

Caregiver Story

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I met Sheri a little over four years ago, when I got a job as a Program Coordinator at NSMHA overseeing a 10-bed group home. Sheri was a long-term resident of the group home, having resided there for roughly 23 years.

Sheri was a person living with Schizophrenia who lived as full a life as could be offered to her. She was a firework. Sassy but kind, loving and very outspoken. She had impeccable taste in fashion-and a personality that shined through a smile that would light up the darkest of rooms.

She was such a free spirit. She liked what she liked, and made sure to share her love for things like iced coffee and cigars with everyone she encountered. Shopping was her all-time favorite thing to do. She took much pride in her appearance and always made sure she looked and smelled her very best. She was loved by many.

I never knew what it meant to be identified as a caregiver until Sheri was diagnosed with cancer in 2016. It was at her initial appointment with her oncologist Dr. Temel, that Sheri and I first met Dr. Irwin and Amy Corvelyn and she was enrolled in a study for patients with Serious mental illness and cancer. Sheri and I both identified myself as her caregiver, as she had no family. I took on the responsibility of bringing Sheri to her appointments to make sure everything was being communicated effectively, and well because I promised Sheri she wouldn't have to face this experience alone. Besides, Sheri had a fun way of making it seem like things were going great, so no one would worry about her, but it wasn't always the case.

Being able to directly engage with Sheri's MGH team was the first time in a long time, I felt supported when it came to the needs of the people I serve. It didn't matter that I didn't have a licensure or that I was merely a Group Home Manager. The team respected my input and acknowledged the bond that Sheri and I had. It also allowed for a direct contact, and not the run around being transferred and leaving numerous messages for various providers. MGH cared for each of their patients and treated them as humans and not number or subjects. A prime example of this was when Sheri was going to have day surgery. I requested she be given something to ease her nerves as she very nervous, and I was afraid she wouldn't get through the procedure since I couldn't stay with her and hold her hand. The rehab gave me such a hard time, even after I explained to them how anxious Sheri was about being put under anesthesia. I met with Dr. Irwin at one of her follow up appointments a week or so later and explained the situation and my concerns. Before I could finish reasoning the need for some medication, I had the script I needed for Sheri to have a successful procedure.

One of the biggest setbacks I've had with Sheri is when she fell out of her bed and broke her hip. She required surgery to put pins in place-and was then transferred to a rehab in Needham, Ma to regain her walking ability. When I first went to visit her, I was accompanied by the clinical coordinator of our group home for support. We made it clear we wanted Sheri back at the group home, but due to policies etc. we could only hold her bed at the group home for a short period. While in that rehab, Sheri engaged with physical therapy, made new friends, and did her best to walk independently. I visited weekly maintaining communication with her social worker, bringing her clothes and money for cigars and just spent quality time with her. I also made sure to send her peers from the group home as well as staff. After a little over a month, despite her best efforts, Sheri was unable to regain the strength required to not only be able to

walk independently without a walker, but to also successfully walk up the large number of steep steps to her group home. Unfortunately, on top of this, Sheri also completely lost eye sight in both eyes due to cataracts. With all these factors, the decision was made to close Sheri's bed out with my group home and she was no longer considered one of the "persons served" under our care.

I was ultimately told I could no longer accompany Sheri to her appointments, despite my argument that she had no one else and we were her family. My higher-ups felt it was the job of the nurses at the rehab to bring her, and I no longer needed to support her. The first thing I could think of was how unfair it was for Sheri to just be left all alone, as if it were her fault she got sick and could no longer return to the place and people she called home for over 23 years. The rehab location was just too far away from her home and friends who resided in Chelsea, the drive itself was 45 minutes or longer with traffic. It was then that I decided to make a few calls and with the permission of Sheri's guardian, I transferred Sheri to a long-term facility only 5 minutes from the group home in Chelsea. This made it ideal for all of Sheri's housemates, day program friends and long term companion to easily come visit her whenever they wanted.

Despite what I was told, I continued to support Sheri and worked longer days to leave early to take her to appointments and just be there when she needed. After her appointments, before I would bring her back to the rehab, Sheri and I would go by the group home and I would sit her on the steps so she could have a cigar and chat with whoever was home at the program during that time. If I couldn't make it to her appointments, I made sure to send another responsible person in my place-usually my APC Melissa was that person. I've seen firsthand the stigma and ignorance towards individuals with mental illness, but when Sheri was diagnosed with Terminal cancer after having been in remission for a while, the incidents of this stigma were more apparent.

One of the very last things I wanted to do for Sheri, was make sure she got her cataract surgery. Despite being told by peers and providers alike "what's the point, she's dying" or "why does it matter, she's too sick to enjoy it". The first time I had scheduled Sheri's eye surgery, I met her at the clinic at 6:45am. She was nervous, and kept calling my name and reaching out for me. I held her hand and reminded her of all the amazing things she would experience again, once her eyesight was fixed. A few minutes later after Sheri's vitals were taken, the nurse came over and asked me if she had taken her morning medication. I explained she was in a nursing facility, and so I needed a few minutes to call and verify. For whatever reason, the nurses at the rehab held Sheri's morning medication, so her blood pressure was extremely high, resulting in her not getting the surgery that day.

I share this story to share- as we were waiting for her blood pressure to come down, one of the nurses walking by motioned to our nurse and said "Oh looks like your babysitting again". I never have been so insulted in my life. How do you "babysit" an adult who is merely patiently waiting for stable vitals so we could leave? Sheri didn't understand what was happening, but I used that comment for fuel to an already burning fire. We rescheduled her surgery and came right back a couple weeks later. I was more determined than ever to see this through. I called the rehab the night before and made sure there was a note that clearly documented Sheri needed all her medication in the morning before her appointment. Sheri and I met up yet again at 6:45am, but this time, she got her eye surgery and I swear I could see an immediate transformation within her once she could see again.

Over time, Sheri's cancer returned, and her MGH team decided we would not be seeking treatment. Sheri was visibly getting weaker, and it became apparent that her mental health was also declining as she began to engage less and no longer wanted to be seen outside of the facility she was in. I was tasked with talking to Sheri about her end of life plans and how she would like to be remembered. With Sheri's mental health declining, there were often periods of time where she wasn't coherent, and I wasn't sure if

she understood what I was saying to her, or if I understood what she was saying to me... but after a few attempts, Sheri could tell me she wanted to be celebrated-and that was alright by me.

I used my role as Sheri's Caregiver to advocate to the very end for what sometimes felt like her basic needs and respect as an individual to be met. I found a sense of purpose in using my voice to elevate hers and make sure it never got lost in translation. Sheri was a very resilient woman, and if she was willing to fight, I wanted to be right beside her. Well, what I wasn't prepared for was the time when Sheri would no longer have the energy to fight and the battle would ultimately be over. It had been a week and a half since I had last saw Sheri. Work had gotten extremely busy and I couldn't squeeze the time during the day to see her as I had before, and at night I was studying for midterms for my college classes. Three days before Thanksgiving, I got a call from Amy saying Sheri wasn't doing so good and if I planned to see her I should go soon. I wasn't ready to say goodbye to Sheri, for selfish reasons, I wanted her with us and to continue to fight. But Sheri was tired and she was ready to let go.

On 11/21/17, I tried to rush through my day so I could get to the rehab to see her. By the time I finally got there, it was already 4:30pm. I got upstairs and began to walk to her bedroom, when I was greeted by a nurse who told me Sheri had just been brought to the ED because she stopped breathing and had turned blue. There's no nice way to express my feelings-I just remember being furious. As it turns out the rehab didn't have the DNR I had been asking the guardian to send over for months. I should've had my own copy. The nurse went on to say how Sheri was suffering and they couldn't bear to see her like that. I remember crying angry tears and frantically calling Amy to help me find Sheri. Meanwhile, I just kept picturing her in the ambulance frightened and alone and barely breathing or already gone. I rushed down to the Mass General Emergency department from Chelsea, and met Amy in the ED. When I saw Sheri, she was semi alert partially laying down/sitting up in the bed. She looked so tiny in a mass of pillows that surrounded her.

At one point, I had walked over to the bedside, and was just holding and rubbing her hands. I remember thinking to myself, but saying out loud how I needed to bring my purple nail polish because her nails were fading from the last time I had painted them. Sheri then suddenly pulled my arms. I couldn't figure out if she was pulling me closer or trying to get me to pull her out of the bed...but either way she knew I was there with her. I stayed for a little over an hour, waiting for her to get a bed on a floor. Eventually, I knew I needed to go because it was getting late, and I had an early meeting the following morning. I whispered to Sheri to hold on and not to leave until I came back the next day. I hoped she heard me.

The next day (11/22/17), I blew through my work and got back to the hospital around 3:45pm. When I saw Sheri, she looked peaceful, but even smaller than the night before. Her features had also changed which threw me off. How could someone change so much in 24 hours? She had on an oxygen mask on, but was breathing with her mouth open. The mask bothered me because her tongue was white and the air appeared to just be making her mouth dry. I politely asked the nurse if we could remove it and she got permission from the doctor to do so. With the oxygen now off, the room was weirdly quiet. So, I decided to play some songs that I knew Sheri enjoyed, and sing to her. I gently brushed her hair, (I've always admired her beautiful golden locks) and just rubbed her arms and legs trying to produce some form of heat. I told her how proud I was for the battle she had fought and how strong she had been, and how I was going to miss her. I just wanted to make sure she knew she was loved and she wasn't alone, even now. Within 30 minutes, Sheri passed away with her left hand in mine, listening to me singing Bruno Mars "Count on Me".

Looking back when I think about supports and things I wish were available for me and Sheri-I wish there was a way for her to stay at the group home and to have been surrounded by all the people who she loved and loved her in return. Continuity of care-especially for those who are getting up in age and have lived in

programs all their lives. I wish there were more resources for myself as her caregiver-to know I wasn't alone and to ease my mind so I wasn't always worried about everything happening with her. Training for group home staff is such a necessity. We have no idea when or how to access palliative care, and most times although we know the clients best, we aren't even involved in the conversations. Staff should feel inspired to advocate for the clients under their care and empowered to seek the best care accessible.

In the end, Sheri taught me about life, love and the importance of being true to yourself regardless of what others think. She taught me to be patient and to never give up for what I felt was right. She taught me it was okay to be compassionate and never back down because someone says No the first time. She made me a better person, mother, student and caregiver. But more importantly, Sheri taught me that everyone deserves a chance at the best Quality of Life possible regardless of any diagnosis. It's been almost 6 months since Sheri passed away and I miss her every day. But I am so thankful she allowed me to fight alongside her-without her I may never have realized just how important the little things in life truly are...and I wouldn't be at MGH now as part of a collaborative team as dedicated and compassionate about patients with Serious Mental Health and Cancer as I am. Thank you Sheri.



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