They were INCREDIBLE! They were AWESOME!! It was as if the whole COVID circumstances brought out the best in people".

Chandra offered the following advice:

- It is important to **"have a sense of humor"**. "It makes life a lot better", especially since you are spending "a lot of time alone, just listening to the machines, staring at the ceiling, or looking in the corridor to see what [the staff] are doing. There is not a lot of stimulation". Staff also appreciate when patients have a sense of humor. Because Chandra was always cheerful, the staff spent more time with her which made her life and stay more enjoyable.
- **Provide patients with information "about what to expect after" being discharged** from the hospital. Although Chandra acknowledges that everybody's recovery from COVID is different, she really wished that there was more information given to patients about the possible side effects from the medications and what to expect. A few days after she came home, she found herself in this weird depressive state. She would sit alone in the living room and cry for five to six hours for no reason at all. Because she didn't know about the side effects of being on high doses of the steroids, she started to freak out. She worried about what caused her to react in that way. She figured out what caused her emotional swings after talking with a therapist. Her employer arranged for her to have phone sessions. Chandra learned that one of the side effects from steroids is wild emotional swings. This helped her to calm down and stop freaking out.
- It is **"important to protect your own family and to make it clear** to your healthcare providers **what you will tolerate and what constitutes no quality of life"**. She understood that healthcare providers have to take care of so many patients and that it was hard to be informed about A to Z every hour for every patient. When a patient cannot speak or is intubated, the burden is on the family to ask the questions. Because she has only been living with her partner for a few years, and because her son is 20 years old, she felt that the only way to protect them was to make it very clear to the hospital what her wishes were.
- It is very **important** for patients **"to self-advocate"** and **"ask as many questions as you can"** so that you can gain an understanding and make the right decision. It's **important to make your wishes known"**. Chandra was adamant about certain things that were important to her. She made it crystal clear to everyone in the hospital that she never wanted to be placed on a ventilator. And she told

them why. Chandra is very clear about her definition of quality of life. Both her son and partner knew. Not only was Chandra getting the best care under the circumstances; the medical staff respected her wishes.

## **Seeing the Glass Half Full**

### **Maurice**

Maurice, who is 66 years old, was hospitalized at the JGH in February 2021. He lives in Montreal with his wife. He is a cyclist, does high endurance sports, and trains six to seven times a week.

On a Sunday evening in February 2021, his wife who is a Director of a Daycare, got a call that some of the teachers at the school did not feel well. Two days later, every teacher tested positive for COVID-19. By the fourth day, all their significant others had COVID-19 as well. Even though Maurice's first test came back negative, he continued to quarantine with his wife. Because he felt lousy, he got retested two days later. By the time he got the test results, he felt terrible. His breathing became more and more labored, and his oxygen level, which he was monitoring on the blood-oxygen meter his niece had bought him, was going lower and lower and lower. His wife drove him to the Jewish General Hospital as his oxygen level was very low. He was examined in the COVID Emergency Section by a very nice and pleasant doctor. The doctor told him to go home and relax. He also cautioned him to keep an eye on his blood oxygen level and to make sure that it did not go below 90. Because Maurice continued to get worse and worse and his oxygen level decreased to a dangerously low level, he returned to the JGH. He was immediately admitted.

Maurice stayed in emergency for two days where he went through a battery of tests and X-rays. They treated him with oxygen and dexamethasone. They transferred him to K9, the COVID ward, once it was confirmed that he had a pretty advanced case of COVID. His lungs were filled with COVID; his liver and adrenal glands were enlarged.

Maurice felt really comfortable on K9. There were only 4 patients on the ward. The room was outstanding, gorgeous. He had no complaints. He had everything he needed. The care was really great; the staff and the doctors were very attentive, and the attention was excellent. He never felt alone or abandoned. The staff all stepped up and did their job. He rarely had to wait for something when needed. More often than not, they would enter the room on a regular basis to check on him. He never had to call them. The staff kept Maurice and his family informed, and they made sure that he would receive anything family and friends would drop off at the reception. According to Maurice, "these guys were working their butts off; they were putting their lives at risk and their families at risk".

When the doctors entered his room, they were in groups of three. They were fully gowned in hazmat head to toe. The doctors were encouraging. The communication between Maurice and the doctors was open. They explained the illness and reviewed his case with him; they told him where he was at. They did not hide his diagnosis or "paint a pretty picture". After reviewing his stats at the mobile desk, they would ask him how he was and if he had any questions. The nurses made sure he got his medications on time and that his vitals were okay. The nurses were very present, supportive, and patient. They showed a lot of care. There was consistency. When Maurice was discharged 4 or 5 days later, he was off oxygen and able to walk around.

Maurice's only complaint is that it took the "longest time to be released." It was "a little bit torturous" as he was very anxious to get home to be with his wife who was alone dealing with her own aches and pains. He was anxious to be together so that they could "bring things to each other and help each other out".

At present, Maurice bikes and goes to work. He has since been doubly vaccinated and even travelled to Israel for his daughter's wedding. However, when he first went biking, he mentioned that he had zero strength and endurance and nearly collapsed. Although he feels he is "moving in the right direction", he still feels a bit frustrated because his strength and endurance has yet to completely return to his normal range.

Maurice offered the following comments on how he feels about life since he got COVID:

- He believes that one should "**remain positive and see the glass half full**". He finds that in North America and the USA, kids and people from his generation have not seen war, terrible adversity, or financial depression. Thus, they often make mountains out of molehills. To them, everything is the end of the world. Instead, he suggests that they need to "realize the good and not sweat the small stuff".
- In Maurice's opinion, "**the staff needs whatever positivity and encouragement they could get.**" It's scary when you are told you have a disease, and you need to be hospitalized because you have it so badly. It is enlightening to have the medical team take care of you. It is a relief because you feel that they can help you; you feel the effect of the care that you are getting. He got everything he expected and wanted; they helped him get better and get out of there.
- "**It's a team effort.** The patient is one part of the mechanism". Everybody needs to have the same goals and work toward them together. That is what Maurice felt when he was in the hospital. "Everyone had the same singular purpose of getting [him] out of there".

## **Singing Praises**

### **Sandra, Jay, and Kelly**

Dad was admitted to the Jewish General Hospital on January 6, 2021. It was a few months before his 90<sup>th</sup> birthday. Dad didn't have any catastrophic illnesses. Other than having a few minor issues (stenosis in the cervical and lumbar spine, dementia, and going to the hospital for a minor prostate issue,) he had not been in the hospital since the day he was born. "If not for COVID, dad would have lingered for a number of years."

Dad and Mom lived autonomously without any real help. They were a movie star looking couple. They had three daughters, Sandra, Jay, and Kelly. Jay is a jewelry designer and Sandra is an alternative health person and does reflexology. Jay had just come back from the States with her husband, and they were in a 14-day quarantine. Kelly lives out of town.

Mom had recently been at the Jewish General Hospital for a noninvasive surgery for aortic stenosis. Luckily, she was in and out. Sandra, Jay, and Kelly were deeply grateful and very appreciative that things had shifted enough that they did not have to wear full PPE and they were able to take her to the hospital and stay with her. Sandra ended up being with her mother most of the steps of the way; Jay was home with Dad keeping him calm while Mom was away. As Dad had dementia, he was pretty lost without Mom. And Mom's anxiety was more about worrying about him than herself. "You could see their relief when she walked back into the apartment. It was very tender."

Sandra commented that it could not have been a better experience. The nurses were extraordinary. Getting access to the hospital, the coming and going and picking up Mom was remarkable. What had alarmed Sandra was learning that when the nurses finished their shift, they had to go to the other side of the hospital to do a whole other shift instead of going home. This brought a great deal of awareness of what was really going on around her on November 15, 2020.

It was New Year's Eve when Sandra got an email late at night from her mother saying that she had chills and a fever and that she thought that she needed to be tested for COVID-19. In the morning, Sandra drove her parents to the MUHC's parking garage to get them both tested from the back seat of her car. After they were swabbed, Sandra "drove them home, put them into the apartment, and told them to stay there." The next morning, she received the call that her Mom had tested positive for COVID; her dad was negative at that point. Sandra later learned that the housekeeper was also diagnosed with COVID.

Although Sandra separated her parents, putting her father in the bedroom and her mother in the guest room, she felt that it would not make a difference as Dad with his dementia kept on going to look for Mom; in the end, it didn't make a difference.

On the morning of the 6<sup>th</sup> of January, Sandra received a call from Mom saying that she found Dad on the bathroom floor in his boxers and a tee-shirt. There was some blood. He couldn't get up. Sandra went over to the apartment, masked, and wearing a shield. Her boyfriend called 911 while she checked Dad out. He was conscious and compos mentis. He was talking. Nothing was broken. He wasn't actively bleeding. He had hit his forehead when he hit the ground. Sandra got Dad comfortable on the bathroom floor, putting towels under his elbow and a cushion under his head. She covered him with blankets. She talked to him. He was able to answer all her questions. Her Dad wanted her to wipe the dry blood off his face and told her that he had been lying there for a while. Sandra made sure that Mom stayed away from him as they thought Dad was still negative. Sandra lay on the floor with her father for 45 minutes waiting for the ambulance to arrive.

Eventually the ambulance came. Before Dad was taken, Sandra put her sisters on video so they could see Sandra on the floor with him. It took three people to get Dad up and onto the gurney, because he was in an awkward space. Sandra gave them information about his medications and as they wheeled him away, Sandra begged them to take him to the Jewish General Hospital because that was where his doctors and his files were. Sandra sensed that she wasn't going to see Dad again. She believed that COVID-19 was making its way into his body. Mom caught it first; Dad caught it second.

They tested Dad, the day they brought him to the hospital; he was positive. When he arrived at the hospital, Dad had bruising from his fall. He looked like he had been in a fight. The sisters were very clear when they spoke to the doctors that as per Dad's wishes, he did not want any extraordinary heroic measures. There was a DNR directive in his medical file. The sisters also knew someone in the Emergency Department (ED); they were able to speak to this person and get some first-hand information about their Dad. They felt lucky to be able to tap into and have that information and particularly in this instance to know that their father was not alone. The sisters also didn't know how confused he was going to be in this scenario.

Dad didn't spend a night in the ED. By the end of that day, he was brought to K8, the COVID floor. They were told that nurses had been reassigned to K8 and it had just freshly opened. Those first couple of days while Dad was in the hospital was difficult for the sisters. It was their absolute worst nightmare. Mom was at home dealing with exhaustion and having a new unknown caregiver in the house with whom she had not made a connection. Sandra and Jay were unable to be in the hospital because they were in quarantine. However, "within twenty-four hours of Dad's arriving, [they] had the names of just about any staff who picked up the phone, their schedules, when they were on, when they were leaving, who was coming, who the doctors were, what their role was with their father, and when that was".

According to Jay, Dad was being taken care of by "some of the amazing nurses and people at the front desk [who] were making time to try to connect with" them and they never made them feel badly for all of the inquiries. The nurses were extraordinary. Twice a day, they gave Jay his blood pressure, and his oxygen level on the phone. When Jay would call "at 7 in the morning,

there would be a litany of information. That was quite extraordinary". They brought in an iPad so that the sisters could Facetime with Dad. "We could see him; he could see us."

Dad was slowly getting gripped by COVID. The 12<sup>th</sup> of January is when it really started to take hold. He was not terribly verbal. Towards the end of his life, he had gotten quiet, more introverted and restrained in his communication. He started to have heart palpitations. They had to start administering oxygen. On the 16<sup>th</sup>, everything seemed okay in the morning. The doctor had said that Dad had rallied the day before; they had been giving him Remdesivir.

When the doctor called Jay around 2:30 that afternoon on January 16, it kind of took her by surprise. He told her he needed to clearly go through what was going on. His tone had completely changed. He ran through everything. Dad's oxygen levels were just not holding. The doctor reaffirmed that she needed to be there and added that she needed to be there now! Jay immediately ran out of the house, without taking any food. She just got in the car and went.

When Jay got to the hospital, there was a nurse who met her downstairs and brought her up to the floor; she showed her how to get dressed in PPE and brought her to the room. That was the first time Jay saw her father. The next day, she knew what to do. From that point on, Jay and her sister Kelly were deemed as caregivers. They did twelve-hour shifts, Jay arriving in the afternoon and Kelly, arriving in the morning. Jay was thankful she and her sister were able to be at the hospital with Dad, especially since she felt that he would have done exactly the same for them. While Jay was in the hospital, she would sit beside the bed and if they came to move Dad, she changed sides. The most important thing was that her Dad knew that somebody was there with him.

Although the hospital allowed only one family member at a time to come in, they allowed Kelly and Jay to be together briefly passing at the elevator bank. After the two sisters embraced each other, they switched places. Nobody said a word. They knew that the sisters were doing what they needed to do for their father. It seemed to be the policy that once the patient was terminal, the family was permitted to come in. But if the patient was being treated, the hospital was not allowing the family into the unit.

When the sisters switched the afternoon of the 17<sup>th</sup>, Kelly shared that she thought that this was the day Dad was going to pass away. Throughout Jay's shift that night, the nurses kept on coming in. The orderlies turned Dad every two hours. At one point they took off the oxygen. They were keeping him comfortable. They gave him dilauid, some by injection, some by patch. Though Dad was non-communicative, Jay told him that "it's okay to go". Jay was told that there was going to be a BIG BREATH and then nothing. Because Dad was taking very long breathes, and Jay wondered each time whether this was it and whether she had missed it. But when a nurse came in around midnight, Dad started breathing regularly. Her first thought was that giving Dad all this dilauid was screwing this whole thing up. But then she repeated, "You need to go. We are giving you permission. You can let go. We got this."



When the sisters met on the morning of the 18<sup>th</sup>, Dad was still alive. Jay went home and Kelly went to their father's room. When Kelly arrived in the room, she found that Dad was "soooo peaceful" and that he "was the most peaceful that [she'd] seen him the whole time [she'd] been there with him. He just looked so calm". When the nurse came in to say good-bye, he looked at Dad and then at Kelly and "sort of acknowledged it. He didn't have to say too much. We sort of nodded to each other" and then he checked Dad. Dad had passed. Dad had had a quiet exit. As Sandra put it, it was "an exit stage right and a blessing that he did not suffer. He did not have pain [and] he knew he was loved. He was taken care of beautifully. And we didn't watch him lose his dignity . . . As big as the loss was, it was almost a gift".

The nurse let Kelly be with her father for just a little longer until she told him that she was ready for him to get the other nurse. Kelly remained in the room while the person declared the death. Kelly was allowed to stay for as long as she wanted. There was no rushing to get out of the hospital. There were no protocols. "There was just a tremendous sense of sensitivity".

All the sisters are grateful for the care their father received and the role they were all able to play in supporting the end of his life. Although these were unusual times, every single person working on that floor was caring even though they were doing 12-hour shifts. They were extremely grateful to everyone who worked on that floor. The nurses would ask them if they needed anything. They made sure that they were okay. Nobody was coming to tell them to leave the hospital. The nurses respected and were sensitive to the family.

Jay never had any experiences like this. She will always be grateful for the experiences she had on the COVID ward at the Jewish General Hospital, especially when a nurse came over to Jay and told her that she couldn't sleep like this again. She then rolled in this oversized wheelchair that reclined and put it beside the bed so that Jay could sit there and hold her father's hand. The nurse also gave Jay a pillow and a blanket because she was worried about her. Even though Jay said that she didn't want them to even think about her, the nurse responded with, "anything that I can do, that's what I'm here for". She will always remember gratefully the positivity of all those wonderful doctors. Jay did not know how it was possible for the medical workers to see all of the sorrow that they had been living through day in and day out.

Jay also commented that everything was such a disconnect. For example, on the night of the 17<sup>th</sup>, when Jay entered a room where she could eat something, she recognized the voice of one of the nurses on the floor. She was finally able to see what she looked like. Jay could only imagine how Dad felt seeing everybody with their masks and visors; you can't see people. It just must have been disconcerting. Even though people are talking to you in a nice voice, it is just that there was no personal contact. That must have been another part of the experience. None of the sisters got to talk to him about that because they were not there when he was alert.

Sandra recognized that there was just not enough staff but that these are the times we are living in right now. Doctors were being called from other parts of the hospital and they did what they had to do even when they knew nothing about caring for seniors or people who were on the COVID floor. It didn't matter what their training or background was. They were so sensitive

when they came in. In their minds, he could hear them. It was as if he was up and conscious and ready for the next day. Jay and Kelly appreciated them telling them that hearing is the last thing to go, especially when they felt depressed and sad. They advised them to play music. Keep talking to him. So, they played music that he loved such as Fiddler on the Roof. They sang to him hoping it would make him happy.

Kelly remembered the careful ways the medical staff explained how to put on the PPE and then to remove it; the gentleness that the nurses all had toward her. She commented that the nurses sometimes checked in to see if she wanted to have a break and offered to come and be with Dad if she needed to go to the bathroom. They were respectful. They would explain what they were doing when one of the sisters came in. They did not treat Dad as if he was just a body. She recalled the way they came in and took such care to turn Dad, speaking to him with a cheery voice, and loud enough so he could hear what they were doing. The nurses shared their impression of what a nice man Dad was even in the short time they were with him and spoke of how Dad would describe who everyone was in the family photos. The staff would come and say goodbye when they were done their shifts. When Dad died, the nurse acknowledging that Dad was gone, asked if Kelly was ready for him to tell the other nurse, and respectfully explained that she could be with Dad for however long she wanted. They were very caring and understanding given the circumstances that they were all living in their jobs. “It was remarkable that they could still have the bandwidth to give more, considering how stretched they already were”. And of course, they were appreciative of Sandra’s home-made brownies that Sandra had individually packaged.

The sisters suggested that the most important thing we could do for the staff at the Jewish General Hospital is **to support** them. One way would be **to give the staff as much recovery break as possible**. They also thought that the **staff should have a way to speak about their experiences**. For example, on the last night Jay was in the hospital, a staff person just held her when they met in the hallway. They had become close. Jay doesn’t know how they are still there. That takes a lot out of the staff.

Sandra, a reflexologist, said that she would be happy to make herself available a couple of days a week, a couple of hours a day to come and treat the nursing staff or doctors or orderlies with reflexology. She feels that “there is a real need to just decompress. They are firing cortisol hormones all the time because everything is urgent, urgent, urgent. You deplete it and it is so hard to refill the well”. She believes that having one or two reflexology sessions is a way to take care of them. It’s a way to acknowledge that they are being seen and heard and that their exhaustion is being validated.

Kelly saw **that there was a need “for the nurses to hear from us”**. What they do has so much impact on the patients and their families and the nurses don’t realize how much of an impact they have. Their impact is big, and it stays with us.

Sandra, Jay, and Kelly went the extra mile to acknowledge the staff. Sandra sent home-made brownies to the ward. Jay made *hands* that were given to nursing staff and care staff. This was

part of a project that two jewellers, one in Brazil and one in the United States started. Jay arranged that every single person on K8, including orderlies, would have a *hand*, which they personally delivered after Dad had passed. The family made a donation to the floor to acknowledge their experience there. They also wrote a letter to be shared with everyone on the floor. Although it is now 10 months after Dad died, Jay “still remembers the names and conversations as if it had happened a couple of weeks ago and still has memories of each of the individual conversations and interactions”.

The following is the letter they sent to the ward:

*To sing praises and recognize your nursing and Resident staff that were on for the 13 days our father was on K8. Of course, it was a very difficult time for our family, but no one EVER made me feel like they didn't have time to talk and fill me in on my dad's progress. Because I wasn't able to come to the hospital immediately, I was a pest and called in the early morning and the evening when the shifts changed to find out how things were. The assigned nurse made herself available to make facetime calls between my mother and father and us daughters as well. That helped keep us all connected to him and to let him know and feel he wasn't alone. When I was finally able to visit my dad, I was fortunate to meet almost everyone I had spoken to and pretty much felt like they were old friends. Not that they weren't professional in any way; it was their compassion and warmth in these terrible times that struck and touched me and my family the most.*

## **“He’s Back! He’s Back!”**

### **Stephano**

Stephano lives in Montreal with his wife. He was 73 years old when he was admitted to the Jewish General Hospital (JGH) on March 31, 2020, which was at the beginning of the pandemic. He woke up from a coma on April 18 and was discharged on May 5, 2020. His daughter resides in Toronto. He believes that it was a miracle that his wife did not get COVID-19.

Prior to contracting COVID-19, Stephano was in Toronto in February for his grandson’s birthday. No one was wearing masks. “There was no fear running through the population”. By the end of March, he literally stayed home with his wife; by this time people were starting to get scared and anxious about COVID-19. His only sojourn out was on a Sunday afternoon when he went to Jean Coutu to pick up a prescription. Stephano noted that nobody was wearing masks and there were no shields in the drugstore.

It was not long after Stephano went to the pharmacy that he became extremely tired; he also had a high temperature. Upon the advice from his doctor, he had his wife drive him to the ‘Jewish’, to the Emergency Department (ED), to get a COVID test although his doctor did not think it was COVID-19. On the drive to the hospital, Stephano could not stay on his feet. His wife waited an hour and a half outside before going into the ED. She was told that Stephano was not a well man and that he had a 3% chance to live.

A doctor in the ED told Stephano that he would be seen in a few minutes and to sit on a gurney while he waited. He lay down on a gurney and went to sleep because he was tired. The next thing he knew was that he was lying in a bed, and there was a nurse standing over him. She quizzed him about his name, where he was, and when he arrived at the hospital. He had been in a coma for almost 3 weeks.

Stephano was totally confused at this point, as all he remembered was getting to the hospital. The next thing he knew was that it was already April 18, 2020, that he had been very sick, that he was on a ventilator, that he had kidney failure, and that he needed dialysis. He was told that he was alive and basically it was a miracle. He believes that he had been moved from the ED, to K9, and then to K10.

Although Stephano understood what the nurse was telling him, he thought he was dead. He was lying on a bed and could not move his legs and arms. Even though the nurse tried to convince Stephano that he was alive, he continued to doubt her because he could not move anything. He was unsure as to whether this was heaven or hell. All he saw was a glass in front of him, a nurse wearing a helmet, and that she had on goggles. He could not see her eyes. He also noticed that the two people standing outside were walking back and forth like zombies. He could not see their faces. He stared at the white digital clock in front of him on the wall and focused his eyes on the seconds and minutes. The doctor was standing outside the room, behind a booth, and spoke to him through a landline phone.

The nurse finally convinced him that he was not dead. She told him the whole story. She said that he had been sleeping for 18 days and had awakened after Passover. She told Stephano that he was VERY SICK and that he fought like a dog. The nurse shared that “most of the people [his] age were not leaving the hospital. They’re dying”. According to Stephano, now they know a little bit more about what to do with a guy his age. At that time, they were going by the seat of their pants. There was no booklet.

Even when the nurse gave him his phone, he was wary because he couldn’t keep it up; it felt like a hundred pounds. The first thing Stephano did was to Google himself on Paperman’s website. He was only convinced he was alive when he didn’t see his name on the list. When he was finally able to hold his phone, Stephano Facetimed his wife, who then reached their daughter in Toronto. She began screaming “He’s back! He’s back!” “Everybody was frantic”.

Stephano remained unsure, trying to figure out how he went from the first to the eighteenth just like that and missed Passover. Eventually he recollected being tied down and being picked up in a net and being moved, but only after watching a segment on TV where a COVID patient was being transported from a bed to a chair by a net. Everybody was walking up to him, poking him, asking him things. He remembered that bunches of doctors walked in and out and asked him all kinds of questions. Because he had difficulty sleeping, they suggested that he take sleeping pills and have a psychologist help him deal with his nightmares and confusion. He had a physiotherapist teach him how to stand up, use the walker, go to the washroom with the walker, and walk without assistance.

Stephano had the most positive experience at the Jewish; he found the care he was getting from the moment he arrived exceptional. Even though information was being thrown at him at first, the staff were just incredible. For Stephano, “the doctors, the nurses, and orderlies were exceptional. They were unbelievable. They were absolutely angels . . . They were gold, diamonds”. They catered to him. It felt like he had his own staff. He had a whole team at his beck and call. They would bathe him. If he rang the buzzer because he was cold, they would give him blankets. They would bring him warm towels. Everybody was there for him from the nurses to the orderlies. The staff answered his wife’s and daughter’s phone calls. Even then, they were being very cordial and doing everything. They did everything to keep him alive and awake, including putting the phone to his ear when his family called. “They DID everything!” According to Stephano, “the hospital was FANTASTIC. There was nothing negative.”

The staff “went beyond the call of duty”. The one exceptional thing a nurse did, which was beyond her call of duty, was to get him a can of ginger ale. Every meal after he asked her to get him a carbonated drink, she brought him a Canada Dry Ginger Ale. As he said, “I had it for lunch. I had it for dinner. I would sip it so slowly. It was like gold”. Stephano was emotional as he recanted the story of the doctors who heeded to his daughter’s request to play a recording of his grandson talking to him and of them singing songs they would sing together when he was in a coma. Daily, a doctor would bring the phone close to his ear. Although he does not

remember what they were doing for him, and he doesn't have any flashbacks, what the staff were doing for him was unbelievable.

Following his discharge, Stephano went to the JGH for blood tests until December 2020 because they wanted to make sure that his kidneys were functioning. Now he sees his own doctors. Today, Stephano feels like he has a new life. He still is extremely tired and can fall asleep anywhere. He cries easily and panics when he awakens after falling asleep in an unfamiliar place. Because he got "so close to the edge", he is "extremely nervous about any little thing". He stays away from anything to do with sadness and COVID-19. Although he could handle dramatic action films in the past, he does not want to watch them now. He lost his taste for watching sports, which he used to love to do and only watches the highlights. He returned to playing golf, but he can no longer spend three hours watching the game on TV. He gets nervous about who is winning. He goes for walks and to restaurants. He literally does not enjoy a drink; in the past, he liked drinking Vodka in the summer, straight and with Scotch. A wonderful thing that happened is that he can now eat spicy foods.

Stephano summarized his stay by explaining that from the moment he walked in, slept, woke up until the moment he got wheeled out onto the street to get picked up, the whole hospital was there including the physiotherapists, occupational therapists, kidney doctors, a cardiologist, and a psychiatrist. For Stephano, they were unbelievable.

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Dr. Neomi Kronish