The Coronavirus-Caused Isolation Brings New Challenges to the Chronically Ill

To be a close friend of Sammi Lindsley implies that you are up-to-date on your vaccinations. It means that you are good at asking questions, but aren’t pushy. You would understand random medical jargon, and be able to speak some of that language on your own. To be one of her friends may involve a late-night run to the grocery store to purchase a can of Coke and some MiraLAX. You might shoot her a text or give her a call to check up on her. You would know if she isn’t answering that she is particularly sick, not just ghosting you. To be a close friend of Sammi Lindsley implies that you haven’t touched her in nearly five months, and you wouldn’t dare come by her house without wearing a mask and standing at least 6 feet away (more like 10, for good measure) from the doorstep.

It’s been nearly six years since Lindsley mysteriously got a virus that essentially rendered her bowels useless. Since then Lindsley has created a methodical schedule to help her cope with her undiagnosed chronic illness. It’s a routine that has become stricter and more uncompromising because of the new coronaviruses. However, despite her ability to acclimate to her daily routine, the pain that she inevitably confronts is something she will never be accustomed to.

Setting up a Facetime call with Lindsley requires that you are both flexible on the time. We plan to start at 11 a.m., when I received this following text: “Hey, can I call later? Feeling really nauseous right now.”

Ten minutes pass and she gives me a call on Facetime. From the orientation of the camera, Lindsley can be seen cutting strawberries. To the left is a white plate rimmed with navy blue. On the dish is a green cup of Activia probiotic peach yogurt and a slice of homemade banana bread. She cuts the strawberries quickly, and arranges them in neat lines on the plate.

“Grams, always appreciates a good plate presentation,” she says whisking the snack out of view as she delivers it to her grandmother who is in the next room. Gasps of joy can be heard through the phone.

“Dee-dee! For me? It’s so beautiful. Thank you,” can be heard.

This interaction has become a tradition of sorts. Every day at around 1 p.m. Lindsley brings her grandma lunch, and the 91-year-old never fails to be shocked by the generosity. On occasion, when Lindsley gives her a freshly-baked chocolate chip cookie, she even cries.

Lindsley’s been a caretaker for her grandmother Marna, who she has nicknamed Grams, for nearly three years now. Despite the daily interactions Marna’s dementia prevents her from remembering the name of her own children, let alone her granddaughter. “Dee-dee” has become a pet name for Lindsley, and really anyone that Marna addresses.

Lindsley returns into the frame, chuckling from a joke Marna had made about giving her a ‘kick in the pants’ if she doesn’t behave. She sits down on the stool. She looks at the camera and laughs.

“I’m not quite sure what makes me a very good profile subject. After spending a day with me, you’ll see I live a pretty boring life,” she says.

Lindsley’s husband Spencer has said before how much she hates talking about herself. “She is so self-deprecating and oftentimes hates telling her story because she doesn’t want other people’s pity. She is always talking about how people are worse off than her. Despite her illness depriving her of so much, she is continually optimistic,” he said.

She walks with the phone downstairs to get a load of laundry done. Today was a good day, and she doesn’t get many of these. She has to be doubly productive in case tomorrow she cannot find the strength to get out of bed.

The basement is where Lindsley and her husband Spencer live. Unlike the main floor that features pale turquoise walls and sky-blue carpet (blue is Marna’s favorite color), the downstairs is various shades of neutral. Two prints hang on the wall featuring tennis rackets. Lindsley calls these a “remnant of my previous life.”

By this Lindsley is referring to a time when she was not dependent on a PICC line (a long catheter inserted in her neck which provides nutrition that goes directly to her heart) and feeding tubes, or even supplementary sustenance. She was healthy, and enjoyed the privilege of sleeping ten hours a night and eating pizza from Little Caesars. In many ways, Lindsley was like most teenage girls: she was smart, talented, kind, and beautiful. She was captain of the tennis team, a student body officer, and dating a varsity football player. However, around fall of 2015 Lindsley started to experience intense gasto-intentestinal discomfort whenever she ate anything.

Lindsley describes the pain as, “Debilitating and completely enervating. All the sudden I was thrown into this reality filled with pain and frustration. Frustration that we couldn’t figure out the problem and that I wasn’t getting better. It was so overwhelming. I was terrified to eat and wanted to avoid any situation involving food.”

Unlike most teenagers, Lindsley spent much of her senior filling out forms in waiting rooms and wearing hospital gowns. In her search for answers she began to understand words like hypokalemia, jejunostomy tube (or J-tube), and refeeding syndrome. She even celebrated her eighteenth birthday in a hospital room.

That was five years ago. Since that time, Lindsley’s life has been a blur of ICU stays, shocked doctors, and routine lab visits to test her blood. Not forgetting the incessant pain that has prevented Lindsley from tennis, vacations, and even school.

Lindsley studies the print for a moment then walks to laundry room and dumps a load of Marna’s whites in the washer.

Today was Monday, or grocery day. At around 2 p.m. her husband returns home from retrieving their Smith’s pickup grocery order. Due to the coronavirus, and both Lindsley’s and Marna’s susceptibility to the disease, grocery shopping has become much more complicated in their household. Lindsley positions the phone in a way that I can observe their sanitizing ritual.

They start by putting on gloves. Each grabs a disinfectant and some sheets of paper towels. They start with the plastic bags, and then move to the individual products. A couple of months ago they used to quarantine the items for a couple of days, now they just opt to vigorously clean each item with the cleaning supplies. The whole process takes around twenty minutes to complete.

“If cleaning was anything like playing an instrument, Sammi would be considered a virtuoso,” Lindsley’s spouse Spencer jokes.

Deep cleaning, sanitizing, and disinfecting is a regular practice in their household. Lindsley obtains all of her nutrition intravenously via a PICC Line, which is essentially a thin tube that is inserted into her sternum. Each night she hooks up to a medical backpack that pumps Total Parenteral Nutrition, TPN, to her subclavian vain which then leads directly to her heart. Due to the vulnerable location of her PICC line and the J-tube on her abdomen, Lindsley is required to routinely sanitize and replace the dressing.

Applying new dressing to a PICC line is not as simple as it seems. It involves a variety of sterilization techniques, and even a certification. Her husband is grateful that he got certified to change Lindsley’s PICC Line dressing when he did. “I’m so glad I got certified. We used to have a nurse come in, but that would be really dangerous given the coronavirus. Getting her the medical care she needs has become a lot more difficult,” said Spencer Lindsley.

If it was Thursday, Lindsley would be getting her blood drawn at about that time. She could be at “frequent flier” status if hospitals or doctor’s offices had such a program. Lindsley gives a more literal meaning to the term “blood drive.” She would pull up to a parking spot and rolls down the window. Chris, the phlebotomist, would approach her Ford Explorer and draw two vials of blood. These samples would be taken to the lab to check on Lindsley’s potassium levels.

If her levels are bad (below 3 millimoles per liter) then she is forced to intravenously feed it through her PICC Line. This takes around two hours and requires that she walk around with a sphere the size and weight of a baseball filled with potassium. This clear substance helps regulate muscle contractions, specifically her heart.

“I can tell when I’m low on potassium. I get winded after walking up two stairs. But mostly I feel my heart pounding, pounding, pounding in my head. It’s like a just ran a marathon. The hard thing is that I get pretty sick when I take the potassium,” Lindsley said.

But because it’s Monday, Lindsley doesn’t have to worry about the results of any blood test just yet. Instead, she gets to work making lasagna. She likes to have a variety of meals waiting in the freezer, in case she has what she calls a “bad day.” On those days, she can hardly get out of bed. She’ll get grandma up, dressed, and situated in a navy leather recliner enjoying the golf channel, before nearly collapsing on a nearby chair.

“Sammi is one of the most selfless people I know. Marna’s health and well-being always comes before her own. I have never met a more compassionate caretaker. She understands Marna’s pain and frustrations in a way that no one else can,” said Kelly Henriod, Lindsley’s older sister.

Lindsley calls me again after dinner. From my vantage point I can see the three of them watching America’s Got Talent. They joke around, and from time to time Marna will wave at Howie Mandel or criticize a contestant’s edgy haircut. At some point an ad about the new coronavirus appears and Marna says, “Oh I do not want to get that coronavirus. I’m staying in.”

Lindsley and her husband laugh knowing that Marna would not leave the comfort of her navy recliner even if there was not a pandemic waiting just beyond their front door. It’s been over seventy days and Lindsley hasn’t left the house.

“I get jealous of those that have the luxury of good health, who can leave their homes whenever they please. But at the end of the day, there is really no place I would rather be,” said Lindsley.

They put Marna to bed around 9 p.m. At 11 p.m. Lindsley starts the long and tedious process of hooking up to her TPN. The process of intravenously feeding typically takes around 10 hours. She prepares for bed and hopes that the next day will be a good one.

According to the National Health Council over 40% of Americans have a chronic illness. Statistically speaking Lindsley’s story may be inconsequential. While Lindsley realizes she is just one of 130 million people living worldwide with an undiagnosed disease, she sees the value in creating a dialogue about chronic illness, even if it is just one narrative at a time.

“I typically hate talking about my illness because I feel defined by it. But I have realized the power that accompanies honest conversations. There are really dark days but there are also really good ones. I hate my illness and what it has taken from me. But I love who I have become because of it. Being sick has helped me to develop empathy and appreciate the small things,” said Lindsley.