

Why we care – the story of Susan and Miss J

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I have been a carer for over two years now. I became a carer with very little experience at 20 years of age. I had been given the idea by my Grandad who explained it would be the perfect job for me. Being so young I wasn't sure I'd cope, but I love it.

Over the two years I have experienced a lot. I have met so many individuals who have welcomed me into their home, trusting me to take care of them. There are a few individuals who stick out to me one being Mr.H, whom I was astonished by as he was 106 years old. He shared many stories with me, which I always found interesting. A lady called Mrs.C also stands out to me. Mrs.C suffers with Lewy Body Dementia and can become a little bit aggressive towards me. I have learnt about her life, family and friends, which has helped her to feel safe and more relaxed around me. Mrs.C has taught me a lot about Dementia. I always try to make sure she is comfortable to help her pass through her spells of confusion and I always remain calm and patient helping her as much as I can.

The person who will forever stand out to me is Miss J. I cared for Miss J for just under a year. She was a 25-year-old woman who suffered with Ovarian Cancer. Being only a few years older than me, Miss J appeared to be a little uncomfortable, as she expected someone much older. Over a few days I proved myself to Miss J making sure she knew I was someone she could rely on. After not long at all, we got on like a house on fire. Miss J lived with her older sister and brother in-law whom she adored. Care via the provider I worked for was in place to give Miss J company whilst her family went to work. I used to sit with Miss J watching television or a film that she had chosen, or I'd walk around the house with her whilst she did the tasks she had planned for the day, keeping close for reassurance. Miss J and I would also go out in the wheelchair shopping or sit in a coffee shop, so she could get some fresh air. Miss J did very well to move around despite the amount of pain she was in. She would hold on to the banisters and walk three flights of stairs, sitting on the steps for a break when it got too much. She was often tired after small tasks and

would hold on to her stomach leaning over trying to handle the pressure of the tumours pressing on her.

After a few weeks I started to become more involved with Miss J's care. I began preparing her meals whilst she sat and pointed to tell me what she wanted, her favourite being Toast with Nutella spread which she then dipped in her cup of tea. I also started to do housework, so I could give Miss J time to herself which she often needed in order to have a little sleep which had to be timed (only 15 minutes were allowed at a time). I also got more involved with her friends who came to visit by insuring they had a drink and something to do as a distraction. Most of Miss J's friends struggled seeing her so unwell. Eventually Miss J made the decision to stop allowing her friends to see her, hoping they would remember her as the athletic girl she once was. I always respected every decision made by Miss J. Except from the last few days Miss J had full capacity to make all decisions for herself, and she always did. Miss J planned exactly what she wanted to happen once she had passed away and decided what was to happen to her own home and car as well as her funeral.

Miss J was emotionally very strong. She remained happy through the pain. When Miss J started more treatment, she started to struggle. One morning Miss J came out of her shower with me standing on the other side of the door for reassurance, and looked very upset, she quietly asked me to clean the shower and sat on the bed waiting for me, I went in and saw massive amounts of her long brown hair that had fallen out. After cleaning her hair away out of her sight, I sat behind her and gently combed what was left of her hair to help comfort her. After I left her home that evening, everything changed for Miss J as her illness was intensifying. Everything also changed for me, in those few moments. I had changed forever. I promised myself never to take things for granted and to help people as much as I could for as long as I could. I grew up.

I was Miss J's main professional carer. She occasionally had one other carer called Miss S whom she also got on well with. After some time, Miss J ended up being in a Princess Alice Hospice for two weeks and came back needing to spend more time in bed. When she was having a bad day, I would encourage her to eat and drink, I would bring her hot water bottles as she found pain relief in the warmth and I would wash her face and hands to keep her feeling fresh. Miss J didn't want any assistance with a full body wash.

Towards the end the most important role of my job was to insure Miss J was always as comfortable as she could be, and I would hold her hand when she would scream in pain. I will always remember how she once turned to me and apologised for being a 'wimp' - she was the complete opposite.

Miss J became very weak in the last few day her well-travelled but too short life. She required extra help. District Nurses tried to help Miss J by putting on a catheter which she hated. They respected her discomfort and took it off her after a few hours. Miss J tried to use a pull-up pad which she also didn't like, but by this point her sister stopped working to help and spend as much time with her sister as possible, and she decided it was in Miss J's best interest to continue using pull-up pads to minimise the

pain and stress brought to her walking to the bathroom. I became involved in caring for her sister emotionally, as they were very close. I would try take her away for a few moments a day to have a conversation with her and see how she was coping with everything. Both Miss J and her sister found this comforting.

Miss J eventually required that I assisted her with personal care. I was with her every day and managed to wash more and more each day as she accepted the help. She was under constant medication at this point which was attached to her arm, causing her to be so tired she could hardly speak. I would still talk to her making sure she was included and kept her dignity throughout. Miss J was always grateful to the District Nurses, holding their hands before they left and cupping her sisters face when she could no longer speak. Miss J stood up in a very wobbly manner during her wash and leaned her head on my shoulder trying to put her arms around me: this reassured me in knowing that I had done everything I could to meet Miss J's needs, physically and emotionally. After this moment I sat her down and as always made sure she was warm and comfortable, with her religious beads and photographs of friends and family in her view.

Miss J sadly passed away a couple of days later in her home with her sister and brother in-law beside her holding her hand.

After caring for Miss J, I learnt the importance of treating each individual in a holistic way, knowing that everyone is different, everyone suffers from different levels of pain and discomfort. I have learnt to find the best way to help every individual as well as I can by getting to know them and reading their personal care plans carefully.

Miss J was a wonderful young woman who worked as a manager at a hotel, enjoyed sports, loved travelling and remained independent as much as she could and loved her sister who has now had a child and named her daughter after Miss J.

Reproduced with permission, from the reflective account of Susan, one of many Diploma Learners and carers who give their all to help others get the most from the life they have.